2024 Annual Report

Task Force on Alzheimer's Disease

(Prepared: January 2025)



Nevada Department of Health and Human Services
NRS 439,5085

TASK FORCE ON ALZHEIMER'S DISEASE

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Introduction

The term 'dementia' refers to a collection of symptoms that comprise 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 60 to 80 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 2024 Alzheimer's Disease Facts and Figures, it is estimated that 6.9 million people are living with dementia in the US. 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.

There is an increased prevalence of Alzheimer's among minority and underserved populations, specifically Black and Latino communities. Older Black Americans are twice as likely to develop Alzheimer's and other dementias than Older Whites, while Older Latino Americans are one and a half times more likely to develop.

In Nevada, the Alzheimer's Association report estimates that there were approximately 54,900 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.

<u>History</u>

During the 2011 Legislative Session, both the Assembly and Senate recognized the need to focus special attention on Alzheimer's disease and unanimously supported the passage of Assembly Concurrent Resolution 10 (ACR 10), sponsored by Assemblywoman Debbie Smith. This resolution directed the Legislative Committee on Health Care to create a task force to develop a "State Plan to Address Alzheimer's Disease" and to submit the State Plan to the 2013 Session of the Nevada Legislature. This plan would serve as a blueprint for identifying specific actions that could pave the way for the development and growth of a high quality and comprehensive support system for individuals affected by dementia.

In 2012, Assemblywoman April Mastroluca, Chair of the Legislative Committee on Health Care, appointed members to the ACR 10 Task Force, to be Chaired by Senator Valerie Wiener. The ACR 10 Task Force met five times and considered more than 100 recommendations, submitted by independent work groups, experts, and the public. During the final meeting in October 2012, the ACR 10 Task Force approved the "State Plan to Address Alzheimer's Disease" (2013), which contained 20 recommendations. These recommendations addressed: access to services; quality of care and quality of life; and public awareness regarding the disease. Though the 2013 State Plan did not have a specific end date, the ACR 10 Task Force recognized the need to set clear timelines and strategies to achieve and revise the recommendations, as necessary.

Chair Mastroluca also reserved a committee Bill Draft Request (BDR) to be used by the ACR 10 Task Force, and the Task Force used this BDR for Assembly Bill 80 to create the Task Force on Alzheimer's Disease (TFAD). During the 2013 Legislative Session, with the passage of Assembly Bill 80, the Task Force on Alzheimer's Disease (TFAD) was created within the Department of Health and Human Services (DHHS), under the Aging and Disability Services Division (ADSD). TFAD includes 10 members, who

represent diverse backgrounds and interests in Alzheimer's disease and other forms of dementia, including medical professionals, care partners, service providers, legislators, educators, policy developers and the general public.

Though TFAD is only statutorily required to meet quarterly, TFAD members determined that the issues are so important that it is essential to meet bimonthly. Continuing with its responsibility for developing, reviewing, and revising the State Plan, TFAD submitted its revised "State Plan to Address Alzheimer's Disease" (2015) to both Governor Brian Sandoval and State Legislature in January 2015. This State Plan included 20 recommendations, including suggested indicators and potential funding sources. TFAD also submitted an updated State Plan (with 16 recommendations, suggested indicators, and potential funding) to the Governor and Legislature in January 2017.

Following the submission of the 2017 State Plan, TFAD began its work on the 2019 State Plan. TFAD adopted the 2019 State Plan in January 2019. The 2019 State Plan included 17 recommendations; four of these were new recommendations. Also, the 2019 State Plan included Appendix A (three recommendations retired from the 2017 State Plan) and Appendix B (Resources).

In January 2021, TFAD finalized and submitted its 5th edition of the State Plan, which included a total of 15 recommendations. Two recommendations from the 2019 plan were retired to the appendix (Affordability' and 'Care Pathways'). Further, one recommendation was reframed from 'Guardianship' to 'Awareness of Dementia and the Legal Profession.' In addition, the 2021 State Plan included a special section in its introduction covering key aspects of appropriate disaster preparation in the context of dementia. This section was precipitated by the significant impact of COVID-19 on older adults and people living with dementia but is framed more generally to provide guidance in managing future crises of any nature.

