

# DEPARTMENT OF HEALTH AND HUMAN SERVICES

# Aging and Disability Services Division Helping people. It's who we are and what we do.



Dena Schmidt

February 1, 2021

Brenda Erdoes, Director Legislative Counsel Bureau 401 South Carson St. Carson City, NV 89701

SUBJECT: Taskforce on Alzheimer's Disease – Annual Report

Dear Ms. Erdoes:

Please find enclosed the final Nevada State Plan to Address Alzheimer's Disease 2021-22. If you have any questions about this report, please do not hesitate to contact me at <a href="mailto:psreed@unr.edu">psreed@unr.edu</a>.

Sincerely,

Peter Reed, PhD, MPH

tu S. Reed

Chair

**Enclosure** 

Cc: Richard Whitley, Director, Department of Health and Human Services

Dena Schmidt, Administrator, Aging and Disability Services Division

# THE NEVADA STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE 2021-2022



January 2021

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

#### TASK FORCE ON ALZHEIMER'S DISEASE

Peter Reed, PhD, MPH, Chair Director, Sanford Center for Aging, School of Medicine Professor, Community Health Sciences University of Nevada, Reno

Tina Dortch, Vice Chair Program Manager, Nevada Office of Minority Health and Equity Nevada Department of Health and Human Services

#### **Members**

Jennifer Carson, PhD Director, Dementia Engagement, Education and Research Program School of Community Health Sciences, University of Nevada, Reno

Lesley Cohen Assemblywoman, Nevada State Legislature

Virginia (Gini) L. Cunningham, M.Ed. Volunteer and Support Group Facilitator, Humboldt Volunteer Hospice and Alzheimer's Association of Northern Nevada

Marilyn Dondero Loop Senator, Nevada State Legislature

Charles Duarte
Dementia Care Director
Alzheimer's Association Northern California and Northern Nevada Chapter

Connie Johnson State Liaison Officer, Northern Nevada State Veterans Home

Wendy Knorr Program Manager, Nevada Department of Veterans Services

Marwan Sabbagh, MD, FAAN, CCRI Camille and Larry Ruvo Chair for Brain Health Director, Cleveland Clinic Lou Ruvo Center for Brain Health

# Nevada State Plan to Address Alzheimer's Disease: 2021-2022 Prepared by the Nevada Task Force on Alzheimer's Disease (TFAD) Nevada Revised Statute 439.5083

#### Introduction

#### The Impact of Dementia:

The term 'dementia' refers to a collection of symptoms that compromise a person's cognitive function, including but not limited to changes in their memory, problem solving, reasoning and capacity to fulfill activities of daily living. While Alzheimer's disease is the most common cause of dementia, comprising about 70 percent of all dementia diagnoses, approximately 130 different causes of dementia have been identified, including Vascular dementia, Lewy Body dementia, Frontotemporal dementia, and many others. Often people living with dementia are experiencing the effects of more than one cause, referred to as 'mixed dementia.'

According the Alzheimer's Association's 2020 Alzheimer's Disease Facts and Figures, it is estimated that 5.8 million people are living with Alzheimer's or other form of dementia in the US, and that the prevalence will increase to 13.8 million people by 2050 (reflecting a 138% increase). Further, one in 10 people ages 65 and older are living with dementia, with dramatic increases as one ages from 65 – 74 (3%) to 85+ (32%). In addition, as noted in the Alzheimer's Association report, the Behavioral Risk Factor Surveillance System (BRFSS), a population-based health study conducted by the Centers for Disease Control and Prevention in conjunction with state health departments, shows that 11% of people in the US ages 45 and older report subjective cognitive decline, while only around half of those experiencing these signs of cognitive impairment have discussed it with a healthcare provider.

In Nevada, the Alzheimer's Association report estimates that there are approximately 49,000 people living with dementia in 2020, and further projects this will increase to 64,000 by 2025, representing a 30.6% increase over five years as the population of Nevada continues to rapidly age. This rate of growth is the third fastest among all US states, behind only Arizona and Vermont. The impact of this large population of people living with dementia in Nevada is, and will continue to be, significant in many ways, including: disenfranchisement and stigma of those living with dementia, challenges among family members and other care partners in effectively supporting people living with dementia, capacity of long-term supports and services, declines in general workforce productivity, and strains on the healthcare workforce and financing (i.e., Medicare and Medicaid). The costs of these impacts are immeasurable.

With this explosive need in Nevada, the Task Force on Alzheimer's Disease (TFAD) contributes timely and essential information as well as insights through its State Plan, Annual Reports, and bi-monthly meetings. On a continuous basis, TFAD provides focused and crucial information about policies, practices, and programs to the Nevada Aging and Disability Services Division and Department of Health and Human Services, which work daily to serve the needs of persons living with Alzheimer's disease and other forms of dementia in Nevada.

#### Additional Context for the State Plan:

The 2021-2022 Nevada State Plan to Address Alzheimer's Disease, prepared by the TFAD, includes fifteen recommendations related to ensuring that effective information, education, care and support and public policy appropriately address dementia on behalf of all Nevadans (see below). Reflected within the formal recommendations, TFAD also states its support for several core concepts forming a general framework for understanding and proactively supporting a positive lived experience of dementia. These include TFAD's support for:

- Dementia-friendly communities, where those living with Alzheimer's disease and other forms of dementia, along with their caregivers, feel and experience respect, dignity, support, value and inclusion in everyday community life;
- Innovative ways of thinking that provide opportunities for persons living with Alzheimer's disease and other forms of dementia to experience full and meaningful lives;
- Proactive collaborations between healthcare professionals, first responders, community organizations, the business community, educators, caregivers, volunteers and others to provide dementia-friendly services and supports that nurture a full and optimal quality of life for persons living with Alzheimer's disease and other forms of dementia;
- Ongoing education and professional development for persons who, directly or indirectly, serve and support persons living with Alzheimer's disease and other forms of dementia, as well as their caregivers;
- Best practices, informed by existing and emerging evidence, for all individuals
  and entities that are making contributions to the quality of life and well-being for
  persons with Alzheimer's disease and other forms of dementia, as well as their
  care partners;
- Continuous and expansive public awareness activities that increase the critical consciousness within Nevada's communities regarding the importance of understanding dementia, honoring the lived experience of dementia and valuing the potential contributions that may be made by people living with dementia;
- Monitoring and surveillance of the presence of dementia within Nevada as well as the impact and effectiveness of TFAD recommendations, state and community-based initiatives to support people living with dementia and their care partners; and last but not least,
- TFAD embraces the foundational assumption that despite the cognitive and physical challenges that accompany dementia, when offered the proper supports and respect, people can live well with dementia.

