

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

**State Plan to Address Alzheimer's Disease**

**Nevada Revised Statute 439.5083**

**Revised June XX, 2016**

***The Impact of Dementia***

Approximately 50 forms of dementia have been identified. Alzheimer's disease is just one form of dementia and comprises about 70 percent of all dementia diagnoses. Currently, one in nine people (11 percent) of those over the age of 65 have Alzheimer's disease. This translates into about 39,000 people in Nevada. To add some perspective, this is a 38 percent increase from ten years ago. Based on current data trends, this number is expected to increase to 64,000 people by 2025. Nationally, Nevada has the third highest growth rate of this disease at 64 percent!

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

***TFAD Supports:***

- Dementia Friendly Communities, where those living with Alzheimer's disease and other forms of dementia, along with their care partners, feel and experience the respect, dignity, support, value, and inclusion in everyday community life.
- Innovative ways of thinking that provide opportunities for persons with Alzheimer's disease and other forms of dementia to experience full and meaningful lives.
- Proactive collaborations between health care professionals, first responders, community organizations, the business community, educators, care partners, volunteers, and others to provide dementia-friendly services and support that nurture a full and optimal quality of life for persons with Alzheimer's disease and other forms of dementia.
- Ongoing education and professional development for persons who, directly or indirectly, serve and support persons with Alzheimer's disease and other forms of dementia, as well as their care partners.

- Best practices for all individuals and entities that are making contributions to the quality of life for persons with Alzheimer’s disease and other forms of dementia, as well as their care partners.
- Continuous and expansive public awareness activities that promote opportunities for expanding dementia-friendly communities.

## **Executive Summary**

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

1. Recommendation #1 (Access to Services).....
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  - 3.
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- Etc.

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### **Recommendation #1: Access to Services/Statewide Information and Referral System—Albert Chavez**

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, with the expectation that the approaches, content, and messaging within these resources helps promote well-being and preserve dignity. Supportive services would include, but are not limited to, Nevada Aging and Disability Resource Centers (ADRC), Family Resource Centers (FRC) and other related informational systems (e.g. websites, helplines, and other technologies).

#### **Indicator**

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

#### **Potential Funding**

Older Americans Act funds. Grants, donations, and/or gifts.

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**Recommendation #2: Access to Services/Rural—Sen. Valerie Wiener (Ret.)**

Moved to the appendix

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**Recommendation #3: Access to Services/Telehealth—Albert Chavez**

Support AB292, passed during the 2015 Legislative Session, which expanded access to Telehealth services throughout the state. This would include supporting the Telehealth Consortium in its efforts to improve Telehealth utilization by encouraging collaboration among network providers, physicians, and service recipients to identify and overcome service delivery barriers, as well as educate providers and the public about the existence of and the benefits to Telehealth services, especially in rural and remote communities throughout Nevada.

**Indicator**

Monitor Telehealth projects across the state to determine if they are: 1) available and accessible, 2) being utilized effectively and efficiently, and 3) providing information/access to follow-up resources. Review evaluation of projects, such as Nevada's Early Stage Dementia Project, Telehealth Early Phase Patient and Family Support Program (TESP), to assess what was done and duplicate the measurements of the success of the projects. Follow the process of development of the Nevada Broadband Telemedicine Initiative (NBTI) using the Nevada Hospital Association (NHA) goals and evaluation.

**Potential Funding**

Alzheimer's Disease Supportive Services Program (ADSSP). The State of Nevada. Grants, donations, and/or gifts.

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**Recommendation #4: Access to Services/Younger-Onset—Sen. Valerie Wiener (Ret.)**

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 (e.g., 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, such as assisted living services.) Continue to monitor NRS provisions related to these populations and other provisions included in the Older Ameri-

cans Act, which affect eligibility requirements for services to allow family caregivers of a person living with Alzheimer's disease and other forms of dementia to be served, regardless of the age of the person.

**Indicator**

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

**Potential Funding**

Aging and Disability Services Division, Nevada Department of Health and Human Services. Grants, donations, and/or gifts.

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**Recommendation #5: Access to Services/Cultural Competency—Dr. Jane Fisher**

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

**Indicator**

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

**Potential Funding**

U.S. Administration on Aging grants. Collaboration with different cultural and ethnic organizations. Grants, donations, and/or gifts.

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**Recommendation #6: Access to Services/Affordability—Wendy Simons**

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

**Indicator**

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

**Potential Funding**

Medicaid expansion. Grants, donations, and/or gifts.

