

THE NEVADA STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE



January 2013

**Legislative Committee on Health Care's Task Force to Develop a State Plan
to Address Alzheimer's Disease**

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

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

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State Plan to Address Alzheimer's Disease

Legislative Committee on Health Care's
Task Force to Develop a State Plan to Address Alzheimer's Disease
Assembly Concurrent Resolution No. 10 (File No. 42, Statutes of Nevada 2011)

January 2013

Executive Summary

Following is a list of the recommendations approved by the Task Force for inclusion in the State Plan:

1. Establish and fund a statewide information and referral system for those with Alzheimer's disease and related disorders, their caregivers, and their families to enable them to connect with local case management and support services. Utilize public service announcements, existing newsletters, and other resources to spotlight where and how to access assistance, e.g., resource centers, such as Nevada Aging and Disability Resource Centers (ADRC).
2. Authorize nurse practitioners to have independent practices to provide better access to care, especially for rural elders. States such as Arizona, Idaho, Oregon, and Wyoming currently authorize such independent practices.
3. Examine and identify funding streams to develop and facilitate the full spectrum of telehealth services to rural communities, including training for providers in rural areas.
4. Remove age barriers that typically keep people with younger-onset Alzheimer's disease and related disorders 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). Adopt the language of the Older Americans Act, which changed eligibility requirements for services to allow family caregivers of a person with Alzheimer's disease or other dementia to be served, regardless of the age of the person with dementia.
5. Disseminate information about the many aspects of Alzheimer's disease and related disorders in a variety of languages to meet the needs of every person and caregiver, regardless of age, gender, language, physical or mental disabilities, race, regional or national origin, religion, sexual orientation, and socioeconomic status. Develop toolkits to assist with outreach to different cultural communities.
6. Address affordability of services for persons with Alzheimer's disease and related disorders by implementing sliding fee scales and other cost-sharing mechanisms.
7. Establish a Nevada consortium to maximize current and future research and diagnostic efforts in our State to address Alzheimer's disease and related disorders.

8. Investigate and encourage expanded research opportunities throughout Nevada to study current and develop new medications that treat Alzheimer's disease and related disorders. Also, promote the dissemination of information about treatments available to persons with Alzheimer's disease and related disorders, including, without limitation: approved drug regimens, investigational drugs available to Nevada residents, and the potential side effects of medications.
9. Review current funding and funding streams to support the development of quality long-term care facilities in Nevada. Provide funding or incentives to encourage long-term care organizations to develop inpatient facilities and to encourage existing facilities to increase inpatient capacity for placement of individuals with Alzheimer's disease and related disorders.
10. Reduce the need for out-of-state placements in Nevada by:
 - a. Reviewing regulatory measures that may serve as barriers to facilities that are willing to retain more behaviorally challenged patients.
 - b. Investigating the feasibility of having specialized units in facilities in Nevada that specialize in dementia care for individuals with challenging behavioral issues.
 - c. Using a higher reimbursement rate as an incentive for facilities to provide specialized care.
 - d. 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.
 - e. Developing a collaborative effort to promote evidence-based, patient-centered approaches to preventing and treating challenging behaviors of individuals with Alzheimer's disease or related disorders.
 - f. Developing plans for more adequate placement of individuals with Alzheimer's disease and related disorders, including the need for in-State facilities to treat more behaviorally challenged patients.

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 related disorders.
 - 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 related disorders in their curriculum and expand related continuing education opportunities for nurses and other health care professionals in the acute care setting.
13. Encourage training and education about Alzheimer's disease and related disorders for all levels of medical personnel in a hospital, including emergency room personnel and others responsible for admission and discharge. Encourage the Nevada Hospital Association, in collaboration with subject matter experts from the Alzheimer's Association, research, and educational organizations, to develop a care pathway plan for the management of patients with cognitive impairment entering the hospital. Provide incentives and recognition for outstanding facilities that have effectively implemented care pathways.
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 related disorders.
15. Provide and expand respite services for family caregivers of persons with Alzheimer's disease and related disorders with the goal of reducing the need for emergency room visits and caregiver stress. Broaden the eligibility requirements for use of respite programs and grants so that more families may benefit from them regardless of financial status or age.
16. Explore the use of volunteers to provide support to family caregivers by collaborating with community organizations and faith-based groups.