#### Monitoring and Surveillance:

#### Ongoing Assessment of TFAD State Plan Recommendations

Each recommendation included in this State Plan notes specific indicators that will be monitored to document progress. TFAD will monitor these indicators on a regular basis during its meetings throughout the timeframe for this plan (2021 – 2022). This monitoring will occur through TFAD invitations to key partners, organizations and programs to present on their work relative to specific recommendations, at least once each biennium. The goal of these partner presentations is to keep TFAD informed of relevant information on related efforts and collaborations across Nevada, as well as to offer TFAD members the opportunity to stay engaged with relevant partners. During these partner presentations, TFAD members will ask clarifying questions and participate in dialogue to offer their insights to the partners.

For example, in Recommendation #1 relating to information and referrals systems, the Nevada Aging and Disability Services Division is specifically noted as a partner monitoring certain aspects of the recommendation. At least once in the two-year cycle of the state plan, ADSD will be invited to present and discuss the data they have collected related to information and referral systems.

#### Healthy People 2030

It is the one of the goals of this Task Force to raise awareness around Alzheimer's disease and related dementias, as well as the importance of getting an early and accurate diagnosis. The impact of Alzheimer's disease and related dementias may be overwhelming for the people living with the disease, as well as for their caregivers and families. Alzheimer's disease awareness needs to be elevated as a public health priority.

Since 1980, the U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion has set measurable goals and objectives for the health and well-being of people nationwide. The initiative, called Healthy People, is in its fifth iteration, Healthy People 2030 (HP 2030). This initiative builds on knowledge and research gained over the preceding four decades and addresses the nation's most pressing public health challenges.

All HP 2030 objectives meet several criteria, including having baseline data, a direct impact on health, and an evidence base. These criteria address the goals related to health, function and quality of life. The HP 2030 framework sets important public health priorities for the nation over the next decade and will measure progress towards meeting those objectives.

By 2060, almost a quarter of the U.S. population will be age 65 or older. Older adults are at a higher risk of chronic health problems including diabetes, osteoporosis, as well as Alzheimer's disease and other dementias. Nearly 6 million people in the United States have dementia, and that number will increase as the population ages. As such, a goal of HP 2030 is to "Improve health and quality of life for people with dementia, including Alzheimer's disease."

HP 2030 includes three objectives related to this goal. These include the following:

1. Increase the proportion of older adults with dementia, or their caregivers, who know they have the disease;

- 2. Reduce the proportion of preventable hospitalizations in older adults with dementia; and
- 3. Increase the proportion of adults with subjective cognitive decline (SCD) who have discussed their confusion or memory loss with a health care professional. <sup>1</sup>

While it is important to monitor all of these objectives, only objective 3 is readily measurable at a state level. Data derived from the Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System (BRFSS) Cognitive Decline survey module, which is conducted biennially in Nevada, is used in this objective.<sup>2</sup>

- 1. In Nevada, 16.3% one in six of those age 45 or older report experiencing confusion or memory loss that is happening more often or is getting worse (subjective cognitive decline); and
- 2. Of those reporting subjective cognitive decline, 49.6% have not talked with a health care professional about it.<sup>3</sup>

While there's no cure for Alzheimer's disease or many other forms of dementia, early diagnosis and supportive care can improve quality of life. Equally important, getting an early and accurate diagnosis can allow the person in the early stages of the disease to be a full participant in planning for their care including advanced directives, legal and financial affairs, and arranging for future care. Making it possible for adults with symptoms of cognitive decline, including memory loss, to obtain an early diagnosis is a public health priority and a key focus of this Task Force.

The HP 2030 objectives for dementia, including Alzheimer's disease, provide a framework for improving health and health equity across the nation by monitoring improvements in early diagnosis for those reporting subjective cognitive decline. To monitor and assess progress toward HP 2030, TFAD strongly encourages the continued collection of the BRFSS module on Cognitive Decline, using any resources available from the Department of Health and Human Services to do so.

#### **Emergency Preparedness:**

Emergency preparedness, as recently highlighted by the COVID-19 pandemic, presents unique challenges for people living with dementia whether at home, in the community, or in congregate care settings such as nursing homes, assisted living communities, or residential group homes. Whether it is a fast-occurring emergency, such as wildfires, blizzards or earthquakes, or a slow-developing emergency, like a viral pandemic, preparation is key.

People living with Alzheimer's disease or other dementias can be disproportionately impacted

<sup>&</sup>lt;sup>1</sup> From website, Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2020, <a href="https://health.gov/our-work/healthy-people-2030">https://health.gov/our-work/healthy-people-2030</a>.

<sup>&</sup>lt;sup>2</sup> From website, Behavioral Risk Factor Surveillance System (BRFSS) Modules and Statistical Briefs, Center for Disease Control and Prevention, <a href="https://www.cdc.gov/brfss/index.html">https://www.cdc.gov/brfss/index.html</a>.