**Recommendations #7: Quality of Care—Dr. Charles Bernick**

Moved to the appendix

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**Recommendation #8: Quality of Care/Care Pathways—Dr. Charles Bernick**

Support the adoption of specialized care pathways. Encourage the Nevada Hospital Association (NHA) to develop a best-practices care plan for the management of patients with cognitive impairment entering the hospital. The NHA is strongly encouraged to develop this plan in collaboration with subject matter experts from the Alzheimer's Association; other research and educational organizations; first responders; and healthcare organizations. In addition, TFAD supports the CARE Act, which helps caregivers when those for whom they care for are hospitalized. TFAD will also serve in an advisory capacity and provide necessary testimony to the Legislative Subcommittee to Conduct a Study of Post-Acute Care.

**Indicator**

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

**Potential Funding**

In-kind contributions from potential participants, i.e. Cleveland Clinic's Lou Ruvo Center for Brain Health, Touro University Nevada, Nevada System of Higher Education (NSHE), and other educational institutions in Nevada. Federal Alzheimer's research grants. Private-sector foundation grants. Cleveland Clinic Lou Ruvo Center for Brain Health. Other grants, donations and/or gifts.

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**Recommendations # 9: Quality of Care/Long-Term Care—Wendy Simons**

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

**Indicator**

Monitor the number of long-term care options for persons with Alzheimer's disease and other forms of dementia across the state.

**Potential Funding**

Medicaid expansion through Home- and Community-Based Services Waiver. Expansion through Behavioral Rate. Veteran's Administration (VA). State funds. Increased supplemental SSI rate. Tax incentives. Grants, donations, and/or gifts.

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**Recommendation #10: Quality of Care/—Dr. Jane Fisher**

Moved to the appendix

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**Recommendation #11: Quality of Care/—Sen. Joseph Hardy**

Moved to the appendix

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**Recommendation #12: Quality of Care/—Sen. Joseph Hardy**

Moved to the appendix

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**Recommendation #13: Quality of Care/—Sen. Joseph Hardy**

Moved to the appendix

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**Recommendation #14: Quality of Care/—Sen. Joseph Hardy**

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**Recommendation #15: Quality of Care/Caregivers—Dr. Jane Fisher**

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.

**Indicator**

Annually monitor waitlists, number of consumers, and hours of caregiver support services provided in the ADSD-funded programs.

**Potential Funding**

Fund for a Healthy Nevada. Retired and Senior Volunteer Program (RSVP). Older Americans Act funding (Title III). the Alzheimer's Association. Grants, donations, and/or gifts.

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**Recommendation #16: Quality of Life/Volunteers—Gini Cunningham**

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

**Indicator**

Monitor organizations that recruit volunteers, such as RSVP, Sanford Center on Aging, Northern Nevada Alzheimer’s Association, Southern Nevada Alzheimer’s Association, and the Cleveland Clinic Lou Ruvo Center for Brain Health. Work with these organizations to track the number of volunteer recruitments, placements, and training.

**Potential Funding**

Voluntary outreach by members of TFAD. Other volunteers and in-kind resources as they become available. Grants, donations, and/or gifts.

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**Recommendation #17: Quality of Life/Guardianship—Sen. Valerie Wiener (Ret.)**

Support the development and implementation of a Guardianship “Bill of Rights,” which includes specific protections for individuals with Alzheimer’s disease and other forms of dementia.

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

**Indicator**

Monitor the coordinated efforts of the appropriate State agencies (DHHS and Medicaid; activities of public guardians) and branches of government (Executive, Legislative, and Judiciary). Monitor any germane recommendations for legislation.

**Potential Funding**

Legislative appropriation. Grants, donations, and/or gifts.

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**Recommendation #18: Quality of Life/Hospital Practices—Sen. Joseph Hardy**



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

### **Indicator**

Monitor the number of hospital transitional care programs that employ best-practice discharge policies.

### **Potential Funding**

Collaboration between Nevada ADSD, Nevada DHCFP, DPBH, and other appropriate State agencies. Grants, donations, and/or gifts.