17. Enforce mandatory administrative or judicial reviews of all persons with dementia under guardianship who are involuntarily placed out of state. These reviews should be conducted at least every six months for this fragile population to reevaluate appropriateness of placement, reasonableness of care, and efforts to return the person to his or her home or to the most homelike, least restrictive setting.
18. Establish 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 altogether, i.e., a mobile dementia team approach.
19. Collaborate with the business community to create employee assistance programs that include education and training for caregivers. Develop partnerships with other organizations that are also affected by Alzheimer's disease and related disorders, such as diabetes, stroke, and heart organizations, to help promote information about services and care for those who have symptoms of dementia.
20. 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 related disorders. 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, hopeful, and likely to access available services. The campaigns will be promoted through television and radio advertisements, 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. The general public.
 - c. 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.

Chapter 1: Introduction

In May 2011, Assembly Concurrent Resolution No. 10 (File No. 42, *Statutes of Nevada 2011*) (Appendix A) created the [Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's Disease](#) (Task Force). The Legislative Committee on Health Care appointed members to the Task Force from diverse disciplines to reflect the many areas affected by Alzheimer's disease.

The members of the Task Force are:

Senator Valerie Wiener, Chair

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

Ruth Gay, M.S., Director, Public Policy and Advocacy, East Bay Office Site Director, Northern California and Northern Nevada Chapter, Alzheimer's Association

Sandra Owens, L.C.S.W., Ph.D., Associate Professor, School of Social Work, University of Nevada, Las Vegas

Wendy Simons, Chief, Bureau of Health Care Quality and Compliance, Department of Health and Human Services

Two alternates for each member of the Task Force were designated. Please see Appendix B for the "Designation of Alternates."

Professional and staff services were provided by:

Casey Catlin, M.A., Doctoral Student, University of Nevada, Reno, State Plan Drafter
Roger McClellan, Health Care Policy Specialist, Research Division, Legislative Counsel Bureau (LCB)

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Brief Review of Task Force Functions and Meetings

Experts in medicine, nursing, psychology, public policy, social work, and related disciplines were called to provide testimony. The Task Force gathered information about existing services and gaps and made recommendations for the State Plan.

Three working groups were created to meet and provide input in the following areas: (1) Access to Services; (2) Quality of Care and Regulation; and (3) Impact on the State, Safety, and Independence.

The Task Force met five times between June and October 2012. All public hearings were conducted through simultaneous videoconferences between legislative meeting rooms at the Grant Sawyer State Office Building in Las Vegas, Nevada, and the Legislative Building in Carson City, Nevada. In addition, each meeting provided time for public comment. Caregivers, educators, health care professionals, working groups, and other members of the public provided input and recommendations for consideration to the Task Force. At the fourth meeting, members adopted several recommendations and goals for inclusion in the State Plan. At the fifth meeting, members conducted a work session in which they adopted the State Plan and a recommendation for legislation. It should be noted that funding sources for the recommendations are suggested but not limited to those enumerated in the report.

What is Alzheimer's Disease?

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" or "early-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 6 million.^{iv} In Nevada, in 2010, the population with Alzheimer's disease was estimated at 29,000, which marked a 38 percent increase from ten years prior. Dementia has been found to occur in approximately 5 percent of individuals aged 71 to 79, 24 percent of individuals aged 80 to 89, and 37 percent of those aged 90 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 2012, the estimated cost of care for Alzheimer's disease was \$200 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 physical health but also his or her mental and 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 Task Force 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.

Chapter 2: 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 informed by the most current science regardless of where they reside in the State.

Home-Based Services

Home-based services or in-home services provide a range of caregiving assistance and services that allow a person with Alzheimer's disease or related disorders to stay in his or her home and also provide much-needed support for caregivers. These services can include: companionship, personal care (assistance with bathing, dressing, eating, et cetera), 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 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 most dementias 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 related disorders 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 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 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: Establish and fund a statewide information and referral system for those with Alzheimer's disease and related disorders, their caregivers, and their families to enable them to connect with local case management and support services. Utilize public service announcements, existing newsletters, and other resources to spotlight where and how to access assistance, e.g., resource centers, such as Nevada Aging and Disability Resource Centers (ADRC).

Indicator: Monitor the number of contacts made by outreach programs, the number of inquiries regarding information or services relating to Alzheimer's disease and related disorders 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, and Alzheimers.gov.

Potential Funding: Older Americans Act funds; free public service announcements; free appearances on public affairs programs; free media resource for news and feature stories (print, electronic, and Internet); other (yet to be identified).