<sup>&</sup>lt;sup>3</sup> From, Cognitive Decline in Nevada: Data from the Risk Factor Surveillance System, Alzheimer's Association, 2016.

during a disaster. Often these individuals also have multiple chronic medical conditions increasing their vulnerability to periods without food, water, shelter, rest or needed medications. They may also have a limited ability to respond and act effectively during an emergency. It is important to encourage people living with dementia to have an advance care plan to clearly state their wishes. To fully support a person's wishes, it is important for both professional and family caregivers to have a plan that considers the special needs and preferences of those living with dementia, taking their advance care plan into consideration.

#### For Those Living at Home

It is important for caregivers to have a disaster plan that can meet the needs of their family for at least 3 to 7 days. This includes having supplies, including items such as incontinence undergarments, wipes and lotions, as well as medications, warm clothing and spare eyeglasses and hearing aid batteries. In addition, it is important to have contact information for one's healthcare provider, as well as copies of legal, medical, insurance and Social Security documents.

Families may also need to be prepared should they become separated from the person living with dementia, for any reason. MedicAlert® identification bands and labels in garments will aid in the identification and safe return of a person living with dementia. Families may also want to have photos of the person available to aide emergency services in case of a search.<sup>4</sup>

There are a number of resources available for caregivers preparing an emergency plan, including but not limited to, the following:

- Administration for Community Living disaster planning toolkit for people living with dementia at <a href="https://www.nia.nih.gov/health/disaster-preparedness-alzheimers-caregivers">https://www.nia.nih.gov/health/disaster-preparedness-alzheimers-caregivers</a>;
- American Red Cross website with general information on preparing for an emergency and where to find shelter and supplies in a disaster at <a href="https://www.redcross.org/get-help.html">https://www.redcross.org/get-help.html</a>; and
- MedicAlert® membership
   https://www.medicalert.org/alz?campaignID=online+:+link+:+1020onlinealz+:+enroll
   &utm source=email&utm medium=link&utm campaign=0719&utm term=renew

#### For Those Living in Long-term or Community-based Care Settings

Emergencies present special circumstances for individuals receiving care in long-term and community-based settings. People in these settings are particularly vulnerable to complications due to age and concurrent medical conditions. Forty-eight percent of nursing home residents and 42% of those living in residential care settings, including assisted living communities, are living with Alzheimer's disease or another form of dementia. Further, more than 30% of those using community-based services, such as home health or adult day services are living with a dementia diagnosis. In addition, more than a quarter of Medicare beneficiaries 65 year or older who are living with Alzheimer's disease or another dementia have five or more chronic conditions, whereas only 4% of Medicare beneficiaries without Alzheimer's disease or another

<sup>&</sup>lt;sup>4</sup> From web article "Disaster Preparedness for Alzheimer's Caregivers," National Institute on Aging, <a href="https://www.nia.nih.gov/health/disaster-preparedness-alzheimers-caregivers">https://www.nia.nih.gov/health/disaster-preparedness-alzheimers-caregivers</a>.

dementia have five or more chronic conditions.<sup>5</sup> The high percentage of persons with Alzheimer's disease or a related dementia living or receiving services in congregate settings, coupled with co-morbid conditions, makes them particularly vulnerable to disease or stress during emergency situations. Persons living with Alzheimer's disease or another dementia may become confused, frustrated or frightened during a crisis. They are often also less able to adapt to changes in setting. Efforts to minimize changes to routine and daily structure may be important.

One of the most important aspects in caring for someone living with dementia during a crisis is to know the person. Person-centered approaches to care and support are vital. Making sure the care setting or community-based program has personal information readily available will allow staff to quickly identify essential information about the person to help them to maintain a stable and comforting environment. Information such as the person's preferred name (or pronoun), cultural background, names of friends and family, details regarding their preferred routine, what upsets the person, and what calms the person down, are some of the aspects of person-centered care that will help during an emergency.<sup>6</sup>

For persons living in a residential setting or attending an adult day program, families or caregivers should learn about their disaster and evacuation plans in the event of an emergency. There is information and other resources available regarding emergency preparedness for persons living in nursing homes, assisted living and residential care communities, as well as those receiving community-based services, such as adult day services. The following are three of these resources:

- "Emergency Preparedness: Caring for persons living with dementia in a long-term or community-based setting," Alzheimer's Association, 2020, <a href="https://alz.org/media/Documents/COVID-19-">https://alz.org/media/Documents/COVID-19-</a> EmergencyTips\_LongTermCommunityBasedDementiaCare\_AlzheimersAssociation.pdf
- "CDC COVID-19 Resources: Guidance for Retirement Communities and Independent Living," Centers for Disease Control and Prevention, 2019, <a href="https://www.cdc.gov/coronavirus/2019-ncov/community/retirement/index.html">https://www.cdc.gov/coronavirus/2019-ncov/community/retirement/index.html</a>
- "Fact Sheet, Emergency Preparedness: Questions Consumers Should Ask," The National Consumer Voice for Quality Long-Term Care, 2018.
   <a href="https://theconsumervoice.org/uploads/files/issues/emergency-preparedness-factsheet-final-june.pdf">https://theconsumervoice.org/uploads/files/issues/emergency-preparedness-factsheet-final-june.pdf</a>

Emergency Situation Checklist – Quick Reference

Not all emergencies can be planned out or predicted. If you need immediate assistance for an emergency situation, dial 911. Additional considerations when you need to act quickly include:

• Remain calm and focus on your immediate safety and the safety of the person living with dementia. Evaluate whether it is safe to travel from your current location.

<sup>&</sup>lt;sup>5</sup> From web article, "Disaster Preparedness for Alzheimer's Caregivers," National Institute on Aging, https://www.nia.nih.gov/health/disaster-preparedness-alzheimers-caregivers

<sup>&</sup>lt;sup>6</sup> From, "Emergency Preparedness: Caring for persons living with dementia in a long-term or community-based care setting," Alzheimer's Association, 2020.

<sup>&</sup>lt;sup>7</sup> From web article, "Disaster Preparedness for Alzheimer's Caregivers, NIH.

