

THE NEVADA STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE



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

TASK FORCE ON ALZHEIMER'S DISEASE

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State Plan to Address Alzheimer’s Disease Nevada Revised Statute 439.5083

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 has Alzheimer’s disease. This translates into about 45,000 people in Nevada. Based on current data trends, with 19.5% anticipated growth in the next five years— and 56% anticipated growth in ten years— this number is expected to increase to 64,000 people by 2025. To add some perspective, the number of people diagnosed with Alzheimer’s disease has increased 130 percent since the year 2000. Nationally, Nevada has the second 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 caregivers, 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, caregivers, 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 caregivers.

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 caregivers.

Continuous and expansive public awareness activities that promote opportunities for expanding Dementia Friendly Communities.

Executive Summary

State Plans to Address Alzheimer’s Disease, created by both the ACR10 Task Force in 2013 and the Task Force on Alzheimer’s Disease (TFAD) in 2015 and 2017, were submitted to both the Governor and the Nevada State Legislature. Nine recommendations from the 2015 State Plan were moved to Appendix A, because TFAD determined that these particular recommendations have been or are being addressed appropriately. All of these recommendations will continue to be monitored between biannual State Plans. If TFAD's review of these recommendations demonstrates a need to re-address one or more of these recommendations, TFAD can include them in its next State Plan.

Following is a list of the recommendations, which have been approved by TFAD for inclusion in the 2019 State Plan, as well as the year they were first included in the State Plan:

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Access to Services

Recommendation #1: Statewide Information and Referral System (2013)

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 would include no wrong door partners, including but not limited to: Nevada 2-1-1, Nevada Care Connection Resource Centers (NCCRC), Family Resource Centers (FRC), and other related informational systems (e.g. websites, helplines, and other technologies).

Indicators

Monitor the establishment of a collaboration that includes resource centers, including, but not limited to, 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 and the number of inquiries regarding information or services relating to Alzheimer's disease and other forms of dementia received by the ADRC. In addition, ADRC will monitor the number of "hits" on information sites, such as an expanded nevadaadrc.com, alz.org, nevadacaregiver.unr.edu, and Alzheimers.gov.

Potential Funding

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

Recommendation #2: Telehealth (2013)

Support expanded access to Telehealth services throughout the state to enhance early detection and diagnosis of care recipients with dementia. Support the utilization of telehealth to promote caregiver 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 with Alzheimer's disease and other forms of dementia, including those from the Telehealth Early Phase Patient and Family Support Program.

Indicators

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 programs to ensure better quality of life for patients living with dementia and their caregivers.

Potential Funding

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

Recommendation #3: Cultural Competency (2013)

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

Indicators

Monitor the development and dissemination of toolkits to organizations serving persons living with Alzheimer's disease and other forms of 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.

Recommendation #4: Affordability (2013)

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. This includes the Department of Health and Human Services (DHHS) Behavioral Rate for skilled nursing facilities. This rate expands the reimbursement options for facilities that serve persons whose challenging behaviors, resulting from a dementia, once necessitated them to

be placed out-of-state for appropriate care.

Indicators

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

Potential Funding

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

Recommendation #5: Outreach to Physicians (2017)

Recommendation

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. Support a meaningful and effective communication continuum between these professionals and community-based service organizations, including referrals to community-based resources.

Indicators

Data gathered by the Alzheimer’s Association.

Potential Funding

Alzheimer’s Association. Grants, donations, and/or gifts.

Recommendation #6: State Match Program for APRNs (2019)

Background

TFAD’s first State Plan to Address Alzheimer’s Disease (2013) included a recommendation to expand access to care for persons with Alzheimer’s disease and other forms of dementia in rural and frontier Nevada. The recommendation focused on growing the number of Advanced Practice Nurses (now Advanced Practice Registered Nurses) in these underserved Nevada communities. When the Legislature passed a law in 2013 to define and increase opportunities for APRNs, TFAD retired its recommendation to the State Plan Appendix (2015). However, though Nevada’s APRN licenses have grown substantially, these areas continue to experience substantial shortages in this kind of essential care. Therefore, TFAD determined that a new incentive to respond to the APRN shortage might answer this need.

Recommendation

Support the establishment of a state match program between the State's Department of Health and Human Services, 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 (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

Health Resources and Administration Grants. Other appropriations. Grants, donations, and/or gifts.

Quality of Care

Recommendation #7: Care Pathways (2013)

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, 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 are hospitalized.

Indicators

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

Potential Funding

In-kind contributions from potential participants, such as the Cleveland Clinic 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. Grants, donations, and/or gifts.

Recommendation #8: Long-Term Care (2013)

Continue to review current funding and 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 patients, their families, and caregivers, feel and experience respect, dignity, support, value, and inclusion in everyday community life.

Indicators

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 the DHHS Behavioral Rate for skilled nursing facilities. Increased supplemental SSI rate. Tax incentives. Grants, donations, and/or gifts.