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 related disorders.

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 or "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: Authorize nurse practitioners to have independent practices to provide better access to care, especially for rural elders. States such as Arizona, Idaho, Oregon, and Wyoming currently authorize such independent practices.

Indicator: Monitor the number of applicants who file to practice independently, the venues where they intend to practice, and the populations they serve.

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

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, the Nevada Hospital Association has received 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), will create a telemedicine system and health information exchange primarily focused on unserved or underserved Nevada communities and is expected to be completed within three years.

Recommendation 3: Examine and identify funding streams to develop and facilitate the full spectrum of telehealth services to rural communities, including training for providers in rural areas.

Indicator: Review evaluation of projects, such as Nevada’s Early Stage Dementia Project, 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 Demonstration Grants to States; other federal grants that can be identified; the State of Nevada; other (yet to be identified).

Early-Stage

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.^{xiv}

Younger/Early-Onset

While Alzheimer’s disease and related disorders 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” or “early-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.^{xv}

Recommendation 4: Remove age barriers that typically keep people with younger-onset Alzheimer’s disease and related disorders 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). Adopt the language of the Older Americans Act, which changed eligibility requirements for services to allow family caregivers of a person with Alzheimer’s disease or other dementia to be served, regardless of the age of the person with dementia.

Indicator: Develop a list of current statutes and regulations that include age barriers or provide the same or similar services but have disparate funding. Periodically, review these statutes and regulations to determine whether barriers and disparate funding have been removed and funding has been established to cover younger-onset funding.

Potential Funding: Aging and Disability Services Division.

Cultural Competency

Nevada's elderly population is growing increasingly more diverse, and, according to available research, minorities are less likely to utilize services.^{xvi} With Nevada's rapidly changing demographics, especially the growth in the Latino population, it is imperative that the State provide access to diagnosis and quality health care for those affected by Alzheimer's disease and related disorders 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. Currently, available services may not be providing what these diverse caregivers need. In surveys, Latino caregivers have indicated that receiving information and services in Spanish is important to them, regardless of their fluency in English.^{xvii} Services provided to these communities must be culturally sensitive with provider awareness.

Recommendation 5: Disseminate information about the many aspects of Alzheimer's disease and related disorders in a variety of languages to meet the needs of every person and caregiver, regardless of age, gender, language, physical or mental disabilities, race, regional or national origin, religion, sexual orientation, and socioeconomic status. Develop toolkits to assist with outreach to different cultural communities.

Indicator: Survey providers and monitor increase in services accessed by different cultural groups.

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

Medicare, Medicaid, Health Insurance, and Financing Care

Calculations from the "2012 Alzheimer's Disease Facts and Figures" report indicate that Medicare pays about 52 percent of the costs of care for Americans, aged 65 and older, with Alzheimer's disease and related disorders, while Medicaid pays about 18 percent. Out-of-pocket payers pay 17 percent and other payers, such as private insurance, health maintenance organizations, other managed care organizations, and uncompensated care, pay 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.^{xviii}

Recommendation 6: Address affordability of services for persons with Alzheimer’s disease and related disorders by implementing sliding fee scales and other cost-sharing mechanisms.

Indicator: Survey providers of aforementioned services, such as Nevada Health Centers, Access to Health Care, Health Access Washoe County, Volunteers in Medicine of Southern Nevada, and monitor expansion of Medicaid Services should the State choose to do so.

Potential Funding: Medicaid expansion.

Chapter 3: Quality of Care

In 1984, the American Medical Association (AMA) characterized high-quality care as “care which consistently contributes to the improvement or maintenance of quality and/or duration of life.” The AMA specified the aspects, or features, of care that should be measured to determine quality. These features included:

- Attention to evidence-based, scientific medicine;
- Timely and efficient use of resources;
- Emphasis on disease prevention and health promotion; and
- Informed participation of patients.^{xix}

Improving the quality of care for people living with Alzheimer’s disease and related disorders is critical in Nevada and across the nation. As the definition notes, quality care includes: research, diagnostic services, residential and long-term care, and well-trained residential and health care professionals.

Research

According to the “National Plan to Address Alzheimer’s Disease,” produced by the U.S. Department of Health and Human Services, 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 Estimated</u>	<u>FY 2013 Estimated</u>
Alzheimer's Disease	\$412	\$457	\$77	\$450	\$79	\$448	\$498	*\$449

* 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, would be \$529 million in FY 2013.