Throughout 2022, TFAD worked to develop its 6th State Plan, which was approved at its meeting in January of 2023 and submitted to Governor Joe Lombardo and the Nevada State Legislature in advance of the 2023 Legislative Session.

In 2024, the TFAD continued its work on updating the 7th State Plan for the 2025 Legislative Session. Additional details on the development and content of this new 2025 – 2026 State Plan are provided below. In preparation for the 2025 Legislative Session, the TFAD approved the creation of a Legislative Subcommittee that would review upcoming bills and help inform the full TFAD on what actions it should take.

In terms of TFAD leadership, in mid-2019, Senator Valerie Wiener (ret.) stepped down as Chair of TFAD (July 2019), and Dr. Peter Reed, TFAD Vice Chair from 2013 – 2019, was elected as Chair. In September 2019, Tina Dortch was elected Vice-Chair, serving in this role until July 2022, when Charles Duarte was elected Vice Chair. In July of 2023, Phil Kalsman was elected Chair and LeeAnn Mandarino was elected Vice-Chair. In July of 2024, Benjamin Challinor Mendez was elected as Chair and LeeAnn Mandarino continued to serve as Vice-Chair.

Legislative Overview

Though TFAD has no authority to introduce legislation directly, it has a long history of developing recommendations suggesting clear policy directions and implications. These recommendations can be picked up by various legislators and committees and introduced in the Legislative Session. Further, TFAD regularly identifies and monitors bills that are relevant to Alzheimer's disease and dementia.

During the **2013 Legislative Session**, three recommendations in State Plan were

supported by both the Legislature and Governor Sandoval. These include:

- Assembly Bill 80 created the Task Force on Alzheimer's Disease within the Department of Health and Human Services.
- Senate Bill 86 required the Department of Health and Human Services to allocate money for certain programs (e.g., respite care) relating to persons with Alzheimer's disease and other forms of dementia.
- Senate Bill 69 proposed revision to the requirements governing Advance Practitioners of Nursing, including independent licensure of APNs. Though the bill was proposed, the ACR 10 Task Force did not proceed. However, Assembly Bill 170, which proposed revisions related to the Advanced Practice Registered Nurse (APRN) did receive legislative support. This measure, which addressed the essence of SB 69, allowed APRNs to establish independent practices to provide better access to care.

Two years later, during the 2015 Legislative Session, six of the 20 recommendations in the 2015 State Plan were addressed legislatively, and two bills and one resolution were passed:

• Senate Bill 177 addressed the continuity of caregiver support for persons being discharged from hospitals or moved to other facilities. This was major legislation for AARP and incorporated key provisions addressed in the 2015 State Plan.

- Senate Concurrent Resolution 2 addressed four of the 20 recommendations in the 2015 State Plan, which strongly "urged and encouraged" specific training for medical care providers and first responders regarding care for persons with Alzheimer's disease and other forms of dementia.
- Senate Bill 196 included a section that authorizes health licensing entities to allow continuing education credits in education related to Alzheimer's disease.

During the **2017 Legislative Session**, TFAD followed many legislative measures that directly or indirectly affect persons with Alzheimer's disease and other forms of dementia. Of particular interest, however, was the passage of *Senate Bill 92*, sponsored by TFAD member Senator Joseph Hardy, which removed the sunset on the Task Force on Alzheimer's Disease. The Task Force is grateful for the overwhelming legislative and gubernatorial support and for Governor Sandoval's decision to select Senate Bill 92 as the first bill of the 2017 Legislative Session to sign into law.

