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Nevada State Plan to Address Alzheimer's Disease and other Dementias 2023-2024

**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.' For the purposes of this plan, labeled as addressing 'Alzheimer's disease and other dementias', the Task Force on Alzheimer's Disease references 'dementia' as the overarching condition being addressed.

According to the Alzheimer's Association's *2022 Alzheimer's Disease Facts and Figures*, it is estimated that 6.5 million people are living with dementia in the US, and that the prevalence will increase to 12.7 million people by 2050 (reflecting a 95% increase). Further, one in nine people ages 65 and older are living with dementia, with dramatic increases as one ages from 65 – 74 (5%) to 85+ (33%). In addition to those estimated to be living with dementia, as noted in the Alzheimer's Association report, approximately 16.6% of people over the age of 65 are living with Mild Cognitive Impairment (MCI), which is a form of cognitive decline that may serve as a precursor to later dementia.

In Nevada, the Alzheimer's Association report estimates that there were 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 (33.3%) and Vermont (30.8%). 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 current and needed policies, practices, and programs to the Nevada State

Legislature, as well as to units of the Nevada Department of Health and Human Services, including the Aging and Disability Services Division, Division of Public and Behavioral Health, and Division of Health Care Financing and Policy, which work daily to serve the needs of people living with dementia across all of Nevada.

Additional Context for the State Plan:

The 2023-2024 Nevada State Plan to Address Alzheimer’s Disease, prepared by TFAD, includes seventeen recommendations related to ensuring that effective information, education, care and support, and public policy appropriately address dementia on behalf of all Nevadans. Among these seventeen recommendations are three newly developed recommendations for 2023 – 2024, adding to the recommendations that were updated and carried forward from previous State Plans. These new recommendations for 2023 – 2024 include:

- Recommendation #5: Dementia Care Specialist (DCS) Program;
- Recommendation #16: Advance Care Planning; and
- Recommendation #17: Choice in Care and Care Settings

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 dementia, along with their care partners, feel and experience respect, dignity, support, value and inclusion in everyday community life;
- Innovative ways of thinking that provide opportunities for people living with dementia to experience full and meaningful lives;
- The promotion of brain health to reduce risk of cognitive impairment and the early detection of cognitive impairment, which are critical tools for addressing cognitive health in states and communities, as outlined in the US Centers for Disease Control and Prevention (CDC) *Healthy Brain Initiative Roadmap 2018 – 2023*, and in alignment with the priorities of the BOLD Infrastructure for Alzheimer’s Act;
- Proactive collaborations between healthcare professionals, first responders, community organizations, the business community, educators, care partners, volunteers and others to provide dementia-friendly services and supports that nurture a full and optimal quality of life for people living with dementia;
- Ongoing education and professional development for people who, directly or indirectly, serve and support people living with dementia, as well as their care partners;
- Preserving the rights of people living with dementia is paramount to their self-determination and quality of life;

- 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 people living with 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 of the State Plan:

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 (2023 – 2024). 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 (ADSD) 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 one of the goals of TFAD to raise awareness of issues related to dementia and to promote brain health, as well as highlight the importance of getting an early and accurate diagnosis. The impact of dementia may be overwhelming for the people living diagnosed, as well as for their care partners and families. Therefore, dementia awareness efforts, supports, services and policies need to be elevated as a public health priority, as encouraged by the CDC Healthy Brain

Initiative Road Map, and as included as a specific goal in Healthy People 2030.

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 this 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. As previously noted, an estimated 6.5 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.

While there is no cure for Alzheimer's disease or many other forms of dementia at this time, 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 is a key focus of TFAD, as noted throughout the State Plan.

The HP 2030 objectives for dementia 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.

Bridging the CDC Healthy Brain Initiative and the Nevada State Plan

As previously noted, the Nevada State Plan is directly aligned with the goals and priorities of the CDC Healthy Brain Initiative Road Map, as well as the BOLD infrastructure for Alzheimer's Act (amending the Public Health Service Act, Section 398A; 42 U.S.C. 280c-3-4), including

increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. Specific efforts were made to incorporate these priorities throughout the relevant recommendations of Nevada's State Plan. Thus, throughout the recommendations is a particular interest in ensuring a strong presence of elements related to promoting brain health (i.e., risk reduction), early detection, effective and efficient healthcare services, along with supportive services for care partners of people living with dementia.

To offer additional detail on the importance of incorporating these priorities, it is important to understand the CDC Health Brain Initiative and the tools it offers. The Healthy Brain Initiative Road Map is a series created by the Alzheimer's Association and the Centers for Disease Control and Prevention (CDC). The series was initially published in 2007. The latest edition, published in 2018, is the *State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. As described in the document, the Healthy Brain Initiative Road Map "outlines how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of those who care for people living with dementia, or care partners." Promoting brain health and supporting people living with dementia and their care partners throughout the life course should be viewed as a central part of public health practice and constitutes the focus of the Healthy Brain Initiative.

The Road Map describes 25 actionable agenda items that follow the *Essential Services of Public Health*: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate.

Following the actions listed in the Health Brain Initiative Road Map, public health community partnerships can:

- Accelerate risk reduction, calling attention to traumatic brain injury, smoking, diet, physical activity, cardiovascular risk, and other modifiable risk factors
- Advance early detection and diagnosis by ensuring healthcare professionals have the best available evidence on dementia and dementia caregiving.
- Ensure safety and quality of care by offering information, guidance, and supportive resources to caregivers and assuring healthcare professionals use evidence-based guidelines and have sufficient training.

Scientific evidence has indicated that the same healthy behaviors that have been shown to prevent cancers, diabetes, and cardiovascular disease may also reduce the risk of cognitive decline. By leveraging the Healthy Brain Initiative Road Map to revise and create recommendations for the State Plan, TFAD encourages state and local partners to incorporate collaborative efforts to promote cognitive health into practice. This effort will promote the reframing of dementia from a disease of old age to a condition developed, in part, through the accumulation of dementia risk factors over the life course. Ultimately, these tools provide a resource for ameliorating the impact of cognitive impairment and dementia in states and communities, as well as enhancing overall quality of life and well-being of the population.

