

Task Force on Alzheimer's Disease

2022 Annual Report



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

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TASK FORCE ON ALZHEIMER'S DISEASE

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Introduction

Alzheimer's disease, and other causes of the symptoms of dementia, dramatically and uniquely impact individuals who are living with the disease, with or without a formal diagnosis, as well as all those who support them, including, without limitation, spouses, family, friends, formal and informal care partners, health care providers, first responders, legal representatives and others. While there are many different causes of the symptoms of dementia, Alzheimer's disease is the most common cause and comprises approximately 70 percent of all dementia diagnoses.

Data released by the Alzheimer's Association (2022) estimates that there were approximately 49,000 people in Nevada living with Alzheimer's disease and other forms of dementia in 2020, though many do not have a formal diagnosis. According to the Alzheimer's Association, the prevalence of dementia for people ages 65 and older will grow more than 30.6% in just five years between 2020 and 2025 to 64,000 Nevadans affected. During this timeframe, Nevada ranks as the state with the third fastest growing population of residents living with dementia behind only Arizona (33.3%) and Vermont (30.8%). This growth in dementia is directly linked to the rapidly aging population of Nevada.

It is estimated that Nevada Medicaid expended \$203 million on people living with dementia in 2020. This amount is expected to grow by 36.5% by 2025, placing increased stress on the state's ability to support high-quality care for people living with dementia, across all care settings. There are additional immeasurable costs as well, which constitute a multiplier effect to the impact of dementia in Nevada. These costs stem from the impact on quality of life of family care partners, including negative effects on the physical, emotional, financial, psychological and social health of those who provide constant uncompensated care and support. The Alzheimer's Association estimates that there are approximately 48,000 caregivers in Nevada, offering a total of 78 million hours of unpaid care each year.

Ensuring that the state has a robust network of support for people living with dementia and their families, along with needed education and training for professionals and health care providers is paramount. The impact of dementia on Nevada is going to continue to grow in coming years, and ensuring quality of life for all Nevadans means tackling the issue of dementia head on. The purpose of TFAD is to do just that, through presenting its recommendations in its biennial State Plan to Address Alzheimer's Disease and Other Dementias, as well as the monitoring of these recommendations over time.

History

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 comprises ten 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 bi-monthly. 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 Legislators 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 Lombardo and the Nevada State Legislature in

advance of the 2023 Legislative Session. Additional details on the development and content of this new 2023 – 2024 State Plan are provided below.

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.

Legislative Successes

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 are often picked up by various legislators and committees and introduced in the Legislature. Further, TFAD regularly identifies and monitors bills that are relevant to Alzheimer’s disease and dementia.

During the **2013 Legislative Session**, three recommendations in the 2013 State Plan were supported by both the Legislature and Governor Sandoval. These include:

- *NRS 439.508* created the Task Force on Alzheimer’s Disease within the Department of Health and Human Services.
- *NRS 439.630* required 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, *NRS 453.128*, 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:

- *Assembly Bill 9* focused on guardianships and addressed concerns about accounting for assets under \$10,000.
Note: TFAD included a new recommendation in the 2017 State Plan that supports the “Guardianship Bill of Rights” (particularly the protections for individuals with Alzheimer’s disease and other forms of dementia), which was created by the Commission to Study the Administration of Guardianships in Nevada Courts.
- *NRS 449* 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. *NRS 439* 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. We are very 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.

For the upcoming **2023 Legislative Session**, there are several bills that TFAD will be monitoring and supporting, as they are directly related to specific recommendations included in the 2023 – 2024 State Plan. Bills of interest to TFAD include the following:

- BDR #298: Nevada Memory Net, sponsored by the Legislative Committee on Senior Citizens, Veterans and Adults with Special Needs, 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 is directly aligned with TFAD 2023-2024 State Plan recommendation #4 on Outreach to Primary Care Providers.
- BDR #TBD, sponsored by Assemblywoman Claire Thomas, proposes 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.