Recommendation #9: Caregiver Support (2019)**Background**

Caregivers of people with Alzheimer’s disease and other forms of dementia frequently report high levels of stress, which can be emotionally, physically, and psychologically harmful to them. According to the Latest Facts and Figures Report from the Alzheimer’s Association, 15.9 million family members and friends provided 18.1 billion hours of unpaid care to those with Alzheimer’s disease and other forms of dementia in 2015. That care had an estimated economic value of \$221.3 billion. Approximately two-thirds of caregivers are women, and 34 percent are age 65 or older. Forty-one percent of caregivers have a household income of \$50,000 or less. On average, care contributors lose more than \$15,000 in annual income as a result of reducing or quitting work to meet the demands of caregiving. Alzheimer’s disease and other forms of dementia take a devastating toll on caregivers. Nearly 60 percent of Alzheimer’s and dementia caregivers rate the emotional stress of caregiving as high or very high; about 40 percent suffer from depression. One in five care contributors cut back on their own doctor visits because of their care responsibilities. And, among caregivers, 74 percent report they are “somewhat” to “very” concerned about maintaining their own health since becoming a caregiver.

Recommendation

Provide caregivers with information about and access to evidence-based education, support services, and resources to: 1) promote knowledge and understanding of Alzheimer's disease and other forms for dementia to best support people living with dementia, 2) provide and expand respite services for family and informal caregivers of persons with dementia and, 3) enhance caregiver well-being. These services include, but are not limited to: family care consultation, solution-focused caregiver support groups, educational programs and services, respite programming, and evidence-based programs in the Nevada Dementia Supports Toolbox. 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 Senior Services, and Nevada Caregiver Support Center.

- 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 Nevada Dementia Friendly 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

Aging and Disability Services Divisions (ADSD) will track and compile data it collects provided in the ADSD-funded programs, as well as data provided by the key partners network and other dementia-related organizations that are working in alignment to support these efforts. ADSD will annually monitor program availability, waitlists, number of consumers, and hours of caregiver support services provided in the ADSD-funded programs and other programs, as feasible. ADSD will also monitor Dementia Friendly Champions, including community action groups throughout Nevada.

Potential Funding

Fund for a Healthy Nevada. Retired and Senior Volunteer Group (RSVP). Older Americans Act Funding. The Alzheimer's Association. Grants, donations, and/or gifts. Explore additional funding opportunities to support caregiver programs once existing funds expire.

Recommendation #10: Dementia Training (2019)

Background

Throughout spring and summer 2018, a TFAD work group convened to explore dementia care provider training needs to ensure that high quality care and support are provided for residents

living with dementia in Nevada’s nursing homes (i.e., skilled nursing facilities). Initially, this work group was precipitated by the question of how providers are offering different and enhanced care with the availability of the Medicaid ‘behavioral rate’ incentive payments. However, the group eventually focused on the landscape of training resources available to all nursing homes, whether or not they are participating in the Behavioral Rate Program. The intent of the work group was to assess the training resources currently being used by nursing homes statewide and determine whether there are opportunities for potential improvements.

The work group conducted a survey of all nursing homes statewide to determine their current approach to training staff on dementia care and support, including: 1) the number of training hours provided; 2) the delivery modalities of training programs and the content of training; and 3) how they are evaluating training impact. Overall, 19 nursing homes responded to the survey, representing 31% of all nursing homes in Nevada. Top-line results indicate that:

- 1) Current State training requirements are being met in terms of initial and annual required hours, but there is inconsistency in delivery approach and content.
- 2) 50% of the nursing homes are using ‘internal’ training resources provided by their corporate headquarters, while the rest are using a range of externally available training options.
- 3) Multiple delivery modalities are being used (e.g., in-person, online, self-directed, consultants, conferences, and videos).
- 4) A wide range of programs are being offered (e.g., Hand-in-Hand, CARES, Teepa Snow Products).
- 5) While program content and delivery are inconsistent, programs largely include the ‘basics of Alzheimer’s disease’ and content on so-called ‘behaviors’.
- 6) Minimal monitoring or evaluation is being utilized to determine the impact of training on direct care and support, as well as training effectiveness in preventing so-called behaviors, which are often a reaction to unmet needs.

The work group concluded that an obvious inconsistency exists in dementia training both in terms of program delivery and content. Therefore, there is a statewide need for widely available training resources with consistent, high-quality, comprehensive content aligned with NRS 449.094 requirements, as well as current national practice recommendations, for supporting quality of life and well-being among nursing home residents living with dementia.

Recommendation

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 must be made available to all nursing homes 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 nursing homes statewide. The identified or developed program is encouraged by key partners. The program is adopted and implemented by an increasing number of nursing homes over a three-year period.

Potential Funding

State appropriation and/or state grants for the proposed dementia training initiative. Grants, donations, and/or gifts.

Quality of Life

Recommendation #11: Volunteers (2013)

Recruit and train community volunteers through collaborations with various organizations, including nonprofits, service organizations, healthcare institutions, and universities, which have existing programs, education, and practices that address Alzheimer's disease and other forms of dementia. Through these collaborations, volunteers will have the opportunity to expand their own knowledge and awareness about all forms of dementia and learn how to effectively participate in the care and support of persons with Alzheimer's disease and other forms of dementia, their families, and their caregivers. In supporting age- and dementia friendly communities, volunteers will learn how to promote each person's well-being, as well as preserve their dignity and respect in everyday community life. Also, by implementing "Train the Trainer" programs, volunteer outreach opportunities can be expanded.