Nevada Task Force on Alzheimer’s Disease

State Plan to Address Alzheimer’s Disease and Other Dementias

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Nevada Task Force on Alzheimer’s Disease 2023–2024 State Plan

RECOMMENDATIONS

Recommendation #1: Statewide Information and Referral System

Sustain a statewide information and referral (I & R) system for people living with Alzheimer’s disease and other forms of dementia, their care partners and other family members to enable them to connect with local care managers and supportive services. It is the expectation that the approaches, content and messaging within these resources will 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:

- 1) Monitor collaborations between resource centers and other available I & R systems to facilitate access and streamline processes connecting services and supports for people living with dementia and their care partners, including but not limited to:
 - Nevada 2-1-1;
 - NCC Resource Centers;
 - Northern California and Northern Nevada Chapter of the Alzheimer’s Association;
 - Desert Southwest Chapter of the Alzheimer’s Association; and
 - The University of Nevada Reno Nevada Caregiver Support Center.
- 2) The Nevada Aging and Disability Services Division (ADSD) will monitor the number of contacts made by the 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.
- 3) ADSD and partners will monitor and report the number of “hits” on Alzheimer’s disease and other dementias websites including, but not limited to:
 - nevadacareconnections.org;
 - Nevada 2- 1-1;
 - NCC Resource Center;
 - Northern Nevada Alzheimer’s Association (to solely focus on Nevada);
 - Southern Nevada Region of the Alzheimer’s Association (to solely focus on Nevada); and
 - The University of Nevada, Reno Nevada Caregiver Support Center.

Potential Funding:

- Grants, gifts and donations
- American Rescue Plan Act (ARPA) funds

Recommendation #2: Telehealth

Support expanded access to telehealth services throughout the state to enhance brain-health promotion, risk reduction, early detection, diagnosis of dementia, care planning and ongoing care management. Encourage the use of telehealth for both people living with dementia and their care partners to support access to care, quality of life and well-being, especially in rural Nevada. Utilize the statewide information and referral system (*see Recommendation #1*) to maintain a list of telehealth providers and connect people living with dementia to available telehealth services statewide.

Indicators:

- 1) 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.
- 2) 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 people living with dementia and their care partners.

Potential Funding:

- Grants, gifts and donations
- Specific sources may include:
 - Older Americans Act (through ADSD)
 - American Rescue Plan Act (ARPA) funds
 - Available federal resources as identified

Recommendation #3: Cultural Competence

To help ensure equitable processes and outcomes, advocates would benefit from engaging in non-stigmatizing cultural competence training that emphasizes cultural humility (i.e., consistent self-reflection and assessment for equitable behavior). The proactive pursuit of cultural humility ensures input from affected communities will be consciously prioritized. Specific activities might include, without limitation:

- Promoting implicit bias testing. Encouraging personnel involved in public-facing engagements with the dementia community to take implicit bias assessments;
- Promoting listening sessions. Before developing campaigns, entities conducting outreach should engage dementia community members to gauge impressions on aging services and healthcare experienced by its culturally-diverse and marginalized members;
- Promoting development and use of culturally-competent ‘toolkits’ as a resource to support entities providing awareness and outreach campaigns for the dementia community; and
- Employing ‘Choice Point Thinking’ that requires the deliberate consideration of impacts on marginalized communities at all points of major decision making.

These activities align with the understanding that person- and relationship-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, as well as all their potential intersections). 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:

- 1) Monitor number of created, adopted and disseminated cultural competence training programs and toolkits, including progress and implementation of Nevada SB 364 and SB470 (2019).
- 2) Monitor number of service providers that report having participated in cultural competence training.

Potential Funding:

- Grants, gifts and donations
- 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 with different cultural and ethnic focused organizations

Recommendation #4: Outreach to Primary Care Providers

The purpose of this recommendation is to inspire change among primary care providers (PCPs) in order to increase dementia screening during Medicare wellness exams and other routine primary care visits. This will be accomplished by continuing 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. These include, but are not limited to, use of validated clinical assessment tools, clinical guidance and toolkits such as the KAER Toolkit for Primary Care Teams developed by the Gerontological Society of America, online trainings, to increase access to an early and accurate diagnosis, quality care and to encourage participation in available clinical trials/studies. Outreach efforts to PCPs should not only focus on the adoption of validated clinical assessment tools, but also how they can effectively use these tools as part of Medicare Annual Wellness Exams.

Specifically, we support local and statewide partnerships and collaborations to increase access to early diagnosis of Alzheimer's disease 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 Geriatric Workforce Enhancement Programs (GWEPs) through the UNR and UNLV Schools of Medicine, the UNR 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, and the Alzheimer's Association.

We support current collaborations to fund Memory Assessment Clinics (MACs), based on a model from Georgia, called Georgia Memory Net (GMN). Work is ongoing between Renown Neurology, the GWEPs at UNR and UNLV Schools of Medicine, the UNR Sanford Center for

Aging, the Cleveland Clinic / Lou Ruvo Center for Brain Health, and the UNLV Brain Health Department. Nevada's MACs will serve as diagnostic hubs and feature primary care practice "spokes" which refer patients to the MACs and receive invaluable training in the treatment and care of those living with dementia, their families and care partners. In addition, the person living with dementia, as well as their care partners will benefit from ongoing care coordination and referral to community-based services by trained Dementia Care Navigators.

Indicators:

- 1) *Cognitive Decline*: DHHS will be asked to report data gathered through the CDC Behavioral Risk Factor Surveillance System (BRFSS) module on subjective cognitive decline. The module is a six-question survey used to determine how Subjective Cognitive Decline (SCD) affects individuals age 45 and older in performing activities of daily living including caring for themselves. The module also asks whether those who report SCD have talked with a healthcare provider about their concerns. This can be used as a subjective measure of provider-patient engagement on SCI as well as ADRD. Further, we ask DHHS to include this information in its Nevada Elders Count report.
- 2) *Survey Community Partners*: To the extent practicable, DPBH should survey community partners to determine the reach of current programs to train PCPs to perform cognitive screenings.
- 3) *Claims Data*: DHHS Office of Analytics will be asked to annually report Nevada Medicaid utilization for enrollees age 55 to 64 of the Cognitive Decline and Care Planning Code (i.e. CPT Code 99483). In addition, the report should include utilization of Medicaid codes G0438 (Annual wellness visit, including personalized plan of care, initial) and G0439 (Annual wellness visit, including personalized plan of care, subsequent) for all enrollees. The report shall include utilization of each code, an unduplicated count of providers utilizing the codes, and an unduplicated count of patients receiving the service. The report will include data from both Fee-For-Service and Managed Care programs. To the extent practicable, the Office of Analytics will determine if it can access Medicare claims data for Nevadans from CMS for the purposes of reporting claims utilization as described above.

Potential Funding:

- Grants, gifts, and donations
- State general funds should also be considered as potential funding sources (i.e., MACs)

Recommendation #5: Dementia Care Specialist (DCS) Program

Background/Justification:

Drawing on best practices nationwide as a potential model for this proposed program, the state of Wisconsin has emerged as a leader with their Dementia Care Specialist (DCS) program. With legislative support, they have a professional (and most often, a graduate-level) DCS in every county. Maryland and Georgia are also looking to emulate Wisconsin's DCS program. Over a period of ten years, the Wisconsin DCS program has grown from 5 DCS positions to 70, including staff in tribal communities. This program has also been highlighted by the U.S. Administration on Community Living.