During the **2019 Legislative Session**, TFAD identified and monitored the progress of a range of bills that were related to Alzheimer's disease. A complete review of Alzheimer's-related bills was created for TFAD by Homa Woodrum, (formerly) Attorney for the Rights of Older Persons, Persons with a Physical Disability, and Intellectual Disability or a Related Condition, Nevada Aging and Disability Services Division. In addition, TFAD Chair, Senator Valerie Wiener provided testimony related to two bills relevant to the recommendations in the *Nevada State Plan to Address Alzheimer's Disease* and the work of TFAD, including: SB 121 – Fiduciaries for Persons with Dementia; and SB102 – Education Funding for APRNs. (*See the TFAD 2021 Annual Report for a complete list of legislative activity during the 2019 session*).

Key legislative successes in the **2021 Legislative Session**, monitored by TFAD, include passage of AB 216: Medicaid coverage for CPT code 99483. In addition, other policy-related successes noted by TFAD included updating the TFAD State Plan to include "Healthy People 2030" in the introduction, aligning our state-level work with federal priorities; and Nevada being a recipient of BOLD Act funding to bring a public health approach to Alzheimer's awareness in the state.

In the 2023 Legislative Session, there were several bills TFAD had an interest in that passed and which related to specific recommendations included in the 2023-2024 State Plan including:

• Assembly Bill (AB) 119, relating to adult maltreatment; creating the Vulnerable Adult Fatality Review Committee; providing for the review

- of deaths resulting from or relating to adult maltreatment; requiring the Committee to perform certain other duties relating to the investigation and prevention of adult maltreatment; providing access for the Committee to certain documents; and providing other matters properly relating thereto.
- Assembly Bill (AB) 208, relating to Medicaid; establishing a program to provide structured family caregiving to certain recipients of Medicaid; and providing other matters properly related thereto.
- Senate Bill (SB) 45, relating to Medicaid; establishing the amount of personal needs allowance provided to certain recipients of Medicaid who reside in facilities for skilled nursing; and providing other matters properly related thereto.
- Senate Bill (SB) 298, relating to residential facilities for groups; prescribing certain grounds for disciplinary action against a residential facility for groups; prohibiting certain persons from serving as the representative of a resident of a residential facility for groups for purposes relating to an involuntary discharge; imposing requirements governing certain contracts between a resident and a residential facility for groups; prohibiting the involuntary discharge of a resident of a residential facility for groups except for certain reasons; imposing requirements governing the procedure for such an involuntary discharge; authorizing a resident or a representative of a resident to request a hearing concerning such an involuntary discharge; requiring the State Long-Term Care Ombudsman to provide certain assistance concerning such a discharge; and providing other matters properly relating thereto.
- Senate Bill (SB) 315, relating to persons with disabilities; prescribing certain rights for persons with disabilities who are receiving certain home and community-based services and persons who are aged receiving such services; prescribing certain rights for pupils with disabilities; and providing other matters properly relating thereto.

Bills which were passed that TFAD would like to revisit include: Assembly Bill (AB) 414, relating to powers of attorney; adopting the Uniform HealthCare Decisions Act; repealing various provisions relating to powers of attorney for health care.

Bills which were not passed that TFAD would like reproposed and more actively supported by our legislative representative include:

 Assembly Bill (AB) 167, sponsored by Assemblywoman Claire Thomas, proposed the funding, development and launch of a Dementia Care Specialist program to embed dementia- specific care managers in each of Nevada's counties, enabling direct supportive services for people living with dementia, including those living in Nevada's rural

- communities. This bill is directly aligned with TFAD 2023-2024 State Plan recommendation #5 focused on creating a Dementia Care Specialists (DCS) Program in Nevada.
- Senate Bill (SB) 297, Nevada Memory Network, sponsored by the Committee on Health and Human Services, proposes the funding, development and launch of an integrated network of memory assessment clinics, coupled with training for primary care providers on cognitive assessments and referrals of patients for comprehensive dementia diagnostic services. This bill was directly aligned with TFAD 2023-2024 State Plan recommendation #4 on Outreach to Primary Care Providers.