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. In Nevada, the ADSD currently provides dementia research and diagnosis funding to the Cleveland Clinic Lou Ruvo Center for Brain Health—Alzheimer's Diagnostic, Las Vegas, through Title III-B of the Older Americans Act. Various program partners and other community organizations, which apply for funding independently, obtain additional funding for research and diagnosis efforts.

Alzheimer's Services—ADSD Grant Funded Services FY 2012-2013			
<u>Type of Funds</u>	<u>Grantee</u>	<u>Type of Service</u>	<u>FY 2012-2013</u>
Fund for a Healthy Nevada			
Independent Living Funds	Northern Nevada Office, Alzheimer's Association	Respite	\$164,099
Independent Living Funds	Northern Nevada Office, Alzheimer's Association	Caregiver Support	\$42,165
Independent Living Funds	Desert Southwest Chapter, Alzheimer's Association	Respite	\$151,919
Independent Living Funds	Desert Southwest Chapter, Alzheimer's Association	Caregiver Support	\$53,550
Older Americans Act Funding			
Title III-B	Cleveland Clinic Lou Ruvo Center for Brain Health	Diagnostic	\$83,088
Title III-E	University of Nevada, Reno	Caregiver Support	\$106,432
Title III-E	Cleveland Clinic Lou Ruvo Center for Brain Health	Caregiver Support	\$72,677
		Total	\$673,930

Alzheimer's Disease Supportive Services Program (ADSSP) FYs 2010-2013*		
<u>Provider</u>	<u>Program</u>	<u>Amount</u>
Northern Nevada Office, Alzheimer's Association	CarePro	\$227,900
Desert Southwest Chapter, Alzheimer's Association	CarePro	\$275,234
Cleveland Clinic Lou Ruvo Center for Brain Health	CarePro	\$260,595
Arizona State University (Research)	CarePro	\$173,435
	Total	\$937,164

*Three-year discretionary grant from the U.S. Administration on Aging

Nevada is in position to compete for additional funding in this area. Testimony presented to the 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 one of the national studies of brain imaging and a blood test for Alzheimer's disease. The early detection tests include:

- Spinal fluid measuring of amyloid;
- Imaging amyloid in the brain through a scan; and
- Testing to measure the volumes of the brain, because when certain areas of the brain start shrinking, it has been found to be an indicator of Alzheimer's disease.^{xx}

In addition, various treatment strategies and prevention trials are being undertaken.

Several issues limit research trials in Nevada and 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 related disorders.

To increase research efforts in Nevada, the Task Force 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. In response to these discussions and after considering various recommendations, the Task Force moved to adopt several recommendations.

Recommendation 7: Establish a Nevada consortium to maximize current and future research and diagnostic efforts in our State to address Alzheimer’s disease and related disorders.

Indicators: Compile a list of Alzheimer’s-related researchers and research facilities in Nevada. Establish a facilitator and key consortium partners.

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.

Recommendation 8: Investigate and encourage expanded research opportunities throughout Nevada to study current and develop new medications that treat Alzheimer’s disease and related disorders. Also, promote the dissemination of information about treatments available to persons with Alzheimer’s disease and related disorders, including, but not limited to: approved drug regimens, investigational drugs available to Nevada residents, and the potential side effects of medications.

Indicators: Compile a list of current research projects. Increase in the number and type of research projects based in Nevada. Increase in utilization of available treatment by individuals in Nevada.

Potential Funding: Federal Alzheimer’s research grants; private-sector foundation grants; Cleveland Clinic Lou Ruvo Center for Brain Health.

Diagnostic Services

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.^{xxi} 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 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 the brain changes that lead to Alzheimer’s disease begin up to ten years before symptoms.^{xxii}

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 Task Force encourages leveraging direct care funding, such as Medicaid Annual Wellness Visits, to promote early detection and diagnosis.

