

THE NEVADA STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE



January 2015

**The Department of Health and Human Services
Task Force on Alzheimer's Disease**

(Assembly Bill No. 80, Committee on Health and Human Services, Statutes of Nevada 2013)

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State Plan to Address Alzheimer's Disease

Department of Health and Human Services Task Force on Alzheimer's Disease
State Plan to Address Alzheimer's Disease
Nevada Revised Statute 439.5083

Revised January 2015

Executive Summary

Following is a list of the recommendations approved by the Task Force on Alzheimer's Disease (TFAD) for inclusion in the State Plan:

1. Sustain a statewide information and referral system for those with Alzheimer's disease and other forms of dementia, their caregivers, and their families to enable them to connect with local case management and support services, e.g., resource centers., such as Nevada Aging and Disability Resource Center (ADRC).
2. Support and continue to monitor the progress of AB 170, passed in the 2013 Legislative Session, which authorizes Advance Practice Registered Nurses (APRNs) to have independent practices to provide better access to care, especially for rural elders. In addition, the TFAD supports the connection between the APRNs and health care teams to provide ancillary services.
3. Evaluate and support legislation that improves access to quality Telehealth Services and work with other initiatives such as Project ECHO Nevada, Renown Medical Center, and the Cleveland Clinic Lou Ruvo Center for Brain Health. The Aging and Disability Services Division (ADSD) will identify funding streams to develop and facilitate the full spectrum of Telehealth services to rural communities, including training for providers in rural areas.
4. Support NRS provisions, including those defined in SB 86 of the 2013 Legislative Session, that remove age barriers that typically keep people with younger-onset Alzheimer's disease and other forms of dementia from receiving services that are only available to seniors (disability services; legal services; meals; respite; and 'continuum of life' programs, such as assisted living services). Continue to monitor NRS provisions, related to these populations—and other provisions included in the Older Americans Act –which affect eligibility requirements for services to allow family caregivers of a person living with Alzheimer's disease and other forms of dementia to be served, regardless of the age of the person.
5. Support efforts to develop toolkits to assist public and private organizations in their outreach to different cultural communities.
6. Assess affordability of services for persons with Alzheimer's disease and other forms of dementia by using national data and explore other cost-sharing mechanisms.
7. Support the Cleveland Clinic Lou Ruvo Center for Brain Health in its establishment of a Nevada consortium to promote current and future research in our state. Expand the ADRC

website to specifically include information on Alzheimer's research that contains information about current research and a registry that allows individuals to register to participate in clinical research.

8. Support the adoption of specialized care pathways. Encourage the Nevada Hospital Association, in collaboration with subject matter experts from the Alzheimer's Association, as well as other research and educational organizations, to develop a best practices care plan for the management of patients with cognitive impairment entering the hospital. In addition, the TFAD supports the CARE Act, which will help caregivers when those for whom they care are hospitalized.
9. Continue to review current funding and potential funding streams to support the development of quality long-term care options for people living with dementia in Nevada. Provide funding or incentives to encourage existing facilities to increase capacity for placement of individuals with Alzheimer's disease and other forms of dementia with an emphasis on person-centered planning and initiatives.
10. Reduce the need for out-of-state placements in Nevada by:
 - a. Preventing the conditions that lead to the development of responsive behaviors and increase the risk of out-of-state placement. Accomplish this by creating a clearinghouse for information on evidence-based, person-centered approaches to promoting the behavioral health and quality of life of individuals with Alzheimer's disease and other forms of dementia and their family caregivers.
 - b. Initiating a public health information program to increase easy access to information on: 1) "optimal" care and quality of life and 2) expected vs. unexpected behavior changes in persons with dementia.
 - c. Increasing the ability of family and professional caregivers (in primary, acute, emergency, and long-term care settings) to appropriately and effectively respond to care needs and behavior changes in persons with Alzheimer's disease and other forms of dementia through education and guided practice by experts in evidence-based methods of behavioral healthcare for persons living with dementia.
 - d. Using a higher reimbursement rate as an incentive for providers to successfully deliver appropriate care.
 - e. Developing mobile individuals or teams that respond to—and evaluate—persons in need of specialized interventions. These multidisciplinary teams or individuals evaluate the person with dementia, provide assessment, and give training to staff and family members before the person with dementia moves into a catastrophic situation.
 - f. Bridging gaps between innovative care approaches and regulatory restrictions.

- g. Reviewing regulatory measures and pursuing regulatory reconciliation in order to assure consistency across agencies, which are involved in regulatory oversight to reduce barriers to providers who are willing to deliver care to persons with dementia.
 - h. Investigating the feasibility of developing units in facilities in Nevada that specialize in dementia care for individuals with a history of being described as “unmanageable” and rejected by other facilities.
- 11. Encourage the Board of Medical Examiners, the State Board of Osteopathic Medicine, professional associations, and educational institutions to promote awareness and education to health care providers by:
 - a. Approving continuing medical education (CME) training programs that provide primary care physicians and other allied health care professionals with ongoing education about recent developments, research, and treatments of Alzheimer’s disease and other forms of dementia.
 - b. Encouraging primary care physicians to refer persons with cognitive deficits for specialized cognitive testing when appropriate.
 - c. Encouraging primary care physicians to refer persons with dementia and their families to dementia-related community resources and supportive programs.
- 12. Encourage schools in Nevada with programs in nursing and other health care professions to ensure that the programs include specific training regarding Alzheimer’s disease and other forms of dementia in their curriculum and expand related continuing education opportunities for nurses and other health care professionals in the acute care setting.
- 13. Encourage and promote training and education opportunities related to Alzheimer’s disease and other forms of dementia for all levels of medical personnel in a hospital, including emergency room personnel and others responsible for admission and discharge.
- 14. Encourage first responders, law enforcement, and fire department personnel to have a specified number of hours of training to help them assess and learn how to respond to people with Alzheimer’s disease and other forms of dementia.
- 15. Provide caregivers with access to evidence-based education and support services that promote knowledge and understanding of Alzheimer’s disease and other forms of dementia and how to best support people living with dementia. Provide and expand respite services for family and informal caregivers of persons with Alzheimer’s disease and other forms of dementia. Broaden the eligibility requirements for use of respite programs and grant funding so that more families may benefit from them regardless of financial status or age.

16. Encourage the active capacity building of community organizations to recruit and manage volunteers. Provide volunteers with training and education so that they can better serve those living with Alzheimer's disease and other forms of dementia and their families.
17. Propose legislation to change NRS 159.076, providing an exception to the law allowing summary administration of a small estate if the ward is living with dementia, including but not limited to Alzheimer's disease. Ask the Legislature to send a letter to all district courts requesting close supervision of all guardians whose wards suffer from dementia, including but not limited to Alzheimer's disease, to insure that all reports on the person and estate of the wards are filed and reviewed according to existing law.
18. Ensure best-practice hospital transitional care programs that include information on community resources for caregivers and persons with dementia. Investigate federal funding opportunities through Medicare Innovations or Centers for Medicare and Medicaid Services to develop a transitions planning program or to avoid the hospital setting completely, i.e., a mobile dementia team approach.
19. Foster the development of three awareness campaigns to provide information about the earliest signs of dementia and to rebuke the stigma of Alzheimer's disease and other forms of dementia. The campaigns will include updates about current research and prevention trials that can delay progression, as well as information about how earlier diagnosis and intervention can lead to a more productive and valuable life. The campaigns will be designed to help citizens feel more supported and hopeful, as well as encourage access to available services. The campaigns will be promoted through public service announcements, broadcast and print interviews, as well as articles in newspapers and magazines, website, and Internet venues. The respective target audiences for each public awareness campaign are:
 - a. Allied health professionals, bankers, emergency first responders, financial planners, lawyers, and other professionals who may have contact with persons with dementia.
 - b. Caregivers and family members of persons with dementia. This campaign will focus on ways to help alleviate the fear, stress, and stigma surrounding dementia and the sense of isolation and aloneness that often accompanies the disease. This includes educating and informing caregivers about support group opportunities and other available supportive services that will help them care for themselves and their family member.
 - c. The general public.
20. Collaborate with the business community to create employee assistance programs that include education and training for employees, including those who are caregivers. Develop partnerships with other organizations that are also affected by Alzheimer's disease and other forms of dementia, such as diabetes, stroke, and heart organizations, to help promote information about services and care for those who have symptoms of dementia.

Chapter 1: The Task Force on Alzheimer's Disease (TFAD)

The Task Force on Alzheimer's Disease (TFAD) was created within the Department of Health and Human Services with the passage of Assembly Bill 80 in the 2013 Legislative Session. The TFAD is responsible for developing, monitoring, and updating the State Plan to Address Alzheimer's Disease. This plan serves as a blueprint for identifying specific actions that will allow for the development and growth of a quality and comprehensive support system for individuals affected by Alzheimer's disease.

The TFAD was formed in late 2013. The TFAD, which is staffed by the Aging and Disability Services Division (ADSD), is made up of ten members from a diverse background of interests in Alzheimer's disease, including medical professionals, caregivers, service providers, legislators, educators, and policy developers. The TFAD, which is required to meet at least quarterly, is authorized to meet through June 2017.