- Keep medication, identification, and important legal and medical documents in a waterproof bag or where they will be readily accessible.
- Pack your cell phone charger and a couple sets of weather-appropriate clothing.
- Bring bottled water and non-perishable food items, such as granola bars.
- Alert others (such as family, friends and medical personnel) if you are changing locations, and ensure they have your contact information.

#### TFAD State Plan to Address Alzheimer's Disease, List of Recommendations

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### Nevada Task Force on Alzheimer's Disease 2021-2022 State Plan – Recommendations

#### Recommendation #1: Statewide Information and Referral System

Sustain a statewide information and referral system for people living with Alzheimer's disease and other forms of dementia, their caregivers, and their families to enable them to connect with local case managers and support services. It is the expectation that the approaches, content, and messaging within these resources help promote well-being and preserve dignity. Supportive services may be accessed through 'no wrong door' partners, including but not limited to: Nevada 2-1-1, Nevada Aging and Disability Resource Centers (ADRCs), also known as Nevada Care Connection (NCC) Resource Centers, Family Resource Centers (FRC), and other related informational systems (e.g. websites, helplines, and other technologies).

#### **Indicators**

Monitor collaborations between resource centers and available information and referral services, including but not limited to: Nevada 2-1-1, NCC Resource Centers, Northern California and Northern Nevada Chapter of the Alzheimer's Association, Southern Nevada Region, Desert Southwest Chapter of the Alzheimer's Association, and University of Nevada, Reno Nevada Caregiver Support Center, to help facilitate access and streamline processes into services and supports for people living with dementia and their care partners. The Aging and Disability Services Division (ADSD) will monitor the number of contacts made by outreach programs and the number of inquiries regarding information or services relating to Alzheimer's disease and other forms of dementia, received by NCC Resource Centers. In addition, ADSD and partners will monitor and report the number of "hits" on information websites, including nevadacareconnection.org and alz.org.

#### **Potential Funding**

Grants, donations and/or gifts. Specific sources may include:

• Older Americans Act funds (through ADSD)

#### **Recommendation #2: Telehealth**

Support expanded access to telehealth services throughout the state to enhance early detection, diagnosis of dementia and ongoing care. Encourage the use of telehealth for both persons living with dementia and family caregivers to support well-being and access to care, especially in rural Nevada. Utilize the statewide information and referral system (Recommendation #1) to include telehealth providers for persons living with dementia and connect to the network of providers convened by the Nevada CAN Geriatrics Telehealth Collaborative, and others as applicable.

#### **Indicators**

Monitor Telehealth projects across the state to determine if they are:

- Available and accessible;
- Being utilized effectively and efficiently; and

• Providing information/access to follow-up resources.

Review telehealth delivery data, including from Medicaid, Medicaid Managed Care Organization and Medicare Dual Special Needs Plans utilization data reports, to ensure better quality of life for patients living with dementia and their caregivers.

#### **Potential Funding**

Grants, donations and/or gifts.

Specific sources may include:

- Older Americans Act (through ADSD)
- Other federal resources: US Health Resources and Services Administration (HRSA) Geriatrics Workforce Enhancement Programs (GWEP), currently in progress at UNR & UNLV); US DHHS Office of Science and Technology.

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#### **Recommendation #3: Cultural Competence**

To help ensure successful processes and outcomes, advocates would benefit from engaging in non-stigmatizing sensitivity training, as well as proactive efforts to gain input from affected communities. Specific activities might include, without limitation:

- 1) Promoting implicit bias testing. Encourage personnel involved in public-facing engagements with the Alzheimer's community to take implicit bias assessments;
- 2) Promoting listening sessions. Before developing campaigns, entities conducting outreach should engage Alzheimer's community members to gauge impressions on aging services and healthcare experienced by its culturally-diverse and marginalized members; and
- 3) Promoting development and use of culturally-competent 'toolkits' as a resource to support entities providing awareness and outreach campaigns for the Alzheimer's community.

These activities align with the understanding that person-centered care involves non-stigmatizing, customized outreach approaches to address a multicultural population (i.e., reflecting differences in ability, generation, ethnicity/race, and sexual orientation/gender identity). Adopting this approach has been shown to increase a person's receptiveness to outreach efforts, improve the quality of their care and minimize their experienced health disparities.

#### **Indicators**

- Monitor number of created, adopted, and disseminated culturally-sensitive training programs and toolkits, including progress and implementation of Nevada SB 364 and SB 470 (2019).
- Monitor number of service providers that report having participated in cultural-sensitivity training.

#### **Potential Funding**

Grants, donations and/or gifts.

Specific sources may include:

- National Resource Center on LGBT Aging;
- US Department of Health and Human Services (US DHHS) Office of Minority Health
- Nevada Department of Health and Human Services (NV DHHS) ADSD Collaboration

\*

#### Recommendation #4: Outreach to Physicians

Continue to support collaborations between medical professionals and medical associations to adopt and promote use of best-practice diagnostic guidelines for Alzheimer's disease and other forms of dementia, to increase access to quality care and to encourage participation in available clinical trials. Support consistent, meaningful, and effective communication between these medical professionals and community-based service organizations, including bidirectional referrals to clinical and community-based resources.

Specifically, support statewide partnerships and collaborations to increase access to early diagnosis of Alzheimer's and other dementias, and to expand dementia care education across primary care practices and health systems in Nevada. These initiatives will include, but are not limited to, the HRSA GWEPs through the UNR and UNLV schools of medicine, the UNR Med Sanford Center for Aging, Project ECHO Nevada, the Cleveland Clinic Lou Ruvo Center for Brain Health, the UNR Dementia Engagement, Education and Research (DEER) Program's Dementia Friendly Nevada initiative, as well as the partnership between the Alzheimer's Association and the Nevada Division of Public and Behavioral Health (DPBH).