Long-Term Care Facilities

In Nevada, the BHCQC is responsible for licensing, inspecting, and regulating all medical and other related facilities in the State. The options for long-term care facilities for individuals with Alzheimer's disease under the BHCQC include residential care facilities for groups and skilled nursing facilities. Surveys (inspections) are conducted in accordance with applicable regulations, based on the type of facility, and follow specific time frames and procedures. The BHCQC also conducts complaint investigations for all licensed and/or certified facilities. Both long-term care facility 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 Alzheimer's patients 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 long-term care administrators in Nevada, including nursing homes and group care facilities/assisted living facilities. 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 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 seniors who are over the age of 60 and 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 facilities must meet certain requirements in Nevada to be recognized as "assisted living facilities." In addition, residential care facilities 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 facilities (assisted living facilities) are licensed, based on the number of residents. The two facility license types are facilities with 10 or fewer residents, which are usually in a residence or home, and facilities with 11 or more residents, which are usually a special unit as a part of a larger assisted living facility. The following chart outlines the distribution of these facilities:

Residential Care Facilities for Groups				
Location	Residents 10 or fewer	Residents 11 or more	Total Number of Licensed Beds	Licensed Beds with Alzheimer's Endorsement
Northern Nevada	0	8	2,616 Statewide	268
Southern Nevada	76	17		1,269

Facilities with an Alzheimer's disease endorsement may charge prices ranging from \$1,000 per month for those declaring to be low-income (42 beds are low-income based on the BHCQC's current database) up to \$5,700 per month. Some larger facilities have the option of shared accommodations and the rate varies from \$2,995 to \$3,850 per month.^{xxiii}

Recommendation 9: Review current funding and funding streams to support the development of quality long-term care facilities in Nevada. Provide funding or incentives to encourage long-term care organizations to develop inpatient facilities and to encourage existing facilities to increase inpatient capacity for placement of individuals with Alzheimer's disease and related disorders.

Indicators: Increased number of long-term care placement options for persons with Alzheimer's disease and related disorders.

Potential Funding: Economic development funds (Economic Development Authority of Western Nevada, Nevada's Office of Economic Development, Nevada Development Authority); tax incentives.

Long-Term Care for Alzheimer's Disease Patients With Challenging Behaviors

Testimony indicated that 35 individuals with Alzheimer's disease or related disorders and behavioral problems are placed in out-of-state nursing facilities at an annual cost to the State of approximately \$2.3 million. Nevada has a shortage of skilled nursing facilities that provide care to this patient group. Presently, eight skilled nursing facilities accommodate individuals in a secured setting; three are in northern Nevada and five are in southern Nevada. Frequently, these patients are seen in hospital emergency rooms to receive medical care and are unable to be placed in a skilled nursing facility.

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

- Industry concerns about increased potential for cited deficiencies and possible sanctions related to aggressive 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; and
- Difficulty in recruiting staff who are trained to manage behavior effectively.

Several methods to address the problem were presented in 2003 and were recounted for the Task Force. Those recommendations include:

- Recruiting an out-of-state provider with a specialty in working with this population to open a facility in Nevada;
- Developing a team to identify behavioral interventions necessary to address the needs of an individual and enhance patient safety. The team would be readily available to assist nursing facilities 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. Reviewing regulatory measures that may serve as barriers to facilities that are willing to retain more behaviorally challenged patients
- b. Investigating the feasibility of having specialized units in facilities in Nevada that specialize in dementia care for individuals with challenging behavioral issues.
- c. Using a higher reimbursement rate as an incentive for facilities to provide specialized care.
- d. 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.
- e. Developing a collaborative effort to promote evidence-based, patient-centered approaches to preventing and treating challenging behaviors of individuals with Alzheimer's disease and related disorders.
- f. Developing plans for more adequate placement of individuals with Alzheimer's disease and related disorders, including the need for in-State facilities to treat more behaviorally challenged patients.

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 collaboration 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 potential grants.

Training, Education, and Professional Development

The 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 related disorders, 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 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.^{xxiv}

The 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. However, educational challenges still exist, including:

- A need to standardize and increase 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;
- Increased 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;

- Greater consideration of, and sensitivity to, cultural issues; and
- Providing continuing education focused on Alzheimer's disease and dementia care for primary care physicians.

Recommendation 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 related disorders.
- 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: Volunteers from the Task Force, Alzheimer's Association, and other advocacy organizations; other potential grant funding sources.

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 related disorders 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 number of quality 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 training and education about Alzheimer's disease and related disorders for all levels of medical personnel in a hospital, including emergency room personnel and others responsible for admission and discharge. Encourage the Nevada Hospital Association, in collaboration with subject matter experts from the Alzheimer's Association, research, and educational organizations, to develop a care pathway plan for the management of

patients with cognitive impairment entering the hospital. Provide incentives and recognition for outstanding facilities that have effectively implemented care pathways.

Indicators: Change in regulations—Chapter 449 of the *Nevada Administrative Code*.