The Nevada State Plan to Address Alzheimer's Disease, deemed as the official plan by the 2013 Legislature, was completed in January 2013. It includes a list of 20 recommendations designed to improve access to services; quality of care and quality of life; and public awareness regarding the disease. The plan does not have a specific end date; therefore the TFAD is working to set clear timelines and strategies to achieve and revise the recommendations as necessary. Some progress has already been accomplished, and Nevada is fortunate to have a Governor, a Legislature, and a system of family and professional caregivers that are committed to assisting with or reducing the physical and financial impact on individuals with Alzheimer's disease and other forms of dementia, their families, and caregivers.

Legislative History

Passed during the 2011 Legislative Session, Assembly Concurrent Resolution No. 10, sponsored by Assemblywoman Debbie Smith, required the development of a State Plan to address Alzheimer's disease. A task force (ACR 10 Task Force) was established to accomplish this requirement. The ACR 10 Task Force met five times. Casey Catlin, who was working on her doctoral degree at the University of Nevada, Reno, drafted the State Plan quickly, and this became her thesis. During the final meeting in October 2012, the plan was approved by ACR 10 Task Force members after a work session. After considering more than 100 recommendations, submitted by independent work groups, experts and the public, the ACR 10 Task Force adopted 20 recommendations. The ACR 10 Task Force also included potential funding sources and indicators to help with monitoring the implementation of each recommendation. The ACR 10 Task Force adopted the plan as a living document. The importance of ongoing discussion and monitoring the implementation progress of each recommendation was noted as essential for the success of the State Plan.

2013 Legislative Successes

During the 2013 Legislative session, Assemblywoman April Mastroluca offered to sponsor an ACR 10 Task Force bill through the Committee on Health and Human Services. The ACR 10

Task Force used this Bill Draft Request for **Assembly Bill 80** to create the Task Force on Alzheimer's Disease (TFAD) within the Department of Health and Human Services (DHHS). AB 80 bill was signed by Governor Brian Sandoval on June 5, 2013, and became effective July 1, 2013. Mike Willden, then-Director of the DHHS, appointed eight members to the TFAD during the first quarter following the close of the 2013 Legislative session and assigned Aging and Disability Services Division staff the responsibility to administratively support the TFAD. On October 3, 2013, Nevada's Legislative Commission appointed two members, representing the Senate and the Assembly, to the TFAD.

The 2013-2015 Task Force on Alzheimer's Disease comprises:

Senator Valerie Wiener (Ret.), Chair
Peter Reed, Ph.D., Director, Sanford Center for Aging, University of Nevada, Vice Chair
Senator Joseph Hardy
Assemblywoman Heidi Swank
Charles Bernick, M.D., Associate Medical Director, Cleveland Clinic Lou Ruvo Center for Brain Health
Albert Chavez, Ed. S., CFLE, Regional Director, Southern Nevada Region, Desert Southwest Chapter, Alzheimer's Association
Virginia (Gini) L. Cunningham, M.Ed., Volunteer and Support Group Facilitator, Humboldt Volunteer Hospice and Alzheimer's Association in Northern Nevada
Jane Fisher, Ph.D., Department of Psychology, University of Nevada, Reno
Wendy Simons, Director, Assisted Living Development at Nevada Health Care Association, Owner at Wendy Simons Consulting
Julie Kotchevar, M.A., Deputy Administrator, Aging and Disability Services, Department of Health and Human Services

The duties of the TFAD are noted below.

NRS 439.5085

The Task Force shall:

- (a) Develop a State Plan to address Alzheimer's disease;***
- (b) Monitor the progress in carrying out the State Plan;***
- (c) Review and revise the State Plan as necessary;***
- (d) Develop and prioritize the actions necessary to carry out the State Plan;***
- (e) Research and review any other issues that are relevant to Alzheimer's disease; and***
- (f) On or before February 1 of each year, prepare and submit a report to the Governor and to the Director of the Legislative Counsel Bureau for transmittal to the Legislature concerning its findings and recommendations.***

Working with Senator Valerie Wiener (Retired), Senator Allison Copenig, chair of the Senate Health Committee (until Election Day 2012), offered two additional Bill Draft Requests (BDRs) to the ACR 10 Task Force for introduction during the 2013 Legislative Session. Both BDRs addressed recommendations in the State Plan.

Senate Bill 86 required the Department of Health and Human Services (DHHS) to allocate money for certain programs relating to persons with Alzheimer's disease and other related dementia. This bill was signed by the Governor on May 21, 2013 and became effective the day of signing. Existing law required the DHHS to allocate money to fund programs that assist senior citizens to live independently, including a program that provides respite care or relief of informal caregivers (NRS 439.630). SB 86 expanded that program to include respite care or relief for informal caregivers of any person with Alzheimer's disease or other related dementia, regardless of the age of the person. In response to the bill's passage, ADSD amended service delivery specifications utilized by agency-sponsored grantees to allow for the provision of respite care to individuals experiencing younger-onset of Alzheimer's disease and other forms of dementia. The passage of SB 86 has allowed for progress, under recommendation #4 of the State Plan, which indicates the necessity of removing "age barriers that typically keep people with younger-onset Alzheimer's disease and other forms of dementia from receiving services that are only available to seniors (disability services, legal services, meals, respite, and "continuum of life" programs such as assisted living services)."

Senate Bill 69 was introduced on January 9, 2013. The bill proposed revisions to the requirements governing Advanced Practitioners of Nursing (APN). The bill introduced the idea of removing the requirement that an APN could only perform duties pursuant to a protocol approved by—and under the supervision of—a licensed physician. The bill proposed that the State Board of Nursing be granted the ability to determine the authorized scope of practice for the nurse. The bill also proposed to remove the provisions that refer to the supervision of an APN by a physician with respect to dispensing and prescribing controlled substances, poisons, dangerous drugs, and devices. The ideas noted in this bill were eventually included in another bill, as noted below.

Assembly Bill 170 was introduced on February 25, 2013, with Assemblywoman Maggie Carlton as the primary sponsor. This bill also proposed revisions related to the Advanced Practice of Nursing. Existing law authorized the State Board of Nursing to grant certain registered nurses a certificate of recognition as an Advanced Practitioner of Nursing and set forth the requirements for obtaining the certification. AB 170 proposed modifying the authority of the Board to allow issuance of a license as an Advanced Practice Registered Nurse (APRN) and to require the maintenance of a policy of professional liability insurance in accordance with regulations adopted by the Board. AB 170 also allowed for an APRN to prescribe a controlled substance if the nurse had at least 2 years or 2,000 hours of clinical experience or if the nurse was prescribing pursuant to a protocol approved by a collaborating physician. The Governor signed AB 170 into law on June 3, 2013. The legislation offers the opportunity to a Registered Nurse who possesses a valid certificate of recognition as an APRN to be deemed to possess a license if the nurse meets requirements set forth in Board adopted regulations, set to be effective July 1, 2014.

The passage of AB 170 has allowed for progress, under recommendation #2 of the State Plan, which indicates the necessity of authorizing “nurse practitioners to have independent practices to provide better access to care, especially for rural elders.”

Chapter 2: Scope and Impact of Alzheimer’s Disease and Other Forms of Dementia

Dementia is an umbrella term for a number of distinct neurological diseases caused by plaques and neurofibrillary tangles, strokes, or other problems in the brain. Alzheimer’s disease is one form of dementia and is the most common, accounting for approximately 70 percent of cases. There are more than 50 identified forms of dementia besides Alzheimer’s disease, including: (1) frontotemporal dementia; (2) Lewy Bodies disease; (3) Parkinson’s disease; (4) Pick’s disease; and (5) vascular dementia. Some forms of dementia may be reversible, but for the majority, including Alzheimer’s disease, there remains no cure.ⁱ

Symptoms include short- and long-term memory loss, difficulties with problem solving and performing step-wise tasks, and impaired communicative abilities. The cognitive decline from dementia is significantly different from what is expected from normal aging and interferes with the completion of activities of daily living. Individuals with dementia may live from 2 to 20 years with the disease, becoming increasingly dependent on others for their care.ⁱⁱ

Though dementia is typically thought of as a disease of the elderly, and indeed the majority of cases affect those ages 65 and older, it actually can be developed at earlier ages. When the first symptoms present before age 65, the illness is considered “younger-onset.” Cases have been documented in individuals as young as 26, and, with better early detection, an increasing number of cases are diagnosed in middle age.ⁱⁱⁱ These individuals face unique challenges compared to their older counterparts, having to find solutions in their workplace, managing unprecedented financial burdens, handling child care and family obligations, obtaining appropriate medical treatment, and obtaining social services. In Nevada, many federal, State, and local programs to support those with dementia have age requirements that keep younger-onset individuals from accessing those essential services.

Prevalence of Alzheimer’s Disease

The number of Americans with dementia is estimated at more than 5.4 million.^{iv} In Nevada, according to the Alzheimer’s Association, in 2014, the population with Alzheimer’s disease was estimated at 37,000, which marked a 38 percent increase from ten years prior. Dementia has been found to occur in approximately 1 in 9 people: 15 percent of individuals, aged 65 to 74; 44 percent of individuals, aged 75 to 84; and 38 percent of those aged 85 and older.^v Research continues to identify various risk factors for dementia (including high blood pressure, diabetes, smoking, and other factors), but the greatest known risk factor is age.^{vi} As the population continues to grow older, nationally and locally, the number of persons with dementia is projected to continue to increase. Nevada’s median age rose from 35 in 2000 to 36.3 in 2010. By 2050, if there is still no cure, the number of Americans—and Nevadans—with dementia is expected to more than double.