With programs such as this, significant cost savings to state Medicaid programs can be achieved through timely and appropriate care partner supports. A 2014 study published by Mary Mittelman,

of the NYU School of Medicine, showed that people living with dementia who received support were able to reside in the community an average of 557 days longer, compared to those in the control group. For the care partner, the intervention was associated with a decrease in depressive symptoms and related symptoms of distress.

The Wisconsin DCS program has three goals, which are referred to as the three pillars of the program. The three pillars are:

- 1) Train staff at the ADRC and other county and municipal offices to assist local systems in becoming dementia capable.
- 2) Help communities become dementia-friendly, enabling people living with dementia to remain active and safe, and care partners to feel supported by their community.
- 3) Provide education and support to people with memory concerns or dementia, and their families, to allow them to live at home safely.

The Wisconsin Department of Health Services has also integrated a dementia crisis response effort into their no wrong door/aging and disability resource center (NWD) model using the DCS Program. This involves a three-pronged approach: the initial crisis response, crisis stabilization, and providing long-term care and supportive services for people behaviorally communicating distress, which is usually an expression of unmet need.

In Wisconsin, the DCS does not go on crisis calls and only operates during regular business hours, however, they are available to:

- Provide training on dementia, and how to work effectively with a person who has dementia in a crisis, to any professional first responder or public safety agency, including law enforcement, emergency medical service providers, fire and rescue teams, adult protective services workers, and crisis response workers within their service area;
- Accompany adult protective services workers on home visits during regular work hours when dementia is suspected to be involved in the case;
- Consult with crisis workers and other emergency responders on individual cases during regular business hours; and
- Consult with or serve on local coalitions or task forces that are working to improve local systemic responses for people with dementia in crisis.

Importantly, the DCS is proactive by working with all people living with dementia and their families to create individual care plans, as well as crisis prevention and preparation plans to prevent an initial crisis from occurring for that individual or family related to the symptoms of dementia. In addition to crisis response, the DCS Program also works to support people living with dementia and their care partners, and to build dementia capability within the community to ensure the highest quality of life possible while living at home. To accomplish this, the dementia care specialists (DCSs), embedded within each county:

- 1) Provide free information and assistance to adults with memory or cognitive concerns, or who have been given a dementia diagnosis as well as.
- 2) Provide information, education and support to family members and friends who are care partners of people living with memory loss and/or dementia.
- 3) Help develop dementia-friendly communities where people living with dementia can remain active and safe, and care partners can feel supported.

- 4) Train Resource Navigators at Nevada Care Connection, i.e., the Aging and Disability Resource Centers (ADRCs) and other county and municipal offices to be more dementia capable.

Nevada is well positioned to replicate this model as part of its Nevada Care Connection network.

Recommendation:

TFAD recommends that the ADSD replicate the Dementia Care Specialists (DCS) program in Nevada by developing funding necessary to establish one or more DCS positions as a pilot. These positions could be housed in county health and human service agencies, senior community centers or non-profit organizations serving older adults.

The DCS team members will serve as the primary, local contact for people living with dementia, their care partners, law enforcement, hospitals, healthcare professionals, community social workers, and other community members who encounter individuals who may have dementia. They will also conduct memory screenings; facilitate obtaining an accurate diagnosis; provide information and assistance to connect families and individuals with community support services; provide evidence-based and/or evidence-informed, person- and relationship-centered education, training and support; connect people with options for counseling as well as access to public and private programs and benefits; provide consumer advocacy; lead and facilitate local dementia-friendly efforts in coordination and partnership with Dementia Friendly Nevada; and conduct other outreach activities with an aim to bring additional dementia-related services to the region.

Expected program outcomes include:

- 1) Replication of the Wisconsin DCS model in Nevada;
- 2) Increased care partner support through implementation of the bi-lingual REACH community intervention; and
- 3) Strengthened ADSD efforts to raise awareness and community support of people living with dementia.

Training and oversight can be provided by the UNR Dementia Engagement, Education, and Research (DEER) Program, which also provides an administrative home for the Dementia Friendly Nevada initiative. Program evaluation could be conducted by the UNR Sanford Center for Aging, or another appropriate academic department experienced in this area.

Indicators:

- 1) Reduction in avoidable emergency department and hospital admissions.
- 2) Reduction in avoidable incarceration of individuals with suspected dementia.
- 3) Increase in pro-active training of first responders, staff in community-based organizations and county agencies serving the elderly.
- 4) Increase in safety and well-being of people living with dementia, their families, and care partners.

Potential Funding:

- Grants, gifts and donations
- State appropriations
- Medicaid administrative claims funding.

Recommendation #6: Residential Long-term Care

The scope of this recommendation includes skilled nursing facilities, assisted living, residential facilities for groups, and homes for individual residential care. To support this recommendation, it is important to continue to review current funding and new funding streams to support residential long-term care for people living with dementia in Nevada.

Establish and sustain a statewide committee with membership from skilled nursing and assisted living sectors, including but not limited to the Nevada Health Care Association, Aging and Disability Services Division's Community- Based Care Program, Long-Term Care Ombudsman Program, the Bureau of Health Care Quality and Compliance, CoMagine Health, at least one family care partner, one resident living with dementia and one member of TFAD. The focus of this statewide committee is to identify and implement recommendations, improvements, and resources within residential long-term care to support the health and well-being of all residents, including residents living with dementia. Engage the statewide committee in developing quality indicators for dementia care and support in long-term care.

Provide funding or incentives to encourage long-term care providers to increase capacity for people living with dementia and the ability to provide person-directed and relationship-centered care. Additionally, emphasize person-centered care planning to ensure residents, their families, and staff feel and experience respect, support, self-worth, empowerment, well-being, and inclusion in everyday community life. Ensure adequate resources for the Long-term Care Ombudsman program to provide education to residents, family care partners and long-term care staff about resident rights and appropriate channels for reporting abuse, neglect, and exploitation.

In addition, require long-term care staff to attend annual continuing education emphasizing the importance of treating co-morbidities, addressing injury risks, utilizing public health guides for emergency preparedness and emergency response (such as those developed by and available through the CDC), and attending to behavioral health needs among residents living with dementia while supporting an increase in accurate diagnoses and providing effective care planning.

Indicators:

- 1) Monitor the number and quality of dementia care and support options within Nevada's long-term care communities in accordance with the quality indicators developed by the statewide committee.
- 2) Successful implementation of an expanded dementia care training requirement for long-term care staff.
- 3) Monitor the workforce capacity and anticipated demand for long-term care services needed to support the growing number of Nevadans living with dementia.
- 4) Evaluate the enforcement and success of continuing education for long-term care staff in accordance with the above recommendation.