#### **Indicators**

Data gathered through the CDC Behavioral Risk Factor Surveillance System (BRFSS) survey modules on subjective cognitive decline and caregiver burden. Alzheimer's Association physician referral data reports, and other data on early detection/diagnosis, as available. To the extent practicable, NV DHHS will track and report Nevada-specific data related to the goal established in Healthy People (HP) 2030: Improve health and quality of life for people with dementia, including Alzheimer's disease. In addition, the Department shall report data for the following HP 2030 Dementia Including Alzheimer's (DIA) objective:

DIA-3: Increase the proportion of adults aged 45 years and older with Subjective Cognitive Decline (SCD) who have discussed their confusion or memory loss with a health care professional.

Data specific to Nevadans in the age group associated with DIA-3 is collected at least biannually by NV DHHS using BRFSS cognitive decline module. The module is a six-question survey used to determine how cognitive decline affects individuals age 45 and older in performing activities of daily leaving including caring for themselves.

#### **Potential Funding**

Grants, donations and/or gifts.

#### **Recommendation #5: State Match Program for APRNs**

Support the establishment of a state match program between the NV DHHS, collaborating with the State Board of Nursing, and federal partners. This match program is intended to address the state's health provider shortage in rural and frontier communities. Match money, which could be offered as loans or scholarships, would be made available to APRNs, who commit to the specified loan or scholarship terms and required service provisions as they relate to providing health care services to underserved rural and frontier areas in Nevada.

#### **Indicators**

Primary Care Workforce Development Office, NV DHHS, working with the State Board of Nursing, would monitor the number of APRNs serving under-served rural and frontier areas in Nevada.

#### **Potential Funding**

Grants, donations and/or gifts. Specific sources may include:

- HRSA grants;
- State appropriations.

#### **Recommendation #6: Long-term Care**

Continue to review current funding and new funding streams to support the development of quality long-term care options for people living with Alzheimer's disease and other forms of dementia in Nevada. Provide funding or incentives to encourage long-term care providers to increase capacity for placement of individuals with Alzheimer's disease and other forms of dementia. Also emphasize person-centered planning that helps promote well-being and preserves dignity, as well as helping residents, their families, and caregivers, feel and experience respect, dignity, support, value, and inclusion in everyday community life. Encourage the identification, adoption and implementation of established, evidence-informed, person- and relationship-centered dementia care training recommendations and training programs, including but not limited to: the Nevada Department of Veterans (NDVS) Services Bravo Zulu program, Alzheimer's Association Dementia Care Practice Recommendations, Dementia Action Alliance/Eden Alternative's Raising the Bar practice guide, and others as appropriate.

#### **Indicators**

Monitor the number of long-term care options for persons with Alzheimer's disease and other forms of dementia across the state, as well as success of long-term care dementia training programs as noted in the recommendation.

#### **Potential Funding**

Grants, donations and/or gifts.

Specific sources may include:

- Medicaid expansion through Home- and Community-Based Services Waiver;
- Expansion through the DHHS Behavioral Rate for skilled nursing facilities;
- Increased supplemental SSI rate;
- Tax incentives.

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#### **Recommendation #7: Caregiver Support**

Provide caregivers with information about and access to evidence-based/informed education, support services, and resources to:

- 1) Promote knowledge and understanding of Alzheimer's disease and other forms for dementia:
- 2) Increase understanding of effective approaches to care and support;
- 3) Provide and expand respite services for family and informal caregivers of persons with dementia; and
- 4) Enhance caregiver well-being.

These services include, but are not limited to, family care consultations, solution-focused caregiver support groups, educational programs and services, respite programming and evidence-based programs as included in the Nevada Dementia Supports Toolbox. Support efforts to promote and fund comprehensive caregiver education and services that are provided by many organizations, including, but not limited to: AARP, Alzheimer's Association, Catholic Charities, the Cleveland Clinic Lou Ruvo Center for Brain Health, UNR DEER Program, NDVS, Nevada Senior Services, UNR Nevada Caregiver Support Center and UNR Med Sanford Center for Aging.

- Broaden the eligibility requirements for programs and grant funding so that more families may benefit from them regardless of financial status or age.
- Support the Dementia Friendly Nevada initiative and the work of the state's Dementia Friendly Community Action Groups throughout Nevada.
- Improve access to support services and programs by sustaining a statewide information and referral system (recommendation #1) for families, caregivers, and individuals with Alzheimer's disease and other forms of dementia.

#### **Indicators**

ADSD and DPBH will track and compile data collected from their respective funded programs. ADSD will annually monitor program availability, waitlists, number of consumers/clients served, and hours of caregiver support services provided through ADSD-funded programs. Key partners and other dementia-related organizations that are working in alignment to support these efforts will also be asked to report on service delivery and outcomes from caregiver support programs.

#### **Potential Funding**

Grants, donations and/or gifts. Specific sources may include:

• Fund for a Healthy Nevada;

- Retired and Senior Volunteer Programs (RSVP);
- Older Americans Act Funding (through ADSD);
- The Alzheimer's Association.

\*

#### **Recommendation #8: Dementia Training**

TFAD encourages the State of Nevada to identify, adopt, and/or develop, a consistent, high-quality, comprehensive dementia training program that aligns with NRS 449.094 requirements and current national practice recommendations. This program should be made available to all residential and community-based aging services through leveraging key partners to encourage and implement the program, including program delivery and evaluation.

#### **Indicators**

A high-quality, comprehensive dementia training program is identified or developed and made available to all residential and community-based aging services statewide. The identified or developed program is encouraged by key partners. The program is adopted and implemented by an increasing number of residential and community-based aging services over the plan's two-year period.

#### **Potential Funding**

Grants, donations and/or gifts. Specific sources may include:

• State appropriation and/or state grants for the proposed dementia training initiative.

#### **Recommendation #9: Volunteers**

Promote collaboration between various organizations including non-profits, service organizations, healthcare institutions, faith-based organizations and universities, which have existing programs, education, and practices that address Alzheimer's disease and other forms of dementia, to recruit and train volunteers in delivering support programs and services, while providing the necessary infrastructure and support to volunteers to ensure their effectiveness. This commitment to education and outreach needs to include rich and abundant train-the-trainer models that permit and encourage volunteers to share knowledge, information, tools and resources in communities while finding, recruiting, and training local residents to continue to learn more about Alzheimer's disease and other forms of dementia. Increased outreach and personal connections among volunteers and community members will help de-stigmatize and reduce fear and misunderstanding associated with dementia through open-conversations and reliable information.