Economic Impact

Estimates for the direct and indirect costs of dementia vary substantially, but a recent review of the literature showed that dementia is consistently ranked as one of the most expensive illnesses to treat—more costly than cancer or AIDS.^{vii} In 2014, the estimated cost of care for Alzheimer’s disease was \$214 billion in the United States and is projected to rise to \$1.1 trillion by 2050. More than 15 million Americans provide unpaid care that is valued at \$210 billion each year. In 2011, more than 130,000 unpaid caregivers in Nevada provided at least \$1.8 billion in unpaid care.^{viii}

The average Medicare payments for an elderly person with dementia are nearly three times higher than for an elderly person without dementia. Medicaid payments are 19 times higher for individuals with dementia. The cost to Medicaid and Medicare has been forecasted to increase by 500 percent by 2050.^{ix}

Social Impact and Stigma

The diagnosis of dementia affects not only a person’s cognitive and physical health but also his or her emotional well-being. Persons with dementia may become socially isolated because of others’ fear of the disease and/or may socially withdraw and experience hypervigilance and shame.^x Awareness and understanding of the disease have improved in recent years, and policymakers and stakeholders are paying attention to the troubling numbers cited above. However, the diagnosis still carries significant stigma in the U.S. and around the world.^{xi} It is the desire of the TFAD not only to draw attention to the problems that dementia can bring, on an individual as well as societal level, but also to reduce stigma and fear about the disease, helping to validate the living experience of those with dementia.

Evidence of the stigmatizing effects of a dementia diagnosis can be found in common standards of care for people living with dementia, which is apparent in the fact that persons diagnosed with Alzheimer’s disease and other forms of dementia are significantly less likely to receive adequate pain management for co-morbid conditions, such as cancer or rheumatoid arthritis, when compared with elderly persons with similar pain-related diagnoses but no cognitive impairment diagnosis.

Further, the stigmatization of persons living with dementia can involve a misinterpretation of their behavior, attributing it to the dementia rather than the more common cause of some other unmet care need, which may result in sub-optimal support in activities of daily living, a lack of treatment of co-morbid medical condition, unnecessary suffering, and, in the worst-case scenario, premature death.

Behavior and Communication

As a starting point for this discussion, it can be stated that behavioral expressions of people living with dementia are a form of communication, which are often understandable responses to external stimuli (i.e. responsive behaviors). Of significant concern in this context is that medical treatment for co-morbid conditions in persons living with dementia may be compromised after

the person: 1) receives a diagnosis of Alzheimer's disease or another form of dementia, and 2) is no longer able to label, report, or seek assistance when experiencing internal physiological conditions, such as pain or discomfort. The behavior and affective changes that often accompany adverse medical events or a lack of appropriate support in daily life among persons with verbal deficits (hereafter referred to as "responsive behaviors") may be misattributed to the neurodegenerative disease and hence go untreated.

Often, because of challenges with communication, people living with dementia exhibit responsive behaviors to express their unmet need in such areas as nutrition, pain, socialization and support with activities of daily living. When people with dementia understandably respond to these unmet needs, by communicating in a manner within their abilities, it is often labelled as a "problem behavior," when in fact the "problem" is in the inadequate care and support being provided, and has nothing to do with the disease. Similarly, a lack of treatment of co-morbid conditions can result in unnecessary suffering of persons living with dementia. For example, behaviors that result when a person living with dementia is experiencing an adverse medical event are often treated with psychotropic medications (e.g., conventional or atypical antipsychotic medications) in an effort to reduce or eliminate the behaviors. Antipsychotic medications have been found to: 1) produce side effects (e.g., increased confusion, delirium, declines in language, impairment in new learning, motoric problems) that mimic the symptoms of dementia and are often misattributed to the progression of the neurodegenerative disease, and 2) increase the risk of premature death. In recognition of these serious risks, in 2005 and 2008, the Food and Drug Administration issued black box warnings against the use of antipsychotic medications "to treat behavioral problems in older persons with dementia."

In 2012, in recognition of the problem of the overreliance on antipsychotic medication in the treatment of persons living with dementia in nursing homes, the U.S. Centers for Medicaid and Medicare Services initiated the National Partnership to Improve Dementia Care in Nursing Homes. A major goal of this initiative is the reduction in the use of antipsychotic medications in nursing homes. Nevada is participating in this program.

Chapter 3: Access to Services

In Nevada, access to services varies depending on public and provider awareness. There is much confusion about the prognosis of Alzheimer's disease, how individuals "get the disease," and what local services may be available to help caregivers and families of those with dementia. It is critical that everyone becomes educated about the disease: its detection, diagnosis and treatment; resources available for support and information; and details of the stages and progression of the disease. Whether in a metropolitan area, such as Las Vegas or Reno, or in a rural community, such as Denio, Nevadans require access to up-to-date information on detection, diagnosis, treatment, and a variety of health services. Many persons with Alzheimer's disease and their families are not aware of specialized diagnosis of the disease through neurological examination and the availability of care and treatment options. This problem is compounded because of the distance to services or a lack of awareness of specialists to consult. Nevadans deserve quality diagnosis and treatment and to be informed about the most current science, regardless of where they reside in the state.

Home- and Community-Based Services

Home-based services or in-home services provide a range of caregiving assistance and services that allow persons with Alzheimer’s disease and other forms of dementia to stay in their homes and also provide much-needed support for caregivers. These services can include: companionship, personal care (assistance with bathing, dressing, eating, and more), homemaker services, and more specialized care. For instance, the Home- and Community-Based Waiver (HCBW) and Community Service Options Program for the Elderly (COPE), administered by the Aging and Disability Services Division (ADSD) of Nevada’s Department of Health and Human Services (DHHS), provide home-based care to help the person maintain independence and delay placement into long-term care facilities. Private home-health agencies, regulated by the Bureau of Health Care Quality and Compliance (BHCQC) in the Health Division of the DHHS, may also be hired to provide a variety of home-based services. In addition, other services, like adult day care programs, provide both an opportunity for social stimulation and, in some cases, medical oversight to the individuals, as well as respite for the caregivers.

Support Services

Though a cure for dementia is not yet available, there are many ways to improve quality of life for caregivers and care recipients. Care management, counseling, socialization programs, support groups, and other programs have been shown to reduce stress and improve quality of life.^{xii}

Many people may believe that both those with Alzheimer’s disease and other forms of dementia and those who care for them prefer to be alone. Because communication can be difficult with persons who have dementia, well-meaning friends often stay away. They may be afraid of interfering or simply fearful of the disease itself, which puts both care recipients and caregivers at risk for social isolation.^{xiii} Socialization programs can provide much-needed social interaction for the care recipient and a break for the caregiver. Caregivers often feel alone and isolated, believing that only they can provide care, even as the persons in their care enter new phases of the disease. Support groups for caregivers are important because they provide: emotional support, stress management, problem-solving and coping skills, and opportunities to learn helpful techniques from others.

Nevada’s Aging and Disability Resource Centers (ADRC) provides a website that lists support groups and other nonmedical services and also publishes a Community Resource Guide. In addition, Alzheimers.gov and alz.org are national websites that connect caregivers to available resources. Even with these referral sites, many of the individuals who testified before the ACR 10 Task Force noted difficulty for families and professionals in locating and connecting with existing resources. Many caregivers are unaware of free or low-cost services that are available in Nevada.

RECOMMENDATION 1: Sustain a statewide information and referral system for those with Alzheimer’s disease and other forms of dementia, their caregivers, and their families to enable

them to connect with local case management and support services, e.g., resource centers., such as Nevada Aging and Disability Resource Center (ADRC).

Indicator: Establish a collaboration that includes recourse centers, such as Nevada ADRC, Northern California and Northern Nevada Chapter of the Alzheimer’s Association, Southern Nevada Region, Desert Southwest Chapter of the Alzheimer’s Association, University of Nevada, Reno, and Nevada Caregiver Support Center, to develop plans for an information and referral system. The Aging and Disability Services Division (ADSD) will monitor the number of contacts made by outreach programs, the number of inquiries regarding information or services relating to Alzheimer’s disease and other forms of dementia received by the ADRC, and the number of “hits” on information sites, such as an expanded nevadaadrc.com, alz.org/norcal for Northern Nevada and alz.org/dsw for Southern Nevada, nevadacaregiver.unr.edu, and Alzheimers.gov.

Potential Funding: Older Americans Act funds and other discretionary grants.



Rural Services

Geographically, Nevada is a unique state. The three metropolitan areas of the state, Reno/Sparks/Carson City, Elko, and Las Vegas, are located in corners of the state with vast stretches of open road and smaller towns between them. People in Nevada’s rural areas are geographically isolated from many services. Consequently, isolated towns have difficulty recruiting specialists in neurology or geriatrics to provide services in their communities. In addition, distance makes face-to-face doctor-patient visits problematic because of the lack of access to transportation services. Providing transportation with well-trained drivers and support personnel is essential to the best care of individuals with Alzheimer’s disease and other forms of dementia.