Potential Funding:

- Grants, gifts and donations
- Specific sources may include:
 - Medicaid expansion through Home and Community-Based Services Waiver

- Increased supplemental SSI rate.
- Tax incentives
- Civil monetary penalty (CMP) funds

Recommendation #7: Care Partner Support

According to the Alzheimer’s Association *2022 Facts and Figures*, an estimated 48,000 care partners are providing 79 million hours of unpaid care to Nevadans living with dementia. Further, 80% of those care partners have chronic health conditions and 18% have depression. Care partner support interventions can help improve the health and well-being of dementia care partners. In addition, effective support for care partners can also delay nursing home admission of the person living with dementia by providing care partners with skills and resources (emotional, social, psychological and/or technological) to continue helping their relatives or friends at home.

Therefore, TFAD supports providing care partners information about and access to evidence-based and evidence-informed education, support services, and resources to:

- 1) Promote knowledge and understanding of Alzheimer's disease and other forms of dementia;
- 2) Increase understanding of effective approaches to care partnering approaches to support people living with dementia;
- 3) Provide and expand respite services for family and informal care partners of people living with dementia; and
- 4) Emphasize the importance of maintaining care partners’ health and well-being.

The support services should include, but are not limited to, family care consultations, care partner support groups, educational programs, including those focused on the proactive promotion of family care partner health, and respite care.

TFAD also supports efforts to promote and fund comprehensive care partner education and services that are provided by many organizations across the state.

TFAD seeks to improve access to support services and programs for family care partners and people living with dementia including, but not limited to, the following:

- Broadening the eligibility requirements for programs and grant funding so that more families may benefit from them regardless of financial status or age;
- Supporting the work of organizations across the state that are focused on improving the lives of those living with dementia, their care partners and families; and
- Sustaining a statewide information and referral system (See Recommendation #1) for families, care partners, and people living with Alzheimer's disease and other forms of dementia.

TFAD, ADSD and the Division of Health Care Financing and Policy (DHCFP, or Nevada Medicaid) shall explore effective home and community-based programs operating in other states. The goal will be to revise existing programs to better identify and deliver individualized training to family care partners that may be offered through a home visit, secure electronic communication, web-based training or other ways that are flexible, accessible and meaningful for the care partner.

In addition, TFAD encourages ADSD to conduct an awareness campaign around eligibility of current respite care programs.

Indicators:

- 1) ADSD and the Division of Public and Behavioral Health (DPBH) are asked to 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 care partner 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 care partner support programs.
- 2) The DHHS Office of Analytics will be asked to report, at least biannually, data from the Nevada BRFSS Caregiver Support survey module. In addition, the Office is asked to conduct a longitudinal review of past BRFSS Caregiver module surveys to better track progress of this recommendation. In addition, TFAD requests that data from this survey be routinely included in the Nevada Elders Count report.

Potential Funding:

- Grants, gifts and donations
- Specific sources may include:
 - Fund for a Healthy Nevada

Recommendation #8: Dementia Training

Expand Nevada’s dementia care training requirement for all long-term services and supports providers, including residential and community-based provider organizations and staff, to ensure that all direct care staff providing care and support to people living with dementia have the information needed to provide effective person-directed and relationship-centered care. Mandate and enforce the identification, adoption and implementation of established, evidence-based and evidence-informed, person- and relationship-centered dementia care training recommendations and training programs, including but not limited to: the Nevada Department of Veterans Services’ (NDVS) *Bravo Zulu: Achieving Excellence in Relationship-Centered Dementia Care* program, Alzheimer’s Association’s *Dementia Care Practice Recommendations*, Dementia Action Alliance/Eden Alternative’s *Raising the Bar* practice guide, and others as appropriate.

Such training programs should be made available to all residential long-term care and community-based aging services organizations through leveraging key partners to implement and evaluate in-person and/or online trainings. Evaluation efforts should include assessment of core competencies.

Indicators:

- 1) High-quality, comprehensive dementia training programs are identified or developed, and made available to all residential and community-based aging services statewide.
- 2) The identified or developed programs are encouraged by key partners.
- 3) The identified or developed programs are adopted and implemented by an increasing number of residential and community-based aging services over the plan’s two-year period.

Potential Funding:

- Grants, gifts and donations
- Specific sources may include:
 - State appropriation and/or state grants for dementia training
 - Civil monetary penalty funds

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 build capacity among volunteers to share knowledge, along with current, reliable information about brain health, dependable tools, and up-to-date resources in communities while finding, recruiting, and training 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 de-stigmatizes and reduces fear and misunderstanding associated with dementia through open-conversation, ongoing engagement opportunities, and reliable information.

In supporting age- and dementia-friendly communities volunteers will learn how to promote each person's well-being, both the individual living with dementia and their family, as well as preserve personal dignity and respect in everyday community life. Competent and confident trained volunteers offer capabilities and wisdom in this vital role.

Indicators:

- 1) Monitor and correspond with non-profits, service organizations, healthcare institutions, and universities that recruit volunteers to learn the number of volunteers recruited and trained, the types of training, presentations, and information sessions offered.
- 2) Track key services being provided for people living with dementia and care partners that engage volunteers in service delivery.
- 3) Determine which additional up-to-date trainings and services might be needed to expand volunteer education and opportunities to build capacity and increase outreach, including health fairs, brain health conferences, and various awareness-raising presentations.

Potential Funding:

- Grants, gifts and donations
- Specific sources may include:
 - AARP
 - American Rescue Plan Act (ARPA) funds

Recommendation #10: Awareness of Dementia and the Legal Profession

In the legal profession, awareness and a fundamental understanding of dementia is crucial for effective representation of clients who are living with dementia. These individuals may seek consultation in any area of the law and thus, knowledge about dementia is essential for all practitioners.

To advance effective legal representation for people living with dementia, TFAD supports the availability of educational options to increase awareness and knowledge of topics related to dementia designed for students pursuing legal professions and licensed professionals completing required continuing legal education (CLE). Judges and court personnel are encouraged to participate in dementia-friendly education and trainings. Educational topics could include, but are not limited to:

- Capacity for decision-making (related to healthcare, finances, living arrangements and other pertinent decisions);
- Advance care planning (completion of documents reflecting an individual's wishes for their healthcare, living arrangements and request to nominate a guardian);
- Estate planning;
- Adult guardianship;
- Risk of exploitation, abuse and neglect;
- Ethical considerations for effective representation of clients living with dementia; and
- Information related to dementia (possible warning signs, diagnostic process, ongoing care and supportive resources, and family caregiving).