In supporting age- and dementia-friendly communities, volunteers will learn how to promote each person's well-being, as well as preserve their personal dignity and respect in everyday community life. It is essential to dispel the myth that volunteers lack the knowledge and capabilities to fulfill this critical role.

#### **Indicators**

Monitor and correspond with non-profits, service organizations, healthcare institutions, and universities that recruit volunteers to learn the number of volunteers recruited, the types of training they offer and how many volunteers they train, as well as to track key services being provided. Determine which additional trainings and services might be needed to expand volunteer education and opportunities.

#### **Potential Funding**

Grants, donations, and/or gifts.

#### Recommendation #10: Awareness of Dementia and the Legal Profession

Awareness of Alzheimer's disease and other forms of dementia is crucial to effective representation of legal services clients. Their need to be protected from exploitation includes, but is not limited to, such areas as: estate planning, guardianship, decision-making and advanced care planning. Students entering law-related professions, including, but not limited to, attorneys, paralegals, and related careers should be offered, through their course of study, opportunities to learn, discuss, and consider the specifics of Alzheimer's disease and other forms of dementia. This includes, but is not limited to, professional responsibility for effective representation of clients with capacity issues and estate planning for clients, who are at risk of exploitation, undue influence, or capacity concerns.

After completion of course study, licensed professionals are urged to pursue continuing legal education (CLE) in the area of Alzheimer's disease and other forms of dementia. The State Bar of Nevada (the licensing entity for Nevada attorneys), the Board of Continuing Legal Education, as well as trade associations, such as the Washoe County Bar and Clark County Bar Associations, are encouraged to promote awareness and education related to Alzheimer's disease and other forms of dementia. These CLE programs would provide legal professionals with ongoing education about recent developments, research, and treatments about Alzheimer's disease and other forms of dementia, including, but not limited to, application to issues of independence, decision making, and advanced care planning. Further, TFAD supports the offering of CLE credits for dementia-related, medically-based courses for legal professionals that could satisfy ethics credits for these licensed professionals.

#### **Indicators**

Increased number of quality educational opportunities, both pre- and post- professional education or training, which are offered in schools of post-secondary education and increased number of students who complete this coursework. Syllabus or other information related to topics covered at UNLV's William S. Boyd School of Law related to encouraged topics of concern. CLE offerings in the topic area, as well as data on professionals, who have taken such training to complete requirements or to advance ongoing education. Determine number of courses offered to interested stakeholders by qualified members of the legal community.

#### **Potential Funding**

Grants, donations and/or gifts. Specific sources may include:

• State appropriations to higher education.

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#### **Recommendation #11: Hospital Transitional Care Practices**

Ensure high quality hospital-to-community (i.e., home and long-term care) care transitions programs are available to persons living with dementia and their caregivers, with key elements including: care/discharge planning, care management, information on community resources, wrap-around services and periodic follow-up check-ins and assessments. One such program specific to Alzheimer's and dementia currently available in Southern Nevada is Nevada Senior Services' Hospital-to-Home program. Another relevant resource is the Community Paramedics program (active in Humboldt County). To explore new innovations, as well as expand and support existing efforts, the NV DHHS should investigate federal funding opportunities through the Centers for Medicare and Medicaid Services (CMS) and the CMS Innovation Center, as well as others. Opportunities to support more widespread use of a care transitions programs should be explored by seeking and establishing key partnerships and identifying available resources.

#### **Indicators**

- Monitor the number of care transitions programs available across Nevada's counties, including those connected to rural hospitals, such as the Community Paramedics program.
- Monitor the ongoing process and impact data of the Hospital-to-Home program, with updates from Nevada Senior Services.

#### **Potential Funding**

Grants, donations and/or gifts.

Specific sources may include:

- Collaboration within DHHS, including between ADSD, Division of Health Care Financing and Policy (DHCFP), DPBH, and other appropriate State agencies;
- Federal innovations and funding opportunities.

#### **Recommendation #12: Veterans and Their Families**

Support the continuation and creation of initiatives to offer culturally-appropriate services to older veterans by all aging services organizations across the state. TFAD encourages programs relating to veterans living with dementia and their families, including the ongoing implementation of the Bravo Zulu: Achieving Excellence in Relationship-Centered Dementia Care program for professional and family caregivers. Further, promote the continued viability and quality of care being offered by Nevada's two veterans' homes, both in Northern Nevada and Southern Nevada.

#### **Indicators**

Monitor the implementation of veteran-focused dementia programs, Bravo Zulu and the services being offered by Nevada's Veterans' Homes. Ensure the Nevada Legislative Interim Committee for Seniors, Veterans and Adults with Special Needs receives updates, as appropriate.

#### **Potential Funding**

Grants, donations and/or gifts. Specific sources may include:

- NDVS:
- Federal sources.

#### Recommendation #13: Driving and Dementia

Support the standardization of the system of driver evaluation. Improve the infrastructure, services, and support for persons living with dementia whose driving ability may be compromised. This includes developing and implementing:

- 1) A uniform set of evidence-based screening tools for healthcare providers, first responders and caregivers;
- 2) A standardized evidence-based evaluation tool for use by the Department of Motor Vehicles (DMV); and
- 3) Dissemination of information regarding driving and safety for persons with dementia as well as development and delivery of relevant training to help support healthcare and DMV professionals.

Information disseminated should convey how to address the multi-faceted needs and concerns of persons with dementia and those who care for them. Specific information should include signs that an individual's driving ability might be compromised and how to access relevant resources to address this concern. Such information should be available on websites, as well as be distributed in printed materials to healthcare and social service providers, first responders, families, caregivers and the public. Engage healthcare providers and first responders to evaluate the utility of the recommended screening tools.