According to the *Nevada Rural and Frontier Health Data Book – 2011 Edition*:

Most of Nevada’s rural and frontier communities are located in sparsely populated counties that are considerable distances from the state’s urban and tertiary care centers. The average distance between acute care hospitals in rural Nevada and the next level of care or tertiary care hospital is 114.7 miles and the average distance to the nearest incorporated town is 46.5 miles. Consequently, the primary health care delivery issue for rural residents and communities in Nevada is how best to overcome the spatial isolation and enormous geographic distances that characterize most of rural and frontier Nevada. The eleven towns in Nevada with federally-designated Critical Access Hospitals (CAHs) are an average distance of 45.5 miles from the nearest incorporated town, an average of 54.4 miles from the next hospital, and an average of 104.8 miles from the next level of care or nearest tertiary care hospital.

RECOMMENDATION 2: Support and continue to monitor the progress of AB 170, passed in the 2013 Legislative Session, which authorizes Advance Practice Registered Nurses (APRNs) to have independent practices to provide better access to care, especially for rural elders. In addition, the TFAD supports the connection between the APRNs and health care teams to provide ancillary services.

Indicator: The ADSD will contact the State Board of Nursing annually to monitor the number of applicants who file to practice independently, the venues where they intend to practice, and the populations they serve. Monitor regulations related to APRNs adopted by the Board of Nursing.

Potential Funding: Health care insurance; Medicaid; Medicare; federally qualified health centers.



Telehealth

As hospitals throughout the state extend the use of telemedicine, diagnosis and treatment will be delivered in a more timely and progressive manner. This will enable patients and families, physicians, and other medical personnel to act and interact to receive the best medical care. Nevada's Early Stage Dementia Project, Telehealth Early Phase Patient and Family Support Program (TESP) was funded primarily by the Administration on Aging, U.S. Department of Health and Human Services, with support from the Aging and Disability Services Division of Nevada's Department of Health and Human Services, which implemented Telehealth and support for caregivers and individuals in the early stages of Alzheimer's disease in rural Nevada. The project also provided the groundwork for providing rural residents access to specialized help for Alzheimer's disease and other dementia patients and their caregivers and families. The project was funded for the period of September 30, 2008, through March 31, 2010. In addition, in September 2010 the Nevada Hospital Association accepted a \$19.6 million grant from the National Telecommunications and Information Administration, U.S. Department of Commerce, to construct and operate a statewide broadband network for the purpose of improving patient care by eliminating technology disparities between rural and urban areas. The project, entitled Nevada Broadband Telemedicine Initiative (NBTI), is creating a telemedicine system and health information exchange primarily focused on unserved or underserved Nevada communities.

According to the University of Nevada School of Medicine website, the school was one of the first in the nation to adopt Project ECHO (Extension for Community Health Outcome). Project ECHO is an innovative health care delivery solution pioneered in New Mexico by Dr. Sanjeev Arora and replicated in Washington, urban Chicago, and now Nevada. Project ECHO is a simple Telehealth linkage connecting University-based faculty specialists to primary care providers in rural and underserved areas to extend specialty care to patients with chronic, costly, and complex medical illnesses. The goal of Project ECHO Nevada is to meet the needs of primary care providers by offering an alternative to costly travel and long waits for patients who need

specialty care. By developing the knowledge base of primary care providers through the innovative Telehealth consultations offered by Project ECHO Nevada, patients in rural and underserved areas benefit from the specialty care available without the cost and time of accessing specialists directly.^{xiv}

RECOMMENDATION 3: Evaluate and support legislation that improves access to quality Telehealth Services and work with other initiatives such as Project ECHO Nevada, Renown Medical Center, and The Cleveland Clinic Lou Ruvo Center for Brain Health. The Aging and Disability Services Division (ADSD) will identify funding streams to develop and facilitate the full spectrum of Telehealth services to rural communities, including training for providers in rural areas.

Indicator: Identify and evaluate what Telehealth projects are available and accessible. Review evaluation of projects, such as Nevada’s Early Stage Dementia Project and Telehealth Early Phase Patient and Family Support Program (TESP), to assess what was done and duplicate the measurements of the success of the projects. Follow the process of development of the NBTI using the NHA goals and evaluations.

Potential Funding: Alzheimer’s Disease Supportive Services Program (ADSSP); the State of Nevada; other grant-funding sources, as identified.



Early-Stage/Mildly Impaired

Those who have been diagnosed with dementia early in the disease process are likely to benefit from interaction with others who are in the same situation. Programs designed specifically for early-stage individuals help promote education, understanding, healthy coping strategies, and ways to maximize remaining abilities. These groups can prevent depression and anxiety, as well as help those affected, to continue leading healthy, active lives.^{xv}

Younger Onset

While Alzheimer’s disease and other forms of dementia are often grouped together, the etiologies and symptoms are quite varied. Additionally, Alzheimer’s disease is typically thought of as a disease of the elderly, when in fact, it may affect those who are still young. The youngest documented case of Alzheimer’s disease was a 26-year-old individual, and an increasing number of cases are diagnosed in individuals who are under the age of 65. Such cases are considered “younger-onset.”

Younger-onset individuals face numerous challenges in the workplace, in medical treatment, and in the availability of the best medical services. Many are denied the care and medications they need, based on their age, because of different funding sources’ age requirements. In Nevada, a

person under the age of 65 with dementia can qualify for Medicare, but must qualify for Social Security disability benefits and then wait a period of 24 months. Thus, when individuals with younger-onset Alzheimer’s disease become unable to work and in need of assistance in their thirties, forties, and fifties, extra stress and expense are experienced by families who are already suffering. Children of these individuals frequently take on caregiving duties out of necessity, which creates a reversal of roles and coping difficulties for children.^{xvi}

During the 2013 Legislative Session, Senate Bill 86 expanded the use of discretionary funding distributed by the Department of Health and Human Services (NRS 439.630). Senate Bill 86 expanded that program to include respite care or relief for informal caregivers of any person with Alzheimer’s disease or other forms of dementia, regardless of the age of the person. In response to the passage of SB 86, ADSD amended service delivery specifications utilized by agency-sponsored grantees to allow for the provision of respite care to individuals experiencing younger-onset Alzheimer’s disease and other forms of dementia.

RECOMMENDATION 4: Support NRS provisions, including those defined in SB 86 of the 2013 Legislative Session, that remove age barriers that typically keep people with younger-onset Alzheimer’s disease and other forms of dementia from receiving services that are only available to seniors (disability services; legal services; meals; respite; and ‘continuum of life’ programs, such as assisted living services). Continue to monitor NRS provisions, related to these populations—and other provisions included in the Older Americans Act –which affect eligibility requirements for services to allow family caregivers of a person living with Alzheimer’s disease and other forms of dementia to be served, regardless of the age of the person

Indicator: Annually, review statutes and regulations to determine whether barriers and disparate funding have been removed and funding has been established to cover younger-onset funding. Continue to collaborate with the Department of Health and Human Services (DHHS) to monitor the progress of respite services for these populations.

Potential Funding: Aging and Disability Services Division, Nevada Department of Health and Human Services.



Cultural Competency

Nevada’s elderly population is growing increasingly more diverse, and, according to available research, minorities are less likely to utilize services.^{xvii} With Nevada’s rapidly changing demographics, especially the growth in the Latino population, it is imperative that the State provides access to diagnosis and quality health care for those affected by Alzheimer’s disease and other forms of dementia. In the minority communities, fear, stigma, and personal and cultural beliefs that dementia is a normal part of aging can be barriers to seeking diagnosis and treatment and may delay individuals and families from seeking help. In addition, the negative and pathology-oriented language that is commonly used to describe the experiences of persons

with dementia and their families (e.g., “burden,” “stress,” “behavioral disturbance”) within public health programs and political advocacy efforts may not accurately reflect the experience of persons from minority cultures. Social service and public health programs often focus exclusively on negative mental and physical health outcomes of caregiving. In contrast, a survey of Hispanic women found that many viewed caregiving as a positive experience and described the responsibility as a duty (as opposed to a burden).^{xviii} Further, within collectivistic cultures, it may be considered disrespectful and unacceptable to disclose personal and family experiences to persons outside of the family or to label a family member as a “burden” or “problem.” Within the Latino community, cultural values including *familism* (the importance of family over the individual and the reliance on both the nuclear and extended family for support), respect for elders, and religious spirituality may protect families from some of the risks associated with dementia caregiving experienced by members of individualistic cultures.

Currently, available services may not be providing what families from diverse cultures need or want. Surveys have found that Latino caregivers use fewer formal support services, provide more hours of care, are less likely to report role strain, are more likely to have an added burden of managing their own chronic illnesses, are younger, have lower incomes, and are more likely to be unemployed relative to White non-Hispanic caregivers. In addition, Latino caregivers report that they often face language barriers, cultural barriers, and discrimination when they do seek care, resulting in reduced help seeking efforts and increased strain.^{xix} In surveys, Latino caregivers have indicated that receiving information and services in Spanish is important to them, regardless of their fluency in English.^{xx} However, given the complexity of cultural differences, simply translating information designed for the English-speaking majority population into another language is not the same as culturally tailoring a service.

RECOMMENDATION 5: Support efforts to develop toolkits to assist public and private organizations in their outreach to different cultural communities.