TFAD encourages UNLV's William S Boyd School of Law, the National Judicial College, the State Bar of Nevada (the licensing entity for Nevada attorneys), trade associations such as the Washoe County Bar and Clark County Bar Associations, and Nevada's legal services providers to promote awareness and education related to dementia. Further, TFAD supports the offering of CLE credits for dementia-related, medically-based courses for legal professionals that could satisfy the annual licensure requirements for ethics.

Indicators

- 1) Assess number, topics and participation rate annually for educational opportunities, both pre- and post- professional education (CLE) offered through UNLV's William S. Boyd School of Law, the legal community, Nevada's senior legal services providers and ADSD.
- 2) Request CLE providers offer feedback from participant evaluations in dementia-related CLE programs.

Potential Funding

- Grants, gifts and donations

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 people living with dementia and their care partners, with key elements including care/discharge planning, care management and associated tools, information on community resources, wrap-around services, periodic follow-up check-ins and assessments, strategies for living well with dementia, and dementia self-management resources. 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, TFAD encourages the Nevada Department of Health and Human Services (DHHS) to investigate federal funding opportunities through the Centers for Medicare and Medicaid Services and the CMS Innovation Center, as well as others. Opportunities to support more widespread use of care transitions programs may be explored by seeking and establishing key partnerships with Nevada's healthcare providers and systems, as well as identifying available resources. New and existing programs should be evaluated to determine program accessibility, effectiveness, and impact.

Efforts should be taken to mobilize continuing education programs designed to build healthcare providers' understanding of the importance of care transition planning and skills in convening interprofessional teams of providers to counsel and support patients at the time of discharge.

Hospital-to-community care transitions programs should emphasize the essential role of family and care partners, and should include the development of care transition plans that support care partner health and well-being.

Indicators:

- 1) Monitor the number of care transitions programs available across Nevada's counties, including those connected to rural hospitals, such as the Community Paramedics program.
- 2) Monitor the ongoing process and impact data of the Hospital-to-Home program, with updates from Nevada Senior Services.
- 3) Monitor the number of continuing education programs for Nevada medical providers that discuss the importance of care transition planning.
- 4) Receive updates on new and existing care transitions programs.
- 5) Review data available on hospital admissions and re-admissions of people living with dementia (i.e., Healthcare Costs and Utilization Project data).

Potential Funding:

- Grants, gifts and donations
- 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. Encourage the implementation of programs relating to veterans living with dementia and their families, including the ongoing implementation of the Nevada Department of Veterans Services' *Bravo Zulu: Achieving Excellence in Relationship-Centered Dementia Care* program for professional and family care partners. Such education programs should include robust information on modifiable risk factors of dementia and the role that lifestyle can play in reducing risk and supporting people living with dementia in living well.

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 including *Bravo Zulu: Achieving Excellence in Relationship-Centered Dementia Care*, 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, gifts and donations
- Specific sources may include:
 - Nevada Department of Veterans Services
 - Civil monetary penalty (CMP) funds

Recommendation #13: Driving and Dementia

Improve Nevada's infrastructure, services, and support for ensuring the safety of people whose driving ability may be compromised by cognitive impairment, and those around them. Develop and implement:

- 1) A public information campaign about cognitive impairment and driving safety, leveraging public service announcements, websites, printed materials, etc., with content including:
 - a) Signs of compromised driving ability and potentially increased driving risk;
 - b) Options for addressing and/or reporting unsafe driving; and
 - c) Options for formal evaluation of driving safety.
- 2) A training program for healthcare providers through continuing education (CE) courses, licensing authority mailings, licensing requirements, kiosks/displays at meetings, etc., with content regarding:
 - a) Nevada statutes and regulations about provider responsibilities when cognitive impairment may compromise driving safety;
 - b) Mechanisms for reporting drivers who may be unsafe because of cognitive impairment;
 - c) Signs of compromised driving ability and potentially increased driving risk;

- d) Options for formal evaluation of driving safety; and
 - e) Options for rehabilitation to safe driving.
- 3) A process to create a standardized evidence-based driving safety evaluation tool for use by entities interested in driver safety and/or cognitive impairment, such as Aging and Disability Services Division (ADSD), geriatrics clinicians, Department of Transportation (DOT), Alzheimer's Association, etc.
 - 4) Provide support for individuals and families when driving must be restricted because of cognitive impairment by:
 - a) Promoting the development of safe, economical alternative means of transportation, including improved public transportation and partnerships with relevant private industries; and
 - b) Assisting families with negotiating, explaining, and reinforcing driving restrictions.

Indicators:

- 1) Program utilization
- 2) Participation (e.g., meeting attendance, website hits, CE credits granted)
- 3) Trips/riders served by alternative means of transportation
- 4) Use of assessment services
- 5) Number of drivers served by support services
- 6) Other assessments (polls, quizzes, focus groups, etc.) of Nevada healthcare providers and residents
- 7) Awareness of guidelines regarding cognitively compromised drivers
- 8) Knowledge of mechanisms for informing DMV about compromised drivers
- 9) Perceived ease of finding information about cognitive impairment and driving in Nevada
- 10) Nevada Department of Transportation (DOT), Highway Patrol, and DMV data
- 11) Total motor vehicle accidents and fatalities in Nevada involving individuals reported by HCPs as having dementia
- 12) Referrals from providers and residents for cognitively compromised driving
- 13) Licenses restricted or revoked because of cognition-related safety concerns
- 14) Older driver crashes and fatalities
- 15) Dated deliverables for creation of driving safety evaluation tool

Potential Funding:

- Grants, gifts and donations
- Specific sources may include:
 - US Department of Transportation
 - US Department of Health and Human Services
 - US Department of Veterans Affairs
 - National Institutes of Health
 - Nevada Department of Motor Vehicles
 - Nevada Department of Transportation

- Regional Transportation Commission
- Aging and Disability Services Division
- Car insurance companies
- Self-driving car manufacturers
- Ride sharing services
- Transportation services (taxis, limos)
- Support and interest groups (e.g., AARP, Alzheimer’s Association)

Recommendation #14: Developing Community Awareness Around Increased Brain Health Literacy

Promote dementia-friendly community awareness programs which are designed to increase knowledge, understanding and access to brain health and dementia-related information and supportive resources. Awareness programs serve to reduce stigma and dispel myths and stereotypes around a diagnosis of dementia, engage care partners and offer support to people living with dementia in living well over the course of their lives. These programs should also provide information that serves to enhance a community’s brain health literacy, enabling people affected by dementia to become partners in their daily care needs, as well as to engage in the search for effective therapies through participation in research, evidence-based interventions and clinical trials, if they choose to do so.