Indicators

Monitor nonprofits, service organizations, healthcare institutions, and universities that recruit volunteers for the number of volunteers they recruit, the types of training they offer, how many volunteers they train, and what other services are provided. Determine which additional trainings and services might be needed to expand volunteer education and opportunities.

Potential Funding

Grants, donations, and/or gifts.

Recommendation #12: Guardianship (2019)

Background

Rights associated with alleged lack of capacity are crucial to a state's approach to Alzheimer's disease and other forms of dementia for individuals with the disease, their supporters, and their caregivers. To help ensure equity for these affected people, legal professionals would benefit from a more comprehensive understanding of Alzheimer's disease and other forms of dementia. Incorporating evidence-based information and approaches into legal training would encourage communities to be much more dementia friendly. Persons with Alzheimer's disease and other forms of dementia should have access to legal counsel and, at the same time, have confidence that those seeking legal process to compound undue influence will not be successful in exploitative use of access to justice.

Recommendation

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, and decision-making. 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. Continuing Legal Education offerings in the topic area, as well as statistics of professionals, who have taken such training to complete requirements or to advance ongoing education.

Potential Funding

State appropriations to higher education. Funding from providers and/or state agencies. Grants, donations, and/or gifts.

Recommendation #13: Hospital Transitional Care Practices (2013)

Ensure best-practices hospital transitional care programs that include information on community resources for caregivers and persons with Alzheimer’s disease and other forms of dementia. Investigate federal funding opportunities, through Medicare Innovations or Centers for Medicare and Medicaid Services, to develop a transitions planning program, which would also include provisions, when appropriate, for non-hospital care, such as a mobile dementia team approach.

Indicators

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

Potential Funding

Collaboration between Nevada ADSD, Nevada Department of Health Care Financing and Policy (DHCFP), Department of Public and Behavioral Health (DPBH), and other appropriate State agencies. Grants, donations, and/or gifts.

Recommendation #14: Veterans and Families (2017)

Recommendation

Support the development and implementation of the Veterans in Care (VIC) initiative, being created and implemented by Nevada Department of Veterans Services to serve as many as 300,000 veterans living in Nevada. In particular, support the specific provisions that relate to individuals with Alzheimer’s disease and other forms of dementia and their families.

Indicators

Monitor the development and progress of the VIC initiative.

Potential Funding

Nevada Department of Veteran Services. Grants, donations, and/or gifts.

Recommendation #15: Driving and Dementia (2017)

Recommendation

Support the standardization of the system of driver evaluation. Improve the infrastructure, services, and support for persons with dementia whose driving ability may be compromised. This includes developing and implementing: 1) a uniform set of evidence-based screening tools for health care providers, first responders, and caregivers and 2) a standardized evidence-based evaluation tool for use by the Department of Motor Vehicles (DMV).

Support the dissemination of information regarding driving safety and dementia. This information 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 health care and social service providers, first responders, families, caregivers, and the general public. Engage health care 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

DMV, partnering with other agencies and organizations, will monitor input from health care 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. DHHS will facilitate the distribution of informational materials related to driving and dementia and how the distribution of information can be expanded and/or improved. DHHS will monitor the number and usage of alternative transportation resources and provide this data to TFAD.

Potential Funding

Federal funding. DMV. Nevada Department of Transportation (NDOT). Regional Transportation Commission (RTC). ADSD grants. Grants, donations, and/or gifts.

Public Awareness

Recommendation #16: Community Outreach (2013)

Foster the development of Dementia Friendly Communities awareness campaigns to provide information about early signs of dementia and to advance Dementia Friendly Communities across the state. The campaigns should include updates on 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 should be designed to help citizens feel better supported and hopeful, as well as encourage access to available services. The campaigns should be promoted through public service announcements, broadcast and print interviews, as well as articles in newspapers and magazines, websites, and other 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 Alzheimer's disease and other forms of dementia.
- b. Caregivers and family members of persons with Alzheimer's disease and other forms of dementia. This campaign should focus on creating and supporting Dementia Friendly Communities, where those living with Alzheimer's disease and other forms of dementia, along with their caregivers, can feel and experience the respect, dignity, support, value, and inclusion in everyday community life. This campaign should 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 should also focus on creating, supporting, and sustaining Dementia Friendly Communities.

Indicators

Monitor the instances of media attention through public service announcements, interviews, and stories. Monitoring should also include: the number of professionals and professional organizations contacted; the number of visits to the Nevada ADRC website and Nevada 2-1-1; and the level of progress in developing and sustaining public awareness campaigns in cooperation with the State Grants Office and DHHS Outreach Services.

Potential Funding

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

Recommendation #17: Business Outreach (2013)

Encourage the business community to establish and implement 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.

Indicators

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.