Duties of TFAD (NRS 439.5085)

The Task Force shall:

- a) Develop a State Plan to address Alzheimer's Disease.
- b) Monitor the progress in carrying out the State Plan.
- c) Review and revise the State Plan, as necessary.
- d) Develop and prioritize the actions necessary to carry out the State Plan.
- e) Research and review any other issues that are relevant to Alzheimer's disease; and
- f) On or before February 1 of each year, prepare and submit a report to the Governor and to the Director of the Legislative Counsel Bureau for transmittal to the Legislature concerning its findings and recommendations.

Current Status of the State Plan

TFAD elected a new Chair and Vice-Chair starting July 1, 2023. Under this leadership, TFAD began the revision and updating of the "State Plan to Address Alzheimer's Disease and Other Dementias: 2025-2026" at a meeting on January 9, 2024. Starting on July 1, 2024, TFAD elected a new Chair to continue the revisions. While the 6th State Plan included 17 separate recommendations, the 7th State Plan retired 3 of the 17 recommendations as they were seen as their work has been incorporated into current programs and can be included in other recommendations. The remaining recommendations have been grouped into four categories to combine the expertise, efforts, and depth of the subject matter. The recommendations will be the action items to advance the four objectives to successful policy outcomes.

- Policy Objective 1: Help direct persons living with dementia to needed
- resources.
- Policy Objective 2: Optimize health care for persons living with

- dementia.
- Policy Objective 3: Formalize protections and rights for persons living with dementia.
- Policy Objective 4: Provide structured, competent, and comprehensive dementia education.

Moving forward, action items may be combined to meet the goals of the objective creating comprehensive policy proposals complete with indicators and potential funding sources. Also, the 2025-2026 State Plan includes Appendix A listing 'retired' recommendations (which include the 3 newly retired recommendations) and Appendix B (Resources).

Continuing in 2024 from previous years, TFAD reviewed and discussed the bills of interest from the 2023 legislative session (noted above). While TFAD celebrated the bills that were passed, discussion continues the worthwhile bills that were not passed with focus on how TFAD can be more proactive in making the case for future objectives.

Several policy issues TFAD intends to revisit include:

- The Nevada Memory Network
 - The Nevada Memory Network is a system of care that starts with training primary care providers across the state to screen patients for cognitive decline and refer them to specialized Memory Assessment Clinics (MACs) for a comprehensive evaluation and diagnosis. Additionally, the NMN would provide Dementia Care Navigators who will work with the primary care provider, the patient, their caregiver, and family to connect them with community support.
- A Dementia Support Specialists (DSS) Program
 - Dementia Support Specialists (formerly Dementia Care Specialist) provide support for individuals with dementia, support for families and caregivers, and training for community-based organizations, making them more dementia-friendly and dementia-capable.

Additionally, the Legislative Subcommittee, after reviewing the recommendations, have identified three legislative actions that the TFAD will pursue:

- Recommendation #10 Choice in Care and Care Settings
 - Forming an expert committee to develop proposed regulatory requirements for the standardization of the assessment and admission process for all locked dementia care settings to ensure

the right to receive care in the least restrictive environment is honored and upheld.

- Recommendation #11 Dementia Training
 - Requiring dementia training for first responders, of which should include law enforcement officers, emergency medical technicians, and firefighters.
- Recommendation #12 Caregiver Support
 - Increasing the respite voucher amount, along with the amount that is appropriated from the State General Fund.