Promote age- and dementia-friendly communities, which provide alternative transportation resources, through volunteerism and public-private partnerships, to maximize an individual's independence and assure public safety.

#### **Indicators**

Communicate and coordinate with the DMV to ensure their awareness of needs and resources. Monitor input from healthcare providers and first responders about the utility of recommended screening tools. DMV will monitor the number of accidents and fatalities and collect data on: the age of drivers; the number of referrals by health care providers, first responders, and caregivers to the DMV; and the number of evaluations conducted by the DMV following referral. NV DHHS will facilitate the distribution of informational materials related to driving and dementia, and will explore how the

distribution of information can be expanded and/or improved over time. NV DHHS will monitor the number and usage of alternative transportation resources and provide this data to TFAD.

#### **Potential Funding**

Grants, donations and/or gifts. Specific sources may include:

- Federal funding;
- DMV;
- NDOT:
- Regional Transportation Commission (RTC);
- ADSD.

#### **Recommendation #14 Community Awareness**

Promote dementia friendly community awareness programs which are designed to increase knowledge, understanding and access to dementia-related information and supportive resources. Awareness programs serve to reduce stigma around a diagnosis of dementia, engage care partners and offer support to individuals living with dementia over the course of their illness. These programs should also provide information to enable those affected by dementia to become partners in the search for effective therapies through participation in research, evidence-based interventions and clinical trials.

Dementia friendly community awareness programs may include, but are not limited to:

- 1) Initiatives to promote brain health for all individuals and reduce risks associated with modifiable lifestyle factors;
- 2) Overview of dementia, including types, early symptoms, diagnosis, treatment, and course of illness;
- 3) Community resources, educational programs and social services including evidence- based programs to support for individuals living with dementia and care partners;
- 4) Highlight opportunities for individuals living with dementia to advocate for their own well-being and participate in meaningful engagement in community life;
- 5) Educational resources to increase awareness about research opportunities and benefits of clinical trials with special consideration for those in underserved, minority communities.

The target audience for community awareness programs includes individuals living with dementia, family care partners, professional care partners, businesses, faith-based communities, first responders, government agencies, social service organizations, community groups and any other interested individuals. Programs promoting community awareness are offered statewide by various organizations and groups including, but not limited to, Dementia Friendly Nevada Community Action Groups, Alzheimer's Association, Cleveland Clinic Lou Ruvo Center for Brain Health and the UNR DEER Program. Various outreach strategies can be used to promote these programs such as broadcast/print interviews, articles in newspapers/magazines/websites and postings on social media sites. The Dementia Friendly Nevada website promotes community awareness programs scheduled in various communities statewide and offered online.

#### **Indicators**

Monitor the number and types of dementia-related community awareness presentations including, but not limited to, those listed on the Dementia Friendly Nevada website and offered through Dementia Friendly Community Action Groups, UNR Sanford Center for Aging, DEER Program, Alzheimer's Association and Cleveland Clinic Lou Ruvo Center for Brain Health.

#### **Potential Funding**

Grants, donations and/or gifts.

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#### **Recommendation #15: Organizational Outreach**

Encourage the business, government, social service, and non-profit sectors to:

- 1) Incorporate dementia-related information/resources into existing employee assistance programs to offer specialized assistance to individuals living with dementia and care partners;
- 2) Offer dementia awareness programs to their employees, including, but not limited to, Dementia Friends, Dementia Friendly Community Awareness Training (CAT) and Alzheimer's Association Education Programs;
- 3) Promote education regarding brain health initiatives; and
- 4) Develop partnerships with statewide Dementia Friendly Community Action Groups.

#### **Indicators**

Monitor dementia friendly activities and collaborations with businesses, government agencies social service organizations and not-for-profit entities.

#### **Potential Funding**

Grants, donations and/or gifts. Specific sources may include:

• Employers and employer organizations.

	Accommendations from Frevious State Frans with Continued Monitoring			
Year	No.	Area of	Recommendation	Monitoring
Initiated		Focus		
2013	2	Access to Services	APRNs 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, TFAD supports the connection between APRNs and health care teams to provide ancillary services.	ADSD will contact the State Board of Nursing annually to monitor: the number of applicants who file to practice independently (and how many licenses are issued in urban, rural, frontier, and out-of-state); the venues where they intend to practice; and the populations they serve. ADSD will monitor regulations related to APRNs adopted by the Board of Nursing.
2013	4		Younger-Onset Alzheimer's Disease Support legislation, including provisions in SB 86 of the 2013 Legislative Session, that removes 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, such as, but not limited to, Extend Elder Protective Services access to individuals under the age of 60 with dementia; disability services; legal services; meals; respite; and "continuum of life" programs, including 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.	ADSD will annually monitor federal and state legislation to determine if there are changes that could affect eligibility for this population.
2013	6	Access to Services	r · · · · · · · · · · · · · · · · · · ·	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.
2013	7		Nevada Research Consortium Support the Cleveland Clinic Lou Ruvo Center for Brain Health in its establishment of a Nevada Consortium to promote current and future research in Nevada. 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.	ADSD will annually monitor: the establishment of key consortium partners; the compilation of a list of current research projects; working with the Alzheimer's Associations, the number of "hits" the Trial Match site receives in Nevada.

			Recommendations from Frevious State Flans with Continued	
Year Initiated	No.	Area of Focus	Recommendation	Monitoring
2013	8		Caregiver Service  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.	
2013	10		Reducing Out-of-State Placement 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 versus 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 respond appropriately and effectively to care needs and behavior changes in persons with Alzheimer's disease and other forms of dementia. This should be accomplished 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 toand evaluate persons in need of specialized interventions. These multidisciplinary teams or individuals should evaluate the persons 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 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 bein	ADSD will annually monitor: the number of out-of-state placements of persons with dementia; the 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 NSHE.