Potential Funding: Nevada BHCQC; Nevada Hospital Association; Alzheimer’s Association; other possible 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 related disorders.

Indicators: Monitor policy changes through law enforcement, Emergency Medical Technician, and fire department associations.

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

Chapter 4: Quality of Life

For the Persons With Dementia

The profound changes brought on by cognitive disorders, such as Alzheimer’s disease, often lead to frustration, sadness, anger, and worry.^{xxv} Individuals with dementia gradually lose the ability to complete activities of daily living and also have a limited ability to seek or access pleasant events and experiences. 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.^{xxvi} Anxiety has been found in 20 percent of community-dwelling individuals with dementia.^{xxvii}

The good news is that depression and anxiety in persons with dementia can be improved with psychosocial interventions.^{xxviii} 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.^{xxix} Physical therapy, aromatherapy, and other interventions have also demonstrated benefits.^{xxx}

Persons with dementia may have comorbid 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.^{xxxi} 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.^{xxxii} Research indicates that persons with dementia and comorbid cancer, or other serious illnesses, are more likely to be given less pain medication than nondemented patients.^{xxxiii}

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.^{xxxiv}

For the 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 noncaregivers of the same age.^{xxxv}

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).^{xxxvi} Families and professionals may remain unaware of reporting criteria and do not have valid screening tools, so many more cases may go unreported.^{xxxvii}

Studies have shown that dementia education and structured support groups are beneficial in reducing caregiver depression, stress, and other problems.^{xxxviii} 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.^{xxxix} 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.^{xl}

Recommendation 15: Provide and expand respite services for family caregivers of persons with Alzheimer's disease and related disorders with the goal of reducing the need for emergency room visits and caregiver stress. Broaden the eligibility requirements for use of respite programs and grants so that more families may benefit from them regardless of financial status or age.

Indicators: Number of caregivers using respite services; hours of respite utilized.

Potential Funding: Fund for a Healthy Nevada; Retired and Senior Volunteer Program (RSVP); Older Americans Act funding.

Recommendation 16: Explore the use of volunteers to provide support to family caregivers by collaborating with community organizations and faith-based groups.

Indicators: Monitor volunteer organizations that agree to provide support.

Potential Funding: Voluntary outreach by members of the Task Force and other volunteers.

Recommendation 17: Enforce mandatory administrative or judicial reviews of all persons with dementia under guardianship who are involuntarily placed out of state. These reviews should be conducted at least every six months for this fragile population to reevaluate appropriateness of placement, reasonableness of care, and efforts to return the person to his or her home or to the most homelike, least restrictive setting.

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: Establish 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 altogether, i.e., a mobile dementia team approach.

Indicators: Increasing number of home-based services and long-term care in the State. Establishing a central location where available appropriate placements can be accessed.

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

Chapter 5: 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.

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.^{xli}

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.^{xlii} 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, 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.^{xliii}

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 should he or she become lost or need assistance. In Nevada, the Alzheimer’s Association has reported that this program has been underutilized.^{xliv}

Driving

Driving is a major public safety issue for persons with Alzheimer’s disease and related disorders. 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.^{xlv} 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: Collaborate with the business community to create employee assistance programs that include education and training for caregivers. Develop partnerships with other organizations that are also affected by Alzheimer’s disease and related disorders, 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.

Recommendation 20: 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 related disorders. 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, hopeful, and likely to access available services. The campaigns will be promoted through television and radio advertisements, 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. The general public.
- c. 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.

Indicators: Number of media advertisements, announcements, interviews, and stories; number of professionals and professional organizations contacted; number of visits to the Nevada ADRC website.

Potential Funding: Volunteers from the Task Force; Alzheimer’s Association; professional licensing boards and organizations; Nevada Broadcaster’s Association; Nevada ADSD; 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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APPENDIX A

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

Assembly Concurrent Resolution No. 10
Assemblywoman Smith

FILE NUMBER 42

ASSEMBLY CONCURRENT RESOLUTION—Directing the
Legislative Committee on Health Care to create a task force
to develop a state plan to address Alzheimer’s disease.

