

Task Force on Alzheimer's Disease

2023 Annual Report



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Submitted by:

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

(Assembly Bill No. 80, Committee on Health and Human Services, Statutes of Nevada 2013)
(Senate Bill No. 92, Committee on Health and Human Services, State of Nevada, 2017)

TASK FORCE ON ALZHEIMER'S DISEASE

Phil Kalsman, Chair (July 2023 – Present)
Director, Southern Nevada Region
Alzheimer's Association Desert Southwest Chapter

LeeAnn Mandarino, MA, Vice Chair (July 2023 – Present)
Program Director of Education, Outreach & Advocacy
Cleveland Clinic Lou Ruvo Center for Brain Health

Peter Reed, PhD, MPH, Chair (July 2019 – June 2023)
Director, Sanford Center for Aging, School of Medicine Professor,
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Nevada Director of Public Policy and Advocacy
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Marilyn Dondero Loop
Senator, Nevada State Legislature

Michelle Gorelow
Assemblywoman, Nevada State Legislature

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, healthcare 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.

In 2023, Alzheimer's disease was estimated to cost Medicare and Medicaid around \$222 billion in care costs. This number is expected to grow to \$644 billion dollars by 2050, 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 healthcare 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. In July of 2023, Phil Kalsman was elected Chair and LeeAnn Mandarinio 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:

- *Assembly Bill 80* created the Task Force on Alzheimer's Disease within the Department of Health and Human Services. Passed.
- *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. Passed.
- *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. Passed.

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. Did not pass.

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.

- *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. Passed.
- *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. Passed.
- *Senate Bill 196* included a section that authorizes health licensing entities to allow continuing education credits in education related to Alzheimer's disease. Passed.

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.

In the **2023 Legislative Session**, there were several bills TFAD supported which related to specific recommendations included in the 2023 – 2024 State Plan including:

- **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. ***It did not pass.***
- **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. ***Passed.***
- **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 relating thereto. ***Passed.***
- **Assembly Bill (AB) 414**, relating to powers of attorney; adopting the Uniform Health Care Decisions Act; repealing various provisions relating to powers of attorney for health care. ***Passed.***
- **Senate Bill (SB) 45**, relating to Medicaid; establishing the amount of the personal needs allowance provided to certain recipients of Medicaid who reside in facilities for skilled nursing; and providing other matters properly relating thereto. ***Passed.***
- **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. *It did not pass.*

- **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. *Passed.*
- **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. *Passed*

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. Except for this change, membership remains the same. Under new leadership, TFAD revised and updated the “State Plan to Address Alzheimer’s Disease and Other Dementias: 2023-2024 at a meeting on January 9, 2024. While the 2023-204 State Plan still includes 17 separate recommendations, we have grouped these recommendations into five categories to combine the expertise, efforts, and depth of the subject matter. The recommendations will be the action items to advance the five objectives to successful policy outcomes.

Policy Objective 1: Help direct persons with dementia (PwD) to needed resources.

Policy Objective 2: Optimize healthcare for PwD.

Policy Objective 3: Formalize protections and rights for PwD.

Policy Objective 4: Provide structured, competent, and comprehensive dementia education.

Policy Objective 5: Provide tools community-wide to help navigate the dementia journey.

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 2023-2024 State Plan includes Appendix A listing 'retired' recommendations (with one recommendation retired from the 2019 State Plan) and Appendix B (Resources).

In the second half of 2023, TFAD reviewed and discussed the bills of interest from the 2023 legislative session (noted above). While we celebrated the bills that were passed, we ruminated on the worthwhile bills that were not, and discussed how TFAD can be more proactive in making the case for past future objectives.