Indicator: Monitor the development and dissemination of toolkits to organizations serving persons living with dementia and their family caregivers, such as ADSD grant-funded partners.

Potential Funding: U.S. Administration on Aging grants; collaboration with different cultural and ethnic organizations.



Medicare, Medicaid, Health Insurance, and Financing Care

According to the Alzheimer’s Association Report, nationally, costs in 2014 for all individuals with Alzheimer’s disease and other dementias are estimated at \$214 billion. Medicare and Medicaid are expected to cover 70 percent of the total health care and long-term care payments. Medicare covers 53 percent of the costs while Medicaid accounts for 17 percent. Out-of-pocket

expenses are expected to reach 17 percent and other payers, such as private insurance, are estimated to account for 13 percent.

Medicare beneficiaries with Alzheimer's disease are more likely to have other chronic diseases or conditions, and they are more likely to be hospitalized than those who have the same conditions but do not also have dementia. Medicaid is the only public program that covers long-term (custodial) care stays.^{xxi}

RECOMMENDATION 6: Assess affordability of services for persons with Alzheimer's disease and other forms of dementia by using national data and explore other cost-sharing mechanisms.

Indicator: The Aging and Disability Services Division will track and analyze national data and make a recommendation of equitable reimbursement rates based on that analysis.

Potential Funding: Medicaid expansion.



Chapter 4: Quality of Care

In 2013, an interdisciplinary workgroup, representing national medical professional organizations and advocacy organizations concerned with the care of persons with dementia, identified reforms in health care design and delivery that were needed in order to achieve substantive improvements in the quality of care of persons with dementia. The effort was led by the American Academy of Neurology (AAN), the American Geriatric Society (AGS), the American Medical Association (AMA), and the American Medical Directors Association (AMDA).

The workgroup determined that desired outcomes in dementia care should include: preserving, to the maximum extent possible, cognitive and functional abilities; reducing the frequency, severity, and adverse impact of neuropsychiatric and behavioral symptoms; sustaining the best achievable general health; reducing risks to health and safety; enhancing caregiver well-being, skill, and comfort with managing patients with dementia in partnership with health care providers, and; informing patients so that they may actively participate in their care.

Improving the quality of care for people living with Alzheimer's disease and other forms of dementia is critical in Nevada and across the nation. In addition to the outcomes listed above, maximizing the self-determination of healthcare and long-term care decisions by persons with dementia should be a priority within Nevada.

Research

According to the “National Plan to Address Alzheimer’s Disease,” produced by the U.S. Department of Health and Human Services in 2011, research is a major area of interest and is necessary to increasing the community’s understanding of the causes, treatment, and prevention of Alzheimer’s disease. The two primary strategies directly related to research in the plan include: (1) the identification of research priorities and milestones and (2) expanding research aimed at preventing and treating Alzheimer’s disease. Private nonprofit entities, organizations, foundations, and the federal government fund Alzheimer’s research. The primary sources of government funding include: the National Institute on Aging, National Institutes of Health, and the U.S. Department of Health and Human Services. Below is a chart, published February 13, 2012, outlining the annual support level for Alzheimer’s disease-related research, based on grants, contracts, and other funding mechanisms used across the National Institutes of Health:

National Institutes of Health Alzheimer’s Disease Related Research Funding (Dollars in millions and rounded)								
<u>Research/ Disease Area</u>	<u>FY 2008Actual</u>	<u>FY 2009Actual (Non- ARRA)</u>	<u>FY 2009Actual (ARRA)</u>	<u>FY 2010Actual (Non- ARRA)</u>	<u>FY 2010Actual (ARRA)</u>	<u>FY 2011Actual</u>	<u>FY 2012 2012Actual</u>	<u>FY 2013 2013Actual</u>
Alzheimer’s Disease	\$412	\$457	\$77	\$450	\$79	\$448	\$503	\$504

* Additional funding was provided through the American Recovery and Reinvestment Act of 2009 (ARRA). The Fiscal Year (FY) 2013 estimated amount for Alzheimer’s disease research does not include \$80 million budgeted in FY 2013 in the proposed Prevention and Public Health Fund allocation to the DHHS General Departmental Management budget. The total Alzheimer’s disease research expenditures, including these resources, were estimated to be \$529 million in FY 2013. Estimates for 2014 and 2015 are \$566 million each year.

According to the National Plan, the federal government intended to allocate \$50 million in new Alzheimer’s disease research funding in FY 2012, and \$80 million in new Alzheimer’s disease research funding in FY 2013.

The following table shows existing programs funded to provide Alzheimer’s related support for caregivers and individuals affected with Alzheimer’s disease or other forms of dementia.

ADSD Funded Alzheimer’s Support Services—FY 15 (7/1/2014 – 6/30/2015)			
<u>Type of Funds</u>	<u>Grantee</u>	<u>Type of Service</u>	<u>FY 2015</u>
Fund for a Healthy Nevada			
Independent Living Funds	Northern Nevada Office, Alzheimer’s Association	Respite	\$175,269
Title III-D/E	Northern Nevada Office, Alzheimer’s Association	Caregiver Support	\$66,291

Independent Living Funds	Desert Southwest Chapter, Alzheimer's Association	Respite	\$178,685
Title III-D/E	Desert Southwest Chapter, Alzheimer's Association	Caregiver Support	\$77,676
Older Americans Act Funding			
Title III-B	Cleveland Clinic Lou Ruvo Center for Brain Health	Diagnostic	\$31,741
Title III-E	University of Nevada, Reno	Caregiver Support	\$107,780
Title III-B	Cleveland Clinic Lou Ruvo Center for Brain Health	Caregiver Support	\$106,499
		Total	\$743,941

In September 2014, the Nevada Aging and Disability Services Division (ADSD) was awarded \$450,000 from a Federal discretionary grant from the Administration for Community Living (ACL) for the 2014 Alzheimer's Disease Supportive Services Program: Dementia Capability for Persons with Alzheimer's Disease and Related Dementia.

ADSD's proposed goals for improving their dementia capability system for persons with Alzheimer's Disease and Related Dementias (ADRD) are to:

1. Develop screening for early identification of Alzheimer's disease or other forms of dementia.
2. Connect individuals living with ADRD and their caregivers to appropriate program and service modalities based on consumer needs and person-centered approaches. (i.e., implementation of BRI Care Consultation and other program expansion planned).
3. Establish and improve datasets to quantify measurable outcomes and expand program evaluation to inform program improvements.

This project is a statewide initiative, which will serve Nevadans with dementia and their family caregivers, and includes activities to develop a fully functional, sustainable dementia-capable system, with Single Entry Point (SEP)/No Wrong Door (NWD) access. ADSD will leverage existing activities and ensure access to a comprehensive, sustainable set of quality services that are dementia capable and provide innovative services to the population with dementia and their family caregivers.

The following table shows grant partners, roles, and funding amounts, as approved by the U.S. Administration for Community Living (ACL).

Nevada 2014 Dementia Capability for Persons with Alzheimer's Disease and Related Dementias – Project Partners		
<u>Provider</u>	<u>Program</u>	<u>Federal Amount</u>
Rosalynn Carter Institute	RCI – Care Consultation	\$118,625
Alzheimer’s Association – Desert Southwest Chapter	(EPIC) Early Stage Partners in Care	\$50,000
Alzheimer’s Association – Northern Nevada Northern California Chapter	(EPIC) Early Stage Partners in Care	\$35,000
University of Nevada Reno	Quality Management	\$97,500
Arizona State University	EPIC – Quality Management	15,000
	Total	\$316,125

*Three-year discretionary grant from the U.S. Administration for Community Living (ACL)

These initiatives will work with existing support services. In Nevada, ADSD currently provides funding for Caregiver Supportive Services, Alzheimer’s Diagnostic, Respite, and Evidence-based services, such as Care Partners Reaching Out (CarePRO), through Title III-B, D, and E of the Older Americans Act and using Independent Living Grant Funding (ILG) from the Fund for a Healthy Nevada.

Nevada is positioned to compete for additional funding in this area. Testimony presented to the ACR 10 Task Force indicated that many different research initiatives are being undertaken, one of which is early detection. The Cleveland Clinic Lou Ruvo Center for Brain Health is involved in national studies of brain imaging and other methods for early detection of Alzheimer’s disease. In addition, various treatment strategies and prevention trials are being undertaken.

Several issues limit research trials in Nevada, as well as across the country, including: challenges to enrolling enough people who are representative of the country’s population in research trials, limited research in basic science in Nevada, and no biotech companies in Nevada focused on Alzheimer’s disease and other forms of dementia. NRS 159.0805 impacts access to research participation by persons living with dementia, who have a court-appointed guardian, because research participation, via surrogate consent, must be approved by the court.

To increase research efforts in Nevada, the TFAD discussed the need for greater education and promotion about clinical trials within the health care system; the development of new

partnerships and outreach; and the need to identify and remove barriers that limit people with dementia from enrolling in studies or trials.

RECOMMENDATION 7: Support the Cleveland Clinic Lou Ruvo Center for Brain Health in its establishment of a Nevada consortium to promote current and future research in our state. Expand the ADRC website to specifically include information on Alzheimer’s research that contains information about current research and a registry that allows individuals to register to participate in clinical research.