Dementia friendly-community awareness programs and brain health literacy efforts may include, but are not limited to, content regarding:

- 1) Promotion of strategies for living well with dementia;
- 2) Initiatives to promote brain health for all people and reduce risks associated with modifiable lifestyle factors;
- 3) Helpful resources to support people living with dementia and their care partners in developing effective strategies;
- 4) Overview of dementia, including prevalence, types, early symptoms, treatment, and course of illness, along with information about the benefits of early detection and diagnosis;
- 5) Community resources, educational programs and social services including evidence-based programs to support for people living with dementia and their care partners;
- 6) Opportunities for people living well with dementia to advocate for their own well-being and participate in meaningful engagement in community life;
- 7) Educational resources to support care partners in fostering their own health and well-being;
- 8) Educational resources to increase awareness about research opportunities and benefits of clinical trials with special consideration for those in underserved, minority communities;
- 9) Information to help people living with dementia, care partners, and community members recognize the signs of abuse, neglect, and exploitation, along with resources to access in such cases; and
- 10) Standards defined as Culturally and Linguistically Appropriate Services (CLAS).

The target audience for community awareness and brain health literacy programs includes people living with dementia, care partners, family members, professional care partners, businesses, faith-based communities, first responders, government agencies, social service organizations, community groups, K – 12 and higher education, along with 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 Groups, Alzheimer's Association, Cleveland Clinic Lou Ruvo Center for Brain Health and the University of Nevada, Reno (UNR) Dementia Engagement, Education, and Research (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, and offers resources for brain health promotion.

In addition to promoting community awareness about brain health literacy and dementia within the broader community, it is important to ensure adequate opportunities to learn about brain health and dementia across K – 12 and institutions of higher education.

Indicators:

- 1) Monitor the number and types of dementia and brain health-related community awareness presentations including, but not limited to, those listed on the Dementia Friendly Nevada website and offered through Dementia Friendly Nevada Community Groups, UNR Sanford Center for Aging, UNR DEER Program, Alzheimer's Association and Cleveland Clinic Lou Ruvo Center for Brain Health.
- 2) Monitor how effectively community awareness campaigns increase brain health literacy.
- 3) Monitor if content in community awareness campaigns around brain health literacy adhere to the Cultural and Linguistically Appropriate Services (CLAS) standards.

Potential Funding:

- Grants, gifts and donations
- Specific resources may include:
 - US Department of Health and Human Services, Office of Minority Health, which releases NOFA's that fund efforts to action CLAS Standards

Recommendation #15: Organizational Outreach

Engage all sectors of the community, including, but not limited to, healthcare, faith-based communities, law enforcement, retail, restaurants, government and long-term residential care and senior living, in:

- 1) Incorporating brain-health and dementia-related information/resources into existing employee assistance programs to offer specialized assistance to people living with dementia and care partners;
- 2) Offering dementia awareness programs to their employees, including, but not limited to, Dementia Friends, Dementia Friendly Community Awareness Training (CAT), Alzheimer's Association education programs, and education programs through the Cleveland Clinic Lou Ruvo Center for Brain Health;
- 3) Promoting education regarding brain health initiatives, dementia risk reduction and living well with dementia; and
- 4) Developing partnerships with local Dementia Friendly Nevada Community Groups, the Dementia Friendly Nevada Initiative as well as other state, local and national initiatives.

Indicators:

- 1) Monitor dementia friendly activities and collaborations across various community sectors.

Potential Funding:

- Grants, gifts and donations
- Specific sources may include:
 - employers and employer organizations

Recommendation #16: Advance Care Planning

Background/Justification:

Advance care planning is considered to be a significant unmet need for persons living with dementia. *Advance Care Planning* refers to a process where an individual clearly documents their wishes for care through advance directives and/or designates someone who can make decisions on their behalf if the individual does not have the capacity to do so. *Advance Directives* are legal and medical documents stating a person's wishes for their future care. Examples are 'Healthcare Power of Attorney', 'Declaration (Living Will)' and 'Do Not Resuscitate (DNR) Order'. Without advance directives in place, an individual's wishes for their care may not be followed, and under some circumstances, a guardian may be appointed to make all healthcare decisions on behalf of the individual. Without data specific to people living with dementia, estimates are that only about half of all those 65+ have completed at least one advance directive, illustrating the scope of unmet need.

As advance directives must be completed when an individual is deemed to have decision-making capacity, there is a heightened sense of urgency for those who are living with dementia, due to changes in cognitive capacity over time. The concept of capacity refers to an individual's ability to make a particular decision at a specific point in time. All adults are presumed to have decision-making capacity. A person with impaired capacity may still have the ability to make decisions related to their advance directives. A capacity assessment completed by a physician can determine whether a person living with dementia has the ability to make a specific decision at that time such as the appointment of a healthcare power of attorney. The evaluation of decision-making capacity assesses whether an individual is able to demonstrate understanding, appreciation and reasoning related to their decision, as well as communicate a consistent choice. Advance Directives go into effect when an individual is evaluated to no longer have capacity to make the decisions specified in each completed document.

People living with dementia often do not complete advance directives due a range of factors. Feedback from individuals, care partners and professionals provide insights into commonly-experienced challenges and obstacles including lack of knowledge, access to resources and misconceptions or misinformation. Many are not aware of the potential benefits of advance care planning or resultant legal processes, such as guardianship that can occur if there are no documented wishes. The process of completing advance directives can seem daunting and may be costly. Some are undecided about their future healthcare wishes; others worry about placing a burden on the person designated as their power of attorney or have no one willing to serve in this capacity. Misconceptions about when documents go into effect lead to concerns about loss of independence once a surrogate decision-maker has been selected. There is apprehension that, once

documented, wishes will not be followed. In some instances, a person living with dementia may be required to obtain a certification of competency prior to being able to fully execute their advance directives. Education about advance care planning is fundamental to address the myriad of obstacles individuals encounter engaging in this process and completing advance directives according to their specific choices.

In a 2016 Civil Legal Needs Study and Economic Impact Assessment, the Nevada Supreme Court Access to Justice Commission found that nearly 76% of civil legal needs in the state go unmet. However, investment in community legal services yields a return on investment of 7 to 1. Nevada legal services providers offering assistance with advance directives has yielded a savings of \$18M statewide. Therefore, access to advance directives is an “access to justice” issue for Nevada citizens.

Healthcare and legal professionals supporting people living with dementia can benefit from education and training about advance care planning focused on such pertinent topics as decision-making capacity for completion of advance directives and when documents such as the healthcare power of attorney go into effect. Education and training can help facilitate discussions with patients and clients about the benefits of advance care planning and support referrals to community resources for assistance.