Accommendations from Trevious State Trans with Continued Monitoring				
Year	No.	Area of	Recommendation	Monitoring
Initiated		Focus		
2013	11	-	Promoting Awareness and Education  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.	ADSD will annually monitor: the number of primary care physician referrals for diagnosis and treatments; the number of early referrals; the number of quality CME training opportunities related to Alzheimer's disease and other forms of dementia diagnoses and treatment.
2013	12	Quality of Care	Promoting Awareness and Education  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.	ADSD will annually monitor classified nursing programs based on content and best practices in education; the number of quality continuing education units for nurses related to treatment and care for persons with Alzheimer's disease and other forms of dementia.
2013	13	Quality of Care	Promoting Awareness and Education  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.	ADSD, working with the Division of Public and Behavioral Health, will annually monitor how many training programs in hospitals are established and how many people participate in the programs specifically relating to dementia; changes in regulations - Chapter 440 of the Nevada Administrative Code.
2013	14	Quality of Care	Promoting Awareness and Education 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.	ADSD will work with the Division of Public and Behavioral Health to annually monitor how many training programs are created and provided, specifically related to dementia, how many people from law enforcement, Emergency Medical Technicians, and fire departments attend these trainings.

Year	No.	Area of	Recommendation	Monitoring
Initiated		Focus		
2013	17	Quality of Care	Guardianship (Completed section from #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 ensure that all reports on the person and estate of the wards are filed and reviewed according to the existing law.	ADSD will monitor the progress of the Bill of Rights proposed by the Commission to Study the Administration of Guardianships in Nevada's Courts, particularly as it relates to persons living with Alzheimer's disease and other forms of dementia who have limited assets.
2015	8	Quality of Care	Care Pathways 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 practice 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.	Monitor through regulatory and hospital associations how many hospitals establish a best practice care plan.
2017	9	Quality of Care	Caregiver Support Support caregivers with information and resources about caring for persons with Alzheimer's disease and other forms of dementia. Provide caregivers with information about, as well as access to, programs, services, and resources that promote their own well-being. These services include, but are not limited to family care consultation, caregiver support groups, educational programs and services, respite programming, and evidence-based programs. Support efforts to promote and fund comprehensive caregiver services that are provided by many organizations, including, but not limited to: AARP, Alzheimer's Associations, Catholic Charities, the Cleveland Clinic Lou Ruvo Center for Brain Health, Nevada Caregiver Support Center, and Nevada Senior Services. Support the Dementia-Friendly America initiative and the work of the state's Dementia-Friendly Champion Groups in northern and southern Nevada. In addition, support the establishment of a key partners' network, which would create a system of referrals to appropriate services.	
2017	11	Quality of Life	Guardianship Support the development and implementation of the Guardianship "Bill of Rights," which was created by the Commission to Study the Administration of Guardianships in Nevada's Courts. Support the specific protections for individuals with Alzheimer's disease and other forms of dementia.	

#### **Appendix B**

# Comprehensive, Dementia-specific Resources for Persons Living with Dementia and their Care Partners

#### **Alzheimer's Association**

The Alzheimer's Association (24/7 Access)	Internet Address: <u>alz.org</u> Telephone: (800) 272-3900
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#### **Cleveland Clinic Lou Ruvo Center for Brain Health**

Cle	veland Clinic Lou Ruvo Center for Brain	Internet Address: <a href="https://my.clevelandclinic.org/locations/nevada">https://my.clevelandclinic.org/locations/nevada</a>
Hea	alth	Telephone: (702) 483-6000

#### University of Nevada, Reno

Dementia Engagement, Education and Research (DEER) Program, School of Community Health Sciences (including Dementia-Friendly Nevada)	<ul> <li>Internet Address:</li> <li>DEER Program: <a href="https://www.unr.edu/public-health/centers/dementia-engagement-education-and-research-program">https://www.unr.edu/public-health/centers/dementia-engagement-education-and-research-program</a></li> <li>Dementia Friendly Nevada: <a href="https://dementiafriendlynevada.org/">https://dementiafriendlynevada.org/</a></li> <li>Telephone: (775) 682-7072</li> </ul>
Nevada Caregiver Support Center	Telephone: (775) 784-4335
Sanford Center for Aging, School of Medicine	Internet Address: <a href="https://med.unr.edu/aging">https://med.unr.edu/aging</a> Telephone: (775) 784-4774

#### **Federal Agencies**

United States Administration for Community Living (Administration on Aging)	Internet Address: <a href="https://acl.gov/">https://acl.gov/</a>
United States Centers for Disease Control and Prevention (Alzheimer's Disease and Healthy Aging Program)	Internet Address: <a href="https://www.cdc.gov/aging/index.html">https://www.cdc.gov/aging/index.html</a>
United States Department of Health and Human Services (Office of the Assistant Secretary for Planning and Evaluation – Alzheimer's / Dementia)	Internet Address: https://aspe.hhs.gov/alzheimers-dementia

#### **State Agencies**

Nevada Aging and Disability Services Division	Internet Address: <a href="http://adsd.nv.gov">http://adsd.nv.gov</a> Telephone: Carson City (775) 687-4210 Reno: (775) 687-0800 Elko: (775) 738-1966 Las Vegas: (702) 486-3545
Nevada Division of Public and Behavioral Health	Internet Address: <a href="http://dpbh.nv.gov/">http://dpbh.nv.gov/</a> Telephone: (775) 684-4200
Nevada Health Division, Bureau of Health Care Quality and Compliance	Internet Address: <a href="http://dpbh.nv.gov/Reg/HealthFacilities/HCQC-Blog/">http://dpbh.nv.gov/Reg/HealthFacilities/HCQC-Blog/</a> Telephone: (775) 687-4475
Nevada Care Connections (Nevada' s Aging and Disability Resource Center)	Internet Address: nevadaadrc.com
Nevada 2-1-1	Internet Address: nevada211 .org/