Indicators: The establishment of a facilitator and key consortium partners. The compilation of a list of current research projects. Monitor, through the Alzheimer’s Association, the number of “hits” the Trial Match site receives in Nevada.

Potential Funding: In-kind contributions from potential participants, i.e., Cleveland Clinic’s Lou Ruvo Center for Brain Health, Touro University Nevada, Nevada System of Higher Education (NSHE), and other educational institutions in Nevada. Federal Alzheimer’s research grants; private-sector foundation grants.



Diagnostic Treatment

Quality care begins with increased detection and diagnosis of Alzheimer’s disease. To address, and ultimately prevent, Alzheimer’s disease, three things are needed: (1) an understanding of the disease process; (2) early detection; and (3) the advent of disease-modifying treatments. An early diagnosis of Alzheimer’s disease, with subsequent treatment, can help patients maintain functionality. In addition, an early diagnosis aids individuals and their families in making plans for the future. Testimony presented to the ACR 10 Task Force and information contained in the National Plan indicate that important developments in the use of imaging and biomarkers in brain, blood, and spinal fluids make it possible to identify the onset of Alzheimer’s disease, track its progression, and observe the effects of treatment in individuals with the disease. These advances have shown that brain changes leading to Alzheimer’s disease begin up to ten years before symptoms.

Barriers to timely Alzheimer’s disease diagnosis include: the lack of a single definitive test or screening method; the lack of or inadequate communication between health care providers and patients or caregivers; the expense and the lack of insurance coverage for diagnostic screening; and cultural barriers and social stigma that prevent people from seeking such a diagnosis. The TFAD encourages leveraging direct care funding, such as Medicaid Annual Wellness Visits, to promote early detection and diagnosis.

The American Association of Retired Persons (AARP) urges lawmakers to enact the Caregiver Advise, Record Enable (CARE) Act to better support family caregivers as they safely help

Nevada seniors stay at home. The CARE Act recognizes the critical role family caregivers play in keeping their loved ones out of costly institutions. The bill features three important provisions: 1) The name of the family caregiver is recorded when a loved one is admitted into a hospital; 2) The family caregiver is notified if the loved one is to be discharged to another facility or back home; and 3) The facility must provide an explanation and live instruction of the medical tasks—such as medication management, injections, wound care, and transfers—that the family caregiver will perform at home.^{xxii}

RECOMMENDATION 8: Support the adoption of specialized care pathways. Encourage the Nevada Hospital Association, in collaboration with subject matter experts from the Alzheimer’s Association, as well as other research and educational organizations, to develop a best-practices care plan for the management of patients with cognitive impairment entering the hospital. In addition, the TFAD supports the CARE Act, which will help caregivers when those for whom they care are hospitalized.

Indicator: Monitor through regulatory and hospital associations how many hospitals establish a best-practices care plan.

Funding: In-kind contributions from potential participants, i.e., Cleveland Clinic’s Lou Ruvo Center for Brain Health, Touro University Nevada, Nevada System of Higher Education (NSHE), and other educational institutions in Nevada. Federal Alzheimer’s research grants; private-sector foundation grants; Cleveland Clinic Lou Ruvo Center for Brain Health.



Long-Term Care

In Nevada, the Bureau of Health Care Quality and Compliance (BHCQC), under the Division of Public and Behavior Health (DPBH), is responsible for licensing, inspecting, and regulating all medical and other related facilities in the state. The options for long-term care for individuals with Alzheimer’s disease and other forms of dementia under the BHCQC include residential care for groups and skilled nursing homes. Surveys (inspections) are conducted in accordance with applicable regulations, based on the type of license, and follow specific time frames and procedures. The BHCQC also conducts complaint investigations for all licensees. Both long-term care types receive annual inspections. Inspection and survey results are posted on the Health Division’s website at: <http://search.health.nv.gov/SOD>.

In addition to the BHCQC, several other State entities provide a role in maintaining the quality of long-term care for persons living with Alzheimer’s disease and other forms of dementia in Nevada. The Nevada State Board of Examiners for Administrators of Facilities for Long-Term Care was created by the Legislature in 1969 (*Nevada Revised Statutes* 654.050). This Board of Examiners for Long-Term Care Administrators (BELTCA) serves as the licensing and regulatory agency for administrators in Nevada, including nursing homes and group care and assisted living. The BELTCA protects public and consumer interests by ensuring long-term care

administrators are of good moral character, properly educated, and trained to care for Nevada’s citizens in a dignified, supportive, and caring manner.

The Office of the State Long-Term Care Ombudsman is a federally mandated service, which is administered by the ADSD. The State Ombudsman advocates for persons who reside in long-term care settings. Certified staff of the Office visit facilities to listen to residents, help resolve problems, and provide information. The Office of the State Ombudsman does not investigate cases of alleged abuse, exploitation, isolation, or neglect. The Elder Protective Services Unit in the ADSD has that responsibility.

Residential care homes must meet certain requirements in Nevada to be recognized as “assisted living facilities.” In addition, residential care homes may have an endorsement for Alzheimer’s disease on their license, which requires a secured environment, as well as enhanced training for their staff. Residential care and assisted living are licensed, based on the number of residents. The two facility license types include those: 1) serving 10 or fewer residents, which are usually in a residence or home and 2) serving 11 or more residents, which are usually a special unit as a part of a larger assisted living. The following chart outlines the distribution of these licensees.

Residential Care Homes for Groups (Alzheimer’s Endorsed) licensed under NRS 449 Bureau of Health Care, Quality, and Compliance Data (December 2014)			
Location	Residents 10 or fewer	Residents 11 or more	Beds with Alzheimer’s Endorsement
Northern Nevada	0	12	395
Southern Nevada	74	18	1263
Total Alzheimer’s Endorsed	74	30	1658

Those residential care homes with an Alzheimer’s endorsement may charge prices ranging from \$1,000 per month, for those declaring to be low-income, up to as much as \$6500 per month.

Recommendation 9: Continue to review current funding and potential funding streams to support the development of quality long-term care options for people living with dementia in Nevada. Provide funding or incentives to encourage existing long-term care providers to increase capacity for placement of individuals with Alzheimer’s disease and other forms of dementia with an emphasis on person-centered planning and initiatives.

Indicators: Increased number of long-term care options for persons with Alzheimer’s disease and other forms of dementia.

Potential Funding: Medicaid expansion, Home- and Community-Based Services Waiver; and expansion through Behavioral Rate, Veteran’s Administration (VA) or Legislative approval of State funds; increased supplemental SSI rate); tax incentives.



Promoting Behavioral Health

Testimony before the ACR 10 Task Force in 2012 indicated that 35 individuals living with Alzheimer’s disease or other forms of dementia who developed responsive behaviors were placed in out-of-state nursing homes at an annual cost to the State of approximately \$2.3 million. Nevada has a shortage of long-term care options, staffed with caregivers who are trained or able to provide care to this group. In December 2014, according to the Nevada Healthcare Association (NHA), only three skilled nursing facilities in Nevada can accommodate individuals in a secured setting, and all of these are located in southern Nevada. This is a reduction from the eight that existed statewide in 2012. Frequently, these persons are seen in a variety of healthcare settings, including primary care, hospital emergency rooms, inpatient psychiatric facilities, and acute care hospitals for treatment of behaviors that developed in response to untreated adverse medical or environmental events. If the responsive behaviors of a person living with dementia are documented as “aggressive,” “assaultive,” or “unmanageable,” the person is at risk for being refused admission to long-term care. Importantly, the responsive behaviors that develop in persons with Alzheimer’s disease are preventable. Ideally, Nevadans living with dementia would receive appropriate support so that they reliably receive medical treatment for conditions (e.g., pain, discomfort, infection, delirium, medication reaction, distress, etc.) that, if left untreated, can lead to responsive behaviors. If co-morbid conditions are treated and appropriate environmental support is provided, persons with dementia should never reach a point where their behavior is considered “unmanageable.”

Several contributing factors for these out-of-state, long-term care placements include:

- Lack of family and professional caregiver knowledge and skill in accurately identifying and effectively responding to behavior changes that are due to treatable medical conditions (e.g., pain, infection, medication side effect) and/or environmental adverse events (e.g., punitive corrective feedback) in persons with Alzheimer’s disease and other forms of dementia. The absence of a timely response to acute affective or behavior changes due to an adverse medical or environmental event increases the risk of the development of responsive behaviors.
- Overreliance on “restraint-based” methods for responding to affective and behavioral changes in persons with dementia. Restraint-based methods are those that produce premature loss of behavior or “excess” disability that results in an individual with dementia needing a more restrictive level of care than would be the case if evidence-based behavioral healthcare were provided;
- Industry concerns about increased potential for regulatory citation and possible sanctions related to behaviors that may result in injury to the resident, other residents, or staff,
- Industry concerns regarding the need for increased staff-to-patient ratios to accommodate residents with more aggressive or challenging behaviors,

- Difficulty in recruiting staff who are trained to manage behavior effectively.

Several methods to address the problem were recounted for the ACR 10 Task Force. Those recommendations include:

- Recruiting an out-of-state provider with a specialty in working with this population to open a nursing home in Nevada;
- Developing a team to identify behavioral or supportive interventions necessary to address the needs of an individual and enhance patient safety. The team would be readily available to assist in a nursing home setting when a resident exhibits behavioral problems; and
- Using State-owned mental health facilities to serve individuals with severe behavioral problems.