Recommendation:

TFAD encourages the Nevada Aging and Disability Services Division (ADSD) to develop and promote education and training resources available to people living with dementia, their care partners and professionals (e.g., medical, legal) to support people living with dementia in completing their advance care planning documents.

The following are potential opportunities that could be implemented and/or expanded:

- 1) Support for people living with dementia and care partners:
 - Promote awareness and distribution of Nevada’s dementia-specific advance care planning documents/instructions through senior law and community service providers:
 - Engage with education initiatives such as the Legal Aid Library Kiosk project to distribute an easy-to-understand explanation of advance care planning, list of resources and Nevada forms/instructions.
 - Encourage Nevada Care Connection Resource Center’s Resource Navigators to assess individual needs for advance care planning and refer to legal services providers.
 - Encourage Nevada’s senior law providers to identify effective approaches to facilitate completion of advance care planning for clients living with dementia.
 - Explore opportunities to work with hospitals and healthcare providers to include community resources for assistance completing advance directives as part of the advance planning information distributed to individuals.
 - Explore potential of convening stakeholders across relevant disciplines along with participation by people living with dementia and care partners to identify specific efforts/collaborations to promote advance care planning.

- 2) Options for professional education/training (legal, healthcare, financial):
 - Encourage and support stakeholders, including but not limited to ADSD, State Bar of Nevada, Nevada Supreme Court Access to Justice Commission, UNLV Boyd School of Law, legal services providers, Volunteer Attorneys for Rural Nevadans (VARN) along with healthcare specialists to offer continuing education/training curricula for professionals and students about advance care planning for people living with dementia.
 - Promote the creation of a state-level clearinghouse for advance care planning information, including, but not limited to, educational materials, Nevada-specific forms, community resources, legal services providers and relevant healthcare providers.
 - Explore opportunities to create medical/legal collaborations to address issues related to the determination of capacity for persons living with dementia.

Indicators:

- 1) Receive updates from ADSD on various advance care planning topics, including, but not limited to:
 - Community education initiatives;
 - Engagement with hospitals/healthcare providers about information targeted to patients/families;
 - Resources/education offered under Older Americans Act (OAA) legal services grants to assist with completion of advance directives;
 - Options to create a state-level clearinghouse for Nevada-specific information; and
 - Engagement with legal community regarding efforts to increase education/training options focused on people living with dementia.
- 2) Monitor data on advance care planning assistance provided by OAA funded legal services providers and advance care planning education/training offered by various stakeholders to include frequency, topics, participation rates and program evaluation.
- 3) Request updates from various stakeholders on feasibility of medical/legal collaborations related to advance care planning.

Potential Funding:

- Grants, gifts and donations
- Specific sources may include:
 - Older Americans Act funds (through ADSD)

Recommendation #17: Choice in Care and Care Settings

Background/Justification:

Increasingly, locked and segregated dementia care is being challenged as a potential violation of a person's human rights and civil liberties. Locked and segregated dementia care, a form of environmental restraint, includes special care units in skilled nursing facilities and assisted living communities, locked residential facilities for groups, and stand-alone memory care communities. As will be made clear by the following discussion of legal statutes and precedent, people living with dementia *have the right to choose* their own care and living environments, and should remain free of forced placement.

It is important to note that holding a power of attorney over someone does not grant the legal authority to place an adult in a locked environment, even if that adult has a medically-confirmed dementia-related diagnosis. There is no legal authority for physicians to confine residents in long-term care facilities, other than in the case of specified involuntary court ordered admissions under NRS 433A (i.e., mental health holds). Similarly, there is no legal authority giving long-term care providers the ability to hold a resident against their will. By law, there are only two people with the authority to consent to an individual's placement in a locked dementia care setting – the individual themselves or a court-appointed guardian.

Unfortunately, unjustly, and perhaps unwittingly, under this standard, long-term care facilities across Nevada may be committing false imprisonment, if they do not have the documented legal consent to confine a resident (or residents) behind locked doors.

While the right to move freely is well-established under general legal principles, there are also Federal and State laws (e.g., Code of Federal Regulations, which are from the federal Nursing Home Reform Act and pertain to regulation of skilled nursing facilities, and Nevada Revised Statutes) specific to long-term care facilities that enhance the general rules, including the right to:

- Self-determination (42 C.F.R. §483.10 and 483.15(b));
- Be free from interference in exercising their rights (42 C.F.R. §483.10(a)(2));
- Refuse treatment to the extent permitted by law and to be informed of the consequences of that refusal (NRS 449A.112(b) and 42 C.F.R. §483.10(b)(4));
- Be free from restraint (NRS 449A.221 and 42 C.F.R. §483.13);
 - Note: In Nevada, environmental restraints are not defined in the NRS. However, according to NRS 449A.221, “mechanical restraint” is defined as the use of devices... “to limit a person’s movement or hold a person immobile.” In this sense, a locked door may be considered a mechanical restraint that limits a person’s movement.
- Free choice in determining treatment (42 C.F.R. 483.10(d)); and
- Considerate and respectful care (NRS 449A.112(a) and 42 C.F.R. 483.15(a)).

Furthermore, people living with dementia, like all Nevadans, have the right to live and receive care and support in the least restrictive environment. The United States Supreme Court 1999 *Olmstead vs. L.C.* decision reinforced the right of people with cognitive impairment to live in an integrated setting for as long as they may safely do so with the necessary supports. Supporting the integration mandate in the Americans with Disabilities Act (ADA; 1990), the *Olmstead* decision asserts that the medically-unjustifiable institutionalization of persons with disabilities constitutes a violation of the ADA. States must provide services to people living with disabilities, including dementia, in the community, as opposed to in an institution, to the greatest practicable extent. Failure to do so constitutes discrimination.

In addition to locked doors, there are a number of other ways long-term care facilities may attempt to confine residents living with (and without) dementia, including:

- Placing alarms on doors;
- “Redirecting” residents to stay inside when they attempt to leave;
- Telling residents, they “cannot leave” or that a “doctor has not signed off on a pass”; or

- By failing to provide physical assistance to residents who say they “want to leave,” but are physically unable to do so.

This right afforded to all people, including people living with dementia, is highlighted in the following quote from the California Advocates for Nursing Home Reform:

All adults have the right to move freely and choose where they want to live and whether or not to receive health care or care services from somebody... When someone goes to a long-term care facility, they do not leave their rights at the door. They have every right not to be imprisoned, even if someone like a doctor, [family member] or a facility administrator believes the resident does not have the capacity to make sound decisions... ***Only a judge has the ability to declare someone incompetent and take away their right to come and go as they please.*** Any other opinion regarding a person’s capacity to make decisions is just that – an opinion – and has no direct legal bearing on that person’s rights... The U.S. Constitution provides a right of privacy and guarantee that liberty interests may not be deprived without due process of law. The right to choose your own residence, be free from detention, and control health care decisions are guaranteed as part of the fundamental concept of liberty that Americans celebrate and defend. (California Advocates for Nursing Home Reform, 2015).