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 approved the “State Plan to Address Alzheimer’s Disease and Other Dementias: 2023 - 2024” at its meeting on January 24, 2023. The 2023-2024 State Plan includes 17 recommendations, including 3 newly-developed recommendations. Each recommendation includes indicators and potential funding sources. Also, the 2023-2024 State Plan includes Appendix A listing ‘retired’ recommendations (with one recommendation retired from the 2019 State Plan) and Appendix B (Resources).

Throughout 2022, TFAD engaged in a collaborative and iterative process to review each of the existing recommendations (from the 2021 – 2022 State Plan). Each recommendation was assigned a TFAD member lead, who proposed either retaining, revising or retiring the recommendation. As noted, 14 of the prior recommendations were carried forward into the new plan (some with minor revisions), while one recommendation (#5: State Match Program for APRNs) was retired, as it has been accomplished.

TFAD also adopted three new recommendations in its 2023-2024 State Plan, identified, developed and proposed by TFAD members. Each of the following three new recommendations include important, specific practice and policy implications:

- Recommendation #5: Dementia Care Specialists (DCS) Program
 - This new recommendation encourages the creation of a Nevada Dementia Care Specialist program. Dementia Care Specialists provide support for individuals with dementia, support for families and care partners, and training for community-based organizations, making them more dementia-friendly and dementia-capable.
- Recommendation # 16: Advance Care Planning

- This new recommendation outlines parameters for ensuring people living with dementia have the necessary support to prepare advance directives that will be honored by families and health care providers. Advance care planning is a process where an individual completes legal and medical documents to state their wishes for future care. As documents must be completed when an individual is deemed to have capacity, there is a heightened sense of urgency to provide education about advance care planning to persons living with dementia.
- Recommendation #17: Choice in Care and Care Settings
 - This new recommendation encourages a) the standardization of the assessment and admission process for all locked dementia care settings; b) awareness-raising by the Nevada State Long-Term Care Ombudsman’s office on the definition of, and issues regarding, unlawful confinement/false imprisonment in long-term care; and c) increased oversight by the Nevada 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, ensuring that each individual’s preferences for care and care setting are clearly documented and honored.

In addition, the 2023 – 2024 State Plan introduction includes a special section titled “Bridging the CDC Healthy Brain Initiative and the Nevada State Plan”. This section discusses the principles and approaches of the CDC’s Healthy Brain Initiative Road Map, as well as the federal BOLD Infrastructure for Alzheimer’s Act. Specific efforts were made in this cycle of developing the State Plan to ensure that the recommendations were aligned with, and supportive of, these federal efforts. These efforts provide a well-articulated, evidence-based public health foundation for reducing risk of cognitive impairment, promoting early detection of dementia and supporting care partners of people living with dementia. Aligning Nevada’s State Plan with these efforts is an important step toward recognizing Alzheimer’s disease and dementia as a population-wide, public health concern in Nevada.

TFAD Activities—2022

TFAD met seven times in 2022: January 18, March 15, May 17, July 19, September 20, November 15 and December 6. The primary focus of each meeting involved engaging in a collaborative process to outline and develop the new State Plan for 2023 – 2024. 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 by TFAD in its knowledge-gathering effort to inform the new State Plan:

January 18:

- Nevada Lifespan Respite Care Coalition
 - Cheryl Dinnell, Executive Director, NLRCC

March 15:

- Update on the American Rescue Plan Act (ARPA) Activities
 - Kirsten Coulombe, Nevada Division of Health Care Financing and Policy
- Nevada Respite Funding Availability
 - Cheyenne Pasquale, Nevada Aging and Disability Services Division

July 19:

- Guardianship and Advance Care Planning
 - Jennifer Richards, Nevada Aging and Disability Services Division
- Health Care Quality and Compliance Regulation Changes Related to Alzheimer's disease.
 - Tina Leopard, Nevada Health Care Quality and Compliance
- Alzheimer's disease Awareness Raising Activities
 - Niki Rubarth, Alzheimer's Association Northern Nevada Office

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 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 care partners.

Throughout the 2023 - 2024 State Plan, TFAD explores 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 care partners. The 17 recommendations 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 more fully develop service delivery and policy goals; 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*.