WHEREAS, Alzheimer’s disease is a progressive, degenerative brain disorder characterized by memory loss, language deterioration, poor judgment and indifferent attitude, but preserved motor function; and

WHEREAS, Approximately 5.4 million Americans now suffer from Alzheimer’s disease, including approximately one in every eight persons over 65 years of age and nearly half of those persons over 85 years of age; and

WHEREAS, The proportion of the country’s population that is over the age of 65 continues to rapidly increase and will escalate in coming years as the “Baby Boomer” generation ages, and at the current rate of incidence, the number of people aged 65 years and older with Alzheimer’s disease may rise to as high as 11 to 16 million by the year 2050, barring the development of medical breakthroughs; and

WHEREAS, This rapid rise is already evident, and is especially dramatic in Nevada, which has seen a 38 percent increase in its population of residents 65 years of age and older with Alzheimer’s disease between 2000 and 2010, and this population is expected to double between 2000 and 2025; and

WHEREAS, Most persons with Alzheimer’s disease will survive for 4 to 8 years after diagnosis but may live as long as 20 years after the onset of symptoms; and

WHEREAS, Nearly 15 million Americans provide unpaid care for a family member or friend who has Alzheimer’s disease or another form of dementia, with more than 60 percent of those caregivers rating the emotional stress of caregiving as high or very high and one-third reporting symptoms of depression; and

WHEREAS, At some point, an Alzheimer’s victim will require 24-hour care, including assistance with such daily activities as eating, grooming and toileting; and

WHEREAS, It has been estimated that expenses for the diagnosis, care and treatment of Americans with Alzheimer’s disease will amount to at least \$183 billion in 2011, with the expected costs of Alzheimer’s to Americans in 2050 totaling \$1.1 trillion in today’s dollars; and

- 2 -

WHEREAS, Alzheimer's disease is the sixth leading cause of death in the United States and the fifth leading cause of death for those aged 65 years and older, and it remains the only cause of death among the top 10 in the country without any known preventive measures or cure; and

WHEREAS, There is a compelling need in this State to prepare and implement strategies to reduce the impact of this heartbreaking disease on patients, caregivers and the economy and to forestall human and financial hardship of exceptional severity; now, therefore, be it

RESOLVED BY THE ASSEMBLY OF THE STATE OF NEVADA, THE SENATE CONCURRING, That the Legislative Committee on Health Care is hereby directed to create a task force to develop a state plan to address Alzheimer's disease; and be it further

RESOLVED, That to the extent that money is available, including, without limitation, money from gifts, grants and donations, the Legislative Committee on Health Care may fund the costs of the task force; and be it further

RESOLVED, That the Legislative Committee on Health Care shall submit a report of the findings and plan developed by the task force and any recommendations for legislation to the 77th Session of the Nevada Legislature.

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APPENDIX B

Designation of Alternates

**Legislative Committee on Health Care's Task Force to Develop a State Plan
to Address Alzheimer's Disease (A.C.R. 10)**

DESIGNATION OF ALTERNATES

July 11, 2012

Task Force Member	First Alternate	Second Alternate
Charles Bernick, M.D. Associate Medical Director, Cleveland Clinic Lou Ruvo Center for Brain Health, Las Vegas	Susan Hirsch, M.S.W., L.C.S.W. Director, Social Programs, Cleveland Clinic Lou Ruvo Center for Brain Health, Las Vegas	LeeAnn Mandarino Program Manager, Cleveland Clinic Lou Ruvo Center for Brain Health, Las Vegas
Albert Chavez, Ed.S., CFLE Regional Director, Southern Nevada Region, Desert Southwest Chapter, Alzheimer's Association	Phil Carl Director of Programs and Advocacy, Southern Nevada Region, Desert Southwest Chapter, Alzheimer's Association	Deborah Schaus Executive 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	Vicki Lebsack Northern Nevada Alzheimer's Association	Joyce Mendiola Winnemucca Alzheimer's Support Group
Ruth Gay, M.S. Director, Public Policy and Advocacy, East Bay Office Site Director, Northern California and Northern Nevada Chapter, Alzheimer's Association	Angie Pratt Regional Director, Northern Nevada Office, Northern California and Northern Nevada Chapter, Alzheimer's Association	Kimberly Weber, M.P.A. Policy Specialist, Northern Nevada Office, Northern California and Northern Nevada Chapter, Alzheimer's Association

Submitted by Roger McClellan, Health Care Policy Specialist, Legislative Counsel Bureau