RECOMMENDATION 10: Reduce the need for out-of-state placements in Nevada by:

- a. Preventing the conditions that lead to the development of responsive behaviors and increase the risk of out-of-state placement. Accomplish this by creating a clearinghouse for information on evidence-based, person-centered approaches to promoting the behavioral health and quality of life of individuals with Alzheimer’s disease and other forms of dementia and their family caregivers.
- b. Initiating a public health information program to increase easy access to information on: 1) “optimal” care and quality of life and 2) expected vs. unexpected behavior changes in persons with dementia.
- c. Increasing the ability of family and professional caregivers (in primary, acute, emergency, and long-term care settings) to appropriately and effectively respond to care needs and behavior changes in persons with Alzheimer’s disease and other forms of dementia through education and guided practice by experts in evidence-based methods of behavioral healthcare for persons living with dementia.
- d. Using a higher reimbursement rate as an incentive for providers to successfully deliver appropriate care.
- e. Developing mobile individuals or teams that respond to—and evaluate—persons in need of specialized interventions. These multidisciplinary teams or individuals evaluate the person with dementia, provide assessment, and give training to staff and family members before the person with dementia moves into a catastrophic situation.
- f. Bridging gaps between innovative care approaches and regulatory restrictions.

- g. Reviewing regulatory measures and pursuing regulatory reconciliation in order to assure consistency across agencies, which are involved in regulatory oversight, to reduce barriers to providers who are willing to deliver care to persons with dementia.
- h. Investigating the feasibility of developing units in facilities in Nevada that specialize in dementia care for individuals with a history of being described as “unmanageable” and rejected by other facilities.

Indicators: Decreased number of out-of-state placements. Establishment of new collaborations to address this population between long-term care providers and behavioral health professionals, such as collaborations with behavioral health programs at institutions within the NSHE.

Potential Funding: Multiple sources, including: the Division of Health Care Financing and Policy (DHCFP) and the ADSD; Medicaid; savings from moving out-of-state placements back in-state; Medicare; and other identified grants (e.g., Civil Monetary Penalties Grant).



Training, Education, and Professional Development

The ACR 10 Task Force heard testimony regarding the need to strengthen the multidisciplinary workforce that cares for aging adults in general, as well as individuals with Alzheimer’s disease and other forms of dementia, throughout the continuum of care. The challenges of maintaining a dementia-competent workforce in Nevada are magnified by an overarching trend—a health care workforce shortage. The shortages in Nevada reflect a national phenomenon, and this greatly concerns many because it compromises access to quality patient care. For the past several years, Nevada has worked through the educational system and the professional licensing process to address this challenge. However, as Nevada addresses the workforce shortage, the State also has the responsibility for maintaining and continuing to develop quality care.

The National Plan states the workforce that cares for people with Alzheimer’s disease includes health care and long-term services and supports providers, such as: primary care physicians; specialists, such as neurologists, geriatricians, and psychiatrists; Registered Nurses and Advanced Practice Registered Nurses; community health workers; social workers; psychologists; pharmacists; dentists; allied health professionals; and direct-care workers, such as home health aides and Certified Nursing Assistants, who provide care at home or in assisted living or nursing homes. These providers need accurate information about caring for someone with Alzheimer’s disease, including: the benefits of early diagnosis; how to address the physical, cognitive, emotional, and behavioral symptoms of the disease; and how to assist caregivers as they cope with the physical and emotional aspects of their caregiving responsibilities.^{xxiii} It is very important to address the needs of the person and ensure the appropriate care for patients with Alzheimer’s disease and other forms of dementia.

The ACR 10 Task Force received presentations and information from various educational institutions, including those within the NSHE and Touro University Nevada. Hosts of educational programs are available across the state to assist in developing and increasing a proficient workforce to address Alzheimer's disease and other forms of dementia. However, educational challenges still exist, including:

- Standardizing and increasing the availability of Alzheimer's disease and dementia care training for all direct care workers, including unlicensed health care workers in the long-term care setting;
- Increasing exposure to geriatrics and Alzheimer's disease and dementia care in a broad spectrum of educational training programs for health care providers, such as physicians, nurses, psychiatrists, social workers, and other allied health professionals;
- Increasing enrollment in geriatric-related specialties;
- Improving consideration of, and sensitivity to, cultural issues; and
- Providing continuing education focused on Alzheimer's disease and dementia care for health care professionals.

RECOMMENDATION 11: Encourage the Board of Medical Examiners, the State Board of Osteopathic Medicine, professional associations, and educational institutions to incentivize and promote awareness and education to health care providers by:

- a. Approving continuing medical education (CME) training programs that provide primary care physicians and other allied health care professionals with ongoing education about recent developments, research, and treatments of Alzheimer's disease and other forms of dementia.
- b. Encouraging primary care physicians to refer persons with cognitive deficits for specialized cognitive testing when appropriate.
- c. Encouraging primary care physicians to refer persons with dementia and their families to dementia-related community resources and supportive programs.

Indicators: Increased number of primary-care-physician referrals for diagnosis and treatments. Increased number of early referrals. Increased number of quality CME training opportunities related to Alzheimer's disease diagnosis and treatment.

Potential Funding: Volunteer and in-kind contributions: the TFAD members, Alzheimer's Association, and other advocacy organizations; other grant-funding sources, as identified.



RECOMMENDATION 12: Encourage schools in Nevada with programs in nursing and other health care professions to ensure that the programs include specific training regarding Alzheimer’s disease and other forms of dementia in their curriculum and expand related continuing education opportunities for nurses and other health care professionals in the acute care setting.

Indicators: Classified nursing programs based on content and best practices in education; increased continuing education units for nurses related to Alzheimer’s disease treatment and care.

Potential Funding: Alzheimer’s Association; State Board of Nursing.



RECOMMENDATION 13: Encourage and promote training and education opportunities to increase awareness and understanding of Alzheimer’s disease and other forms of dementia for all levels of medical personnel in a hospital, including emergency room personnel and others responsible for admission and discharge.

Indicators: Work with the Division of Public and Behavioral Health on how many training programs in the hospitals are established and how many people participate in the programs annually. Change in regulations—Chapter 449 of the *Nevada Administrative Code*.

Potential Funding: Division of Public and Behavioral Health; Nevada Hospital Association; Alzheimer’s Association; other identified grant-funding sources.



RECOMMENDATION 14: Encourage first responders, law enforcement, and fire department personnel to have a specified number of hours of training to help them assess and learn how to respond to people with Alzheimer’s disease and other forms of dementia.

Indicators: Work with the Division of Public and Behavioral Health to monitor how many training programs and participants are established through law enforcement, Emergency Medical Technician, and fire department associations by assessing data from the Division of Public and Behavioral Health or related professional associations.

Potential Funding: Continuing education programs; other identified grant-funding sources.



Chapter 5: Quality of Life

Persons with Dementia

The profound changes brought on by cognitive disorders, such as Alzheimer's disease, often lead to frustration, sadness, anger, and worry.^{xxiv} Individuals with dementia gradually lose the ability to complete activities of daily living and may experience a reduced ability to independently seek or access pleasant events and experiences. As a result of reductions in pleasant experiences and the ability to independently manage environmental demands, the prevalence of depression and anxiety in dementia is very high. Clinically significant depression has been found in 20 to 30 percent of individuals with dementia living in the community, which is significantly higher than the estimated 2 percent prevalence of depression in individuals over the age of 65.^{xxv} Anxiety has been found in 20 percent of community-dwelling individuals with dementia.^{xxvi}

The good news is that depression and anxiety in persons with dementia can be improved with psychosocial interventions.^{xxvii} Support groups have also been developed to help those with dementia better maintain their current skill set, plan for the future, and stay engaged with activities they care about.^{xxviii} Physical therapy, exercise, and other interventions have also demonstrated benefits.^{xxix}

Persons with dementia may have co-morbid conditions that are made more difficult to treat because of the dementing illness. Persons with dementia may not be able to verbally report internal sensations, such as pain, fatigue, or hunger.^{xxx} This can make symptoms more difficult to detect. This verbal impairment puts people with dementia at risk for experiencing excess disability, defined as greater impairment than what would be expected from the underlying condition alone.^{xxxi} Research indicates that persons with dementia and co-morbid cancer, or other serious illnesses, are more likely to be given less pain medication than non-demented patients.^{xxxii}

Another primary concern to persons with dementia is preserving a sense of independence. Unfortunately, because of the disease, persons with dementia will gradually become more reliant on others. However, families and care providers can preserve the individuals' safety and well-being while still offering choices and dignity. Substantial research has shown significant benefits of this person-centered promotion of choice.^{xxxiii}

Caregivers

Caregivers of those with dementia also report high rates of anxiety, burnout, depression, and stress. These may manifest in physical symptoms as well, with caregivers at an increased risk of cardiovascular disease, high blood pressure, and impaired immune systems. Elderly caregivers have a 63 percent higher mortality rate than non-caregivers of the same age.^{xxxiv}

The high stress on caregivers, particularly combined with a lack of education about dementia and poor coping skills, can put the care recipient at an increased risk of elder abuse. More than half a million reports of elder abuse were investigated in the fiscal year reported in the last Adult Protective Services national report in 2004 (National Center on Elder Abuse, 2006).^{xxxv} Families and professionals may remain unaware of reporting criteria and do not have valid screening tools, so many more cases may go unreported.^{xxxvi}

Studies have shown that dementia education and structured support groups are beneficial in reducing caregiver depression, stress, and other problems.^{xxxvii} It is important for caregivers to remain connected to their social network and valued activities, as they may also suffer from the stigma attached to dementia. Family and friends may be less willing to spend time with the family, and caregivers may feel ashamed and reluctant as well.^{xxxviii} Additionally, the time and effort required to be a primary caregiver is a barrier to socializing, pursuing enjoyable activities, and even maintaining self-care. Respite—meaning a brief break from caregiving responsibilities—has consistently been identified as a vital service to maintain caregiver health and well-being.^{xxxix}

RECOMMENDATION 15: Provide caregivers with access to evidence-based education and support services that promote knowledge and understanding of Alzheimer’s disease and other forms of dementia and how to best support people living with dementia. Provide and expand respite services for family and informal caregivers of persons with Alzheimer’s disease and other forms of dementia. Broaden the eligibility requirements for use of respite programs and grant funding so that more families may benefit from them regardless of financial status or age.