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### **Recommendation #19: Public Awareness/General—Dr. Charles Bernick**

Foster the development of dementia-friendly awareness campaigns to provide information about early signs of dementia and to advance dementia-friendly communities across the state. 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 meaningful life. The campaigns will be designed to help citizens feel better supported and hopeful, as well as encourage access to available services. The campaigns will be promoted through public service announcements, broadcast and print interviews, as well as articles in newspapers and magazines, website, and Internet venues. The respective target audiences for each public awareness campaign may include, but are not limited to:

- a. Allied health professionals, bankers, emergency first responders, financial planners, lawyers, and other professionals who may have contact with persons with dementia.
- b. Caregivers and family members of persons with dementia. This campaign will focus on creating and supporting dementia-friendly communities, where those living with Alzheimer's disease and other forms of dementia, along with their care partners, can feel and experience the respect, dignity, support, value, and inclusion in everyday community life. This campaign will also focus on ways to help alleviate the fear, stress, and stigma surrounding dementia, which includes educating and informing caregivers about support group opportunities and other available supportive services that will help them care for themselves and their family member.
- c. The general public. This campaign will also focus on creating, supporting, and sustaining dementia-friendly communities.

### **Indicator**

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

### **Potential Funding**

Volunteers from TFAD members. Alzheimer's Associations. Professional licensing boards and organizations. Nevada Broadcaster's Association. Nevada ADSD. Grants, donations, and/or gifts.

### **Recommendation #20: Public Awareness/Business Community—Dr. Charles Bernick**

Encourage the business community to implement established employee assistance programs and dementia-friendly activities that encompass education and training for employees, including those who are caregivers. Specifically, foster partnerships with other organizations that are also affected by Alzheimer's disease and other forms of dementia, such as diabetes, stroke, and heart organizations, to help promote information about services and care for those who have symptoms of dementia.

### **Indicator**

Monitor the number of employee assistance programs with caregiver education and training. Monitor the number of partnerships with other dementia-related organizations.

### **Potential Funding**

Employers and employer organizations. Grants, donations, and/or gifts.

New recommendations to be discussed at the next TFAD meeting on 8/5/16

- Caregiver Support
- Driving and dementia
- Outreach to physicians about timely and accurate diagnoses
- End-of-life planning (POLST)
- Veteran's and families impacted by dementia

### **APPENDIX (previous recommendations)**

**Recommendation #2: Access to Services/APRNs—Sen. Valerie Wiener (Ret.)**

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

**Monitoring:**

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. Monitor regulations related to APRNs adopted by the Board of Nursing.

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**Recommendations #7: Quality of Care/Research Consortium—Dr. Charles Bernick**

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

**Monitoring:**

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.

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**Recommendation #10: Quality of Care/Out-of-State Placements—Dr. Jane Fisher**

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

- a. Preventing the conditions that lead to the development of responsive behaviors and increase the risk of out-of-state placement. Accomplish this by creating a clearinghouse for information on evidence-based, person-centered approaches to promoting the behavioral health and quality of life of individuals with Alzheimer's disease and other forms of dementia and their family caregivers.

- b. Initiating a public health information program to increase easy access to information on: 1) "optimal" care and quality of life and 2) expected vs. unexpected behavior changes in persons with dementia.
- c. Increasing the ability of family and professional caregivers (in primary, acute, emergency, and long-term care settings) to appropriately and effectively respond to care needs and behavior changes in persons with Alzheimer's disease and other forms of dementia through education and guided practice by experts in evidence-based methods of behavioral healthcare for persons living with dementia.
- d. Using a higher reimbursement rate as an incentive for providers to successfully deliver appropriate care.
- e. Developing mobile individuals or teams that respond to--and evaluate--persons in need of specialized interventions. These multidisciplinary teams or individuals evaluate the 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 in order to assure consistency across agencies, which are involved in regulatory oversight, to reduce barriers to providers who are willing to deliver care to persons with dementia.
- h. Investigating the feasibility of developing units in facilities in Nevada that specialize in dementia care for individuals with a history of being described as "unmanageable" and rejected by other facilities

**Monitoring:**

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 the NSHE.

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**Recommendation #11: Quality of Care/Healthcare Providers—Sen. Joseph Hardy**

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.

**Monitoring:**

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.

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**Recommendation #12: Quality of Care/Nursing—Sen. Joseph Hardy**

Encourage schools in Nevada with program 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.

**Monitoring:**

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.

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**Recommendation #13: Quality of Care/Hospital Personnel—Sen. Joseph Hardy**

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.

**Monitoring:**

ADSD will work with the Division of Public and Behavioral Health to 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 449 of the Nevada Administrative Code.

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**Recommendation #14: Quality of Care/First Responders—Sen. Joseph Hardy**

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.

**Monitoring:**

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, along with how many people from law enforcement, Emergency Medical Technicians, and fire departments attend.

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