**Legislative Committee on Health Care's Task Force to Develop a State Plan
to Address Alzheimer's Disease (A.C.R. 10)**

DESIGNATION OF ALTERNATES

July 11, 2012

Task Force Member	First Alternate	Second Alternate
Sandra Owens, Ph.D. Associate Professor, School of Social Work, University of Nevada, Las Vegas	Pam S. Gallion, M.Ed. Director, Cannon Survey Center in Educational Outreach, University of Nevada, Las Vegas	
Wendy Simons Chief, Bureau of Health Care Quality and Compliance, Health Division, Department of Health and Human Services	Mary Liveratti Administrator, Aging and Disability Services Division, Department of Health and Human Services	Diane Allen HFI IV, Bureau of Health Care Quality and Compliance, Health Division, Department of Health and Human Services

Revised July 10, 2012

APPENDIX C

Resources for Persons and Caregivers of Persons With Alzheimer's Disease or Related Disorders

Resources for Persons and Caregivers of Persons With Alzheimer's Disease or Related Disorders

Alzheimer's Association

The Alzheimer's Association	Internet Address: alz.org Telephone: (800) 272-3900
Alzheimer's Association, Northern California and Northern Nevada Chapter	Internet Address: http://www.alz.org/norcal/index.asp Telephone: (775) 786-8061
Alzheimer's Association, Desert Southwest Chapter (Southern Nevada)	Internet Address: http://www.alz.org/dsw/ Telephone: (702) 248-2770

Federal Agencies

United States Administration on Aging	Internet Address: http://www.aoa.gov Telephone: (800) 677-1116
United States Department of Health and Human Services	Internet Address: Alzheimers.gov

State Agencies

Nevada Division on Aging and Disability Services	Internet Address: http://aging.state.nv.us Carson City Telephone: (775) 687-4210 Reno: (775) 688-2964 Elko: (775) 738-1966 Las Vegas: (702) 486-3545
Nevada Health Division, Bureau of Health Care Quality and Compliance	Internet Address: http://health.nv.gov/HCQC.htm Telephone: (775) 684-1030
Nevada's Aging and Disability Resource Center	Internet Address: nevadaadrc.com

Resources for Persons and Caregivers of Persons With Alzheimer's Disease or Related Disorders

Medical Center

Cleveland Clinic Lou Ruvo Center for Brain Health	Internet Address: http://my.clevelandclinic.org/neurological_institute/lou-ruvo-brain-health/default.aspx Telephone: (866) 588-2264
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Service Organization (Respite Services)

Nevada Rural Counties Retired and Senior Volunteer Program	Internet Address: http://www.nevadaruralrsvp.org Telephone: (775) 687-4680
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Universities

Touro University Nevada	Internet Address: http://www.tun.touro.edu/ Telephone: (702) 777-8687 <ul style="list-style-type: none"> • Geriatricians provide care to community members at the Touro Health Center and throughout the community. • Active Aging Center • Geriatric Education Consortium • Caring Without Walls: http://tun.touro.edu/wp-content/uploads/CaringWithoutWalls_information_request-form.pdf • Student-run free Physical Therapy Clinic: http://tun.touro.edu/wp-content/uploads/TUN_StudentPT_Clinic.pdf Telephone: (702) 777-3974
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Resources for Persons and Caregivers of Persons With Alzheimer's Disease or Related Disorders

<p>University of Nevada, Las Vegas</p>	<ul style="list-style-type: none"> • School of Dental Medicine Community Outreach: Geriatric Population: http://www.unlv.edu/icare Telephone: (702) 774-2667 E-mail: georgia.dounis@unlv.edu • The Partnership for Research, Assessment, Counseling, Therapy, and Innovative Clinical Education Clinic (The Practice): http://education.unlv.edu/practice Telephone: (702) 895-1532 • UNLV Cannon Survey Center, A Portrait of Nevada's Seniors: http://surveys.unlv.edu/cscdrupal/sites/online.unlv.edu.cscdrupal/files/SeniorStudy_0.pdf Telephone: (702) 895-5462
<p>University of Nevada, Reno</p>	<ul style="list-style-type: none"> • Sanford Center for Aging: http://www.unr.edu/sanford Telephone: (775) 784-4774 • Orvis School of Nursing Care of Community and Mental Health Populations: Practice: http://www.unr.edu/nursing Telephone: (775) 784-6841 • Senior Outreach Services: http://www.unr.edu/sanford/programs/sos Telephone: (775) 784-7506 • The Nevada Caregiver Support Center: http://www.unr.edu/sanford/ncsc/default.aspx Telephone: (775) 784-4335