Indicators: Monitor the number of consumers and hours of caregiver support services provided in the ADSD-funded programs.

Potential Funding: Fund for a Healthy Nevada; Retired and Senior Volunteer Program (RSVP); Older Americans Act funding (Title III); the Alzheimer’s Association.



RECOMMENDATION 16: Encourage the active capacity building of community organizations to recruit and manage volunteers. Provide volunteers with training and education so that they can better serve those living with Alzheimer’s disease and other forms of dementia and their families.

Indicators: Monitor such organizations that recruit volunteers, such as RSVP, to track the number of volunteer recruitments, placement, and training.

Potential Funding: Voluntary outreach by members of the TFAD; other volunteer and in-kind resources as they become available.



Often, guardians oversee the affairs of individuals with dementia. These guardians make decisions about where their wards live and who provides care. NRS 159.076 states that if the ward has an estate of \$10,000 or less, the guardian can use that money to provide for the ward and not provide any additional reports to the court regarding the ward’s finances until the guardianship is dissolved. This is called an “order for summary administration” and applies when the ward does not own a home or other real property. Often, though, a small amount of savings, when combined with regular income, can help keep a ward in a familiar setting. With no supervision of how the money in the estate is spent, guardians have been known to spend the savings and then move the ward to an unfamiliar and less expensive setting, where the ward’s income supplements the guardian’s living expenses. This will not be examined by the court as a financial issue if there has been a summary order regarding the ward’s estate. Additionally, there have been cases involving guardians who have received this type of order and proceeded to sell everything the ward owns within a short period of time. If the ward recovers or is subsequently judged to be capable of returning to his or her own home, that person has nothing left from a former life.

RECOMMENDATION 17: Propose legislation to change NRS 159.076, providing an exception to the law allowing summary administration of a small estate if the ward is living with dementia, including but not limited to Alzheimer’s disease. Ask the Legislature to send a letter to all district courts requesting close supervision of all guardians whose wards live with dementia, including but not limited to Alzheimer’s disease, to insure that all reports on the person and estate of the wards are filed and reviewed according to existing law.

Indicators: Coordinate with the appropriate agencies (Medicaid, judiciary, public guardians, and the Legislature) for development of recommendations for legislation.

Potential Funding: Legislative appropriation.



RECOMMENDATION 18: Ensure best-practice hospital transitional care programs that include information on community resources for caregivers and persons with dementia. Investigate federal funding opportunities through Medicare Innovations or Centers for Medicare and Medicaid Services to develop a transitions planning program or to avoid the hospital setting completely, i.e., a mobile dementia team approach.

Indicators: Monitor the number of hospital transitional care programs employing best-practice discharge policies.

Potential Funding: Collaboration between Nevada ADSD, Nevada DHCFP, DPBH, and other appropriate State agencies.



Chapter 6: Public Awareness

Public Safety Programs

Although Nevada has yet to implement a state-specific dementia awareness program, the Alzheimer’s Association and the U.S. Department of Health and Human Services have begun television, radio, and print advertisements describing Alzheimer’s disease and research efforts, which encourage visits to informational websites, such as Alzheimers.gov.

In 2012, The ADSD created an Elder Abuse Training Program, which has been given to social workers and care providers throughout the state. This training is available on the ADRC website. The training defines different types of abuse in detail and describes potential signs of abuse. It is difficult to estimate how much elder abuse goes unreported, but research suggests that many cases are not reported.^{xi}

Other states and countries have implemented programs of public education for professionals who have frequent contact with the public (e.g., pharmacists, government officials, police, et cetera) about characteristics of dementia. Even though dementia care is not the focus of their work, these people may still come in contact with persons with dementia and benefit from knowing what to expect and how to better communicate.^{xii} These programs may also better prepare citizens to report suspected elder abuse even when they are not mandated reporters.

Wandering

Because of deficits in short- and long-term memory, as well as spatial orientation and way-finding, persons with dementia are at risk for wandering—walking away, while often purposeful, and forgetting where they are going or how to get home. Tragically, this can lead to the person with dementia being exploited, becoming injured, and even dying. This process can also be very distressing to family members and can be grounds for dismissal from a long-term care facility.^{xiii}

Senate Bill 245 (Chapter 184, *Statutes of Nevada 2011*) created the Statewide Alert System for the Safe Return of Missing Endangered Older Persons, a type of “Silver Alert” program that has been successfully implemented in 28 other states. It is the goal of this program to quickly and safely return a wandering individual to his or her home.

Another example of a safety program to help in situations of wandering is the MedicAlert® + Alzheimer’s Association Safe Return® bracelet program. This program provides a bracelet with identifying and contact information, which can be worn at all times by

the person with dementia. The bracelet helps identify the person if he or she becomes lost or needs assistance. In Nevada, the Alzheimer's Association has reported that this program has been underutilized.^{xliii}

Driving

Driving is a major public safety issue for persons with Alzheimer's disease and other forms of dementia. Driving is an important part of independence and identity for many people, and individuals often choose to continue driving even after receiving a diagnosis of dementia.^{xliv} Individuals may also feel that they need to continue driving out of necessity, as public transit or other transportation options are very limited in Nevada. Because of the visual, spatial, motor coordination, planning, and memory deficits inherent in dementia, driving is very dangerous. The Department of Motor Vehicles (DMV) may revoke an individual's license if he or she fails a paper or driving test. Physicians or friends may make referrals to the DMV if they are concerned about someone's driving abilities. However, public safety could be greatly improved if efforts were taken to ensure that individuals with dementia are more reliably tested for driving safety and given assistance in securing alternative modes of transportation.

RECOMMENDATION 19: Foster the development of three awareness campaigns to provide information about the earliest signs of dementia and to rebuke the stigma of Alzheimer's disease and other forms of dementia. The campaigns will include updates about current research and prevention trials that can delay progression, as well as information about how earlier diagnosis and intervention can lead to a more productive and valuable life. The campaigns will be designed to help citizens feel more supported and hopeful, as well as encourage access to available services. The campaigns will be promoted through public service announcements, broadcast and print interviews, as well as articles in newspapers and magazines, website, and Internet venues. The respective target audiences for each public awareness campaign are:

- a. Allied health professionals, bankers, emergency first responders, financial planners, lawyers, and other professionals who may have contact with persons with dementia.
- b. Caregivers and family members of persons with dementia. This campaign will focus on ways to help alleviate the fear, stress, and stigma surrounding dementia and the sense of isolation and aloneness that often accompanies the disease. This includes educating and informing caregivers about support group opportunities and other available supportive services that will help them care for themselves and their family member.
- c. The general public.

Indicators: Monitor the instances of media attention through public service announcements, interviews, and stories; number of professionals and professional organizations contacted; number of visits to the Nevada ADRC website; and level of progress made to develop and sustain public awareness campaigns in cooperation with the State Grants Office and DHHS Outreach Services.

Potential Funding: Volunteer services from the TFAD members; Alzheimer’s Association; professional licensing boards and organizations; Nevada Broadcaster’s Association; Nevada ADSD; other identified grant-funding sources.



RECOMMENDATION 20: Collaborate with the business community to create employee assistance programs that include education and training for employees, including those who are caregivers. Develop partnerships with other organizations that are also affected by Alzheimer’s disease and other forms of dementia, such as diabetes, stroke, and heart organizations, to help promote information about services and care for those who have symptoms of dementia.

Indicators: Number of employee assistance programs with caregiver education and training; number of partnerships with other dementia-related organizations.

Potential Funding: Employers and other potential grant funding sources.

Conclusion

In conclusion, the Task Force views this plan as a living document. It is important to continue the discussion and monitor the implementation of the recommendations.

I married the love of my life a few years ago and we moved to Reno. I started noticing several things going on and we had to fight, fight, fight to get someone to pay attention to it. I had to go back to work because he lost his job, and we couldn’t get any information about what was happening. We lost the only friends we had in Reno because the stigma is terrible. It doesn’t matter who you are—this disease can happen to you. My husband continues to decline and now I had to leave my work because I developed pneumonia and it has gone on for more than a month. This is a disease that can happen to anyone.

–Melissa, primary caregiver for her husband

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