TFAD Activities—2024

TFAD met six times in 2024: January 9, March 12, May 14, July 9, September 10, and November 12 with the Legislative Subcommittee meeting twice on August 28 and October 21. Key agenda items included hearing presentations from state and community experts on specific topics related to the recommendations that were being developed for the new State Plan, or presentations by TFAD members on existing or new recommendations being considered for inclusion in the new State Plan. The following presentations and presenters were heard:

January 9 Full TFAD

- Review and Approval of the TFAD's 2023 Annual Report
- Presentation on Advance Care Planning
 - o Lisa Evans, Executive Director, Northern Nevada Legal Aid
 - Jennifer M. Richards, Directing Attorney, Northern Nevada Legal Aid
- Presentation on Nevada Lock Box
 - Maggie Salas Crespo, Deputy Secretary of State, Nevada Secretary of State
- Discussion and prioritization of monitoring recommendations from the TFAD 2023-2024 State

March 12 Full TFAD

- Presentation on the Nevada Memory Net
 - o Benjamin Challinor Mendez, Alzheimer's Association
- Discussion on the creation of Legislative Subcommittee

May 14 Full TFAD

- Elections for Chair and Vice Chair
- Presentation on the Alzheimer's Association 2024 Alzheimer's Disease Facts and Figures
 - o Benjamin Challinor Mendez, Chair

- Presentation on Dementia Care Specialist Program
 - o Jennifer Carson, PhD
- Presentation on Developing Community Awareness Around Increased Brain Health Literacy
 - o LeeAnn Mandarino, Vice-Chair

July 9 Full TFAD

- Discussion and Approval of Legislative Subcommittee Goals, Purpose and Objectives
- Review and Approve Recommendations to be Retained, Retired, or Revised

August 28 Legislative Subcommittee

- Chair Election
- Approval of Legislative Subcommittee Goals, Purpose and Objectives
- Discuss, identify and approval of potential topics for Legislative actions from TFAD's Recommendations

September 10 Full TFAD

- Annual Training and Presentation on TFAD's Bylaws, Open Meeting Law, and Satisfactory Conduct Guided by Roberts' Rules of Order
 - o Samantha D'Ambrosia-Garcia, ADSD
- Discussion of Legislative Subcommittee Goals, Purpose, Objectives
- Review and Approve Recommendations to be Retained, Retired, or Revised

October 21 Legislative Subcommittee

- Presentation on Long-Term Care Facilities Training Hours
 - Tina Leopard, HCQC
- Discussion of potential topics for Legislative actions from TFAD's Recommendations

November 12 Full TFAD

- Final Discussion, identify and approval of potential topics for Legislative actions from TFAD's Recommendations
- Review of First Draft of 2025-2026 State Plan

Conclusion

The members of the Nevada Task Force on Alzheimer's Disease appreciate the opportunity to serve the State in this very worthwhile endeavor. The TFAD also acknowledges the need for continually monitoring the progress of the recommendations within the State Plan. This is to ensure that the needs and the quality of life of those the TFAD members represent are not only being met but improved upon. The creation, review, and revision of the

State Plan to Address Alzheimer's Disease and Other Dementias (2013, 2015, 2017, 2019, 2021, 2023) is an essential and relevant tool for addressing vital issues, crafting viable recommendations, and recognizing needed solutions and resources for people living with Alzheimer's disease and other forms of dementia, their families, and their caregivers.

Throughout the 2025 - 2026 State Plan, the TFAD continues to explore key practice and policy ideas to build a network of support that enables continuous improvement in quality of life for people living with dementia and their caregivers. The reintroduced proposals outlined in the new State Plan provide a foundation of well-informed ideas to promote these goals but can only succeed if action is taken to implement them and monitor progress. Thus, TFAD encourages all relevant State and local agencies, along with community-based health and social service providers to review the State Plan, identify recommendations aligned with their organization's core strengths and pursue achieving an impact on behalf of Nevadans living with dementia. Nevada should take pride in its proactive efforts to plan for the inclusion, respect, care, and support of people living with dementia.

In their ongoing commitment to these special needs in our state, TFAD members will proudly continue their work to develop service delivery and policy goals more fully; identify and pursue funding for recommendations; and recommend necessary statutory changes that are essential to the success of the ever-evolving *State Plan to Address Alzheimer's Disease and Other Dementias*.