Several policy issues we would like to revisit include:

- The Nevada Memory Network (NMN)
 - With new disease modifying therapies available, early diagnosis can be key to staving off the symptoms of dementia. Unfortunately, diagnoses don't usually happen until the disease is more obvious in the mid-stages when there is little that can be done medically. NMN 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. Besides providing a diagnosis, the MACs will work with the patient and their care partner on a complete plan of care. The patient and care partner, along with a care plan, will be sent back to the primary care provider for ongoing care. Dementia Care Navigators will work with the primary care provider, the patient, their caregiver, and family to connect them with community support. The entire system of care will be an invaluable source of data for impactful research going on at UNLV and UNR.
- A Dementia Care Specialists (DCS) Program
 - Dementia Care Specialists 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.
- Advance Care Planning
 - This recommendation outlines parameters for ensuring people living with dementia have the necessary support to prepare advance directives that will be honored by families and healthcare 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.
- 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 caregivers 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—2023

TFAD met six times in 2023: January 24, March 7, May 2, July 5, September 5, November 7. 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 24:

- Presentation on Dementia in the State Olmstead Plan.
 - Cheyenne Pasquale, Planning Chief, ADSD, and Lisa Watson, Social Entrepreneurs, Inc Client Services Manager
- Review and Approval of the TFAD’s 2023-2024 State Plan
- Review and Approval of the TFADs 2022 Annual Report
- Discussion and prioritization of monitoring recommendations from the TFAD 2023-2024 State

March 7:

- Presentation on Choice in Care and Care Settings
 - Marie Coe, State Long Term Ombudsman
- Legislative Priorities Updates Concerning Alzheimer’s and other Dementias.
 - Charles Duarte, Nevada Director of Public Policy and Advocacy, Alzheimer’s Association
- Presentation, Discussion and Approval of the Executive Order 2023-03
 - Peter Reed, Chair

May 2:

- Status and Updates on Legislation related to Alzheimer’s and other Dementias.
 - Jeff Duncan, ADSD, Agency Manager
- Update on the Aging and Disability Services Divisions: (ADSD) State Olmstead Plan.
 - Cheyenne Pasquale, ADSD, Planning Chief
- Presentation and Discussion related to crossover between ADSD State Plan on Aging and the State Plan to Address Alzheimer’s
 - Cheyenne Pasquale, ADSD, Planning Chief
- TFAD Election of Chair and Vice Chair
- Presentation/Discussion and approval of TFAD’s Definition of Capacity
 - Susan Hirsch, TFAD Member

July 5:

- Update from Health Care Quality and Compliance (HCQC) on Regulations pertaining to Residential Care Facilities regarding care of persons with Dementia/Alzheimer's.
 - Tina Leopard, Health Facilities Inspection Manager
- Presentation Nevada Office of Minority Health and Equity (NOMHE)
 - Amanda Annan, NOMHE Management Analyst
- Status and Updates on Legislation related to Alzheimer's and other Dementias.
 - Cheyenne Pasquale, ADSD, Planning Chief

September 5:

- Status and Updates on Senate Bill (SB) 390 related to the University of Nevada Las Vegas (UNLV), establishing and maintaining a system for reporting and analyzing neurodegenerative information.
 - Samantha John, PhD, Cognitive Aging and Neuropsychological Equity Lab Director
- Legislative Open Meeting Law Changes
 - Trisha Chapman, Deputy Attorney General
- Update on the Aging and Disability Services Divisions: (ADSD) State Olmstead Plan
 - Cheyenne Pasquale, ADSD, Planning Chief
- Discuss, Review and Approval of letter to be sent to the Legislative Council Bureau (LCB) for potential Senate and Assembly TFAD Representative Appointments
 - Phillip Kalsman, Chair
- Review and Approval of TFAD's 2023 Recommendations in the State Plan to Address Alzheimer's for potential presentation grouping, subcommittees, and combined efforts.
 - LeeAnn Mandarino, Vice-Chair

November 7:

- Presentation and Discussion: Decision-making Capacity for Persons Living with Dementia
 - Susan Hirsch, TFAD Member, Jennifer