Recommendation:

The State of Nevada must ensure inclusive communities for people of *all* abilities, and uphold the rights of people living with dementia to have a say in the decisions that affect their lives, including all care decisions and choice of care setting. To protect these rights, TFAD encourages the standardization of the assessment and admission process for all locked dementia care settings. In addition, TFAD encourages the Nevada State Long-Term Care Ombudsman’s office to raise awareness across Nevada, and especially within long-term care facilities, of the definition of, and issues regarding, unlawful confinement/false imprisonment in long-term care. TFAD further encourages the Ombudsman’s office to work collaboratively with all residents, including residents living with dementia, who do not consent to long-term care placement, and help them explore other options and alternatives, ensuring each individual’s right to live in the least restrictive environment.

In addition, it is the responsibility of Nevada’s Bureau of Health Care Quality and Compliance (HCQC) to ensure legal and regulatory compliance regarding the requirement for consent to placement, ensuring that no individual is confined against their will, unless authorized by a court-appointed guardian, and that each individual’s preferences for care and care setting are clearly documented and honored.

Indicators:

- 1) Clear messaging disseminated by the Nevada State Long-Term Care Ombudsman’s Office and Bureau of Health Care Quality and Compliance (HCQC) outlining the legal rights of people living with dementia to choose their care and living environment, and be free from unlawful confinement/false imprisonment.

- 2) Proactive advocacy and education by Ombudsman on behalf of long-term care residents living with dementia to facilitate decision making regarding their care setting and living environment.
- 3) HCQC brings visibility to the clear legal standards protecting choice in care setting/living environment and holds long-term care organizations accountable for compliance.

Potential Funding:

- Established or enhanced operating budgets within the Ombudsman's Office and HCQC.

DRAFT

Appendix A: Recommendations from Previous State Plans with Continued Monitoring

Year Initiated	No.	Area of Focus	Recommendation	Monitoring
2013	2	Access to Services	<p><u>APRNs</u> 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.</p>	<p>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.</p>
2013	4	Access to Services	<p><u>Younger-Onset Alzheimer's Disease</u> 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.</p>	<p>ADSD will annually monitor federal and state legislation to determine if there are changes that could affect eligibility for this population.</p>
2013	6	Access to Services	<p><u>Affordability</u> Address affordability of services for persons with Alzheimer's disease and related disorders by implementing sliding fee scales and other cost-sharing mechanisms.</p>	<p>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.</p>
2013	7	Quality of Care	<p><u>Nevada Research Consortium</u> 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.</p>	<p>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.</p>

Appendix A: Recommendations from Previous State Plans with Continued Monitoring

Year Initiated	No.	Area of Focus	Recommendation	Monitoring
2013	8	Quality of Care	<p><u>Caregiver Service</u> 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.</p>	
2013	10	Quality of Care	<p><u>Reducing Out-of-State Placement</u> Reduce the need for out-of-state placements in Nevada by:</p> <ul style="list-style-type: none"> 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 appropriately and effectively respond 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 to--and 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 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. 	<p>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.</p>

Appendix A: Recommendations from Previous State Plans with Continued Monitoring

Year Initiated	No.	Area of Focus	Recommendation	Monitoring
2013	11	Quality of Care	<p><u>Promoting Awareness and Education</u> 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:</p> <ul style="list-style-type: none"> 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. 	<p>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.</p>
2013	12	Quality of Care	<p><u>Promoting Awareness and Education</u> 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.</p>	<p>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.</p>
2013	13	Quality of Care	<p><u>Promoting Awareness and Education</u> 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.</p>	<p>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.</p>
2013	14	Quality of Care	<p><u>Promoting Awareness and Education</u> 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.</p>	<p>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.</p>

Appendix A: Recommendations from Previous State Plans with Continued Monitoring

Year Initiated	No.	Area of Focus	Recommendation	Monitoring
2013	17	Quality of Care	<p><u>Guardianship</u> (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.</p>	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	<p><u>Care Pathways</u> 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.</p>	Monitor through regulatory and hospital associations how many hospitals establish a best practice care plan.
2017	9	Quality of Care	<p><u>Caregiver Support</u> 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.</p>	<p>New recommendation developed to continue focus:</p> <ul style="list-style-type: none"> • 2021: Recommendation #7: Caregiver Support • 2023: Recommendation #7: Care Partner Support
2017	11	Quality of Life	<p><u>Guardianship</u> 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. In particular, support the specific protections for individuals with Alzheimer's disease and other forms of dementia.</p>	TFAD receiving regular updates on guardianship issues from Nevada State Elders Rights Attorney

Appendix A: Recommendations from Previous State Plans with Continued Monitoring

Year Initiated	No.	Area of Focus	Recommendation	Monitoring
2019	5	Access to Services	<p><u>State Match Program for APRNs</u></p> <p>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.</p>	<p>Periodic monitoring by TFAD to assure program is continued.</p>

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: alz.org Telephone: (800) 272-3900
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Cleveland Clinic Lou Ruvo Center for Brain Health

Cleveland Clinic Lou Ruvo Center for Brain Health	Internet Address: https://my.clevelandclinic.org/locations/nevada Telephone: (702) 483-6000
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University of Nevada, Reno

Dementia Engagement, Education and Research (DEER) Program, School of Community Health Sciences (including Dementia-Friendly Nevada)	Internet Address: <ul style="list-style-type: none">• DEER Program: https://www.unr.edu/public-health/centers/dementia-engagement-education-and-research-program• Dementia Friendly Nevada: https://dementiafriendlynevada.org/ Telephone: (775) 682-7072
Nevada Caregiver Support Center	Telephone: (775) 784-4335
Sanford Center for Aging, School of Medicine	Internet Address: https://med.unr.edu/aging Telephone: (775) 784-4774

Federal Agencies

United States Administration for Community Living (Administration on Aging)	Internet Address: https://acl.gov/
United States Centers for Disease Control and Prevention (Alzheimer's Disease and Healthy Aging Program)	Internet Address: https://www.cdc.gov/aging/index.html
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: http://adsd.nv.gov 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: http://dpbh.nv.gov/ Telephone: (775) 684-4200
Nevada Health Division, Bureau of Health Care Quality and Compliance	Internet Address: http://dpbh.nv.gov/Reg/HealthFacilities/HCQC-Blog/ Telephone: (775) 687-4475
Nevada Care Connections (Nevada's Aging and Disability Resource Center)	Internet Address: https://www.nevadacareconnection.org/
Nevada 2-1-1	Internet Address: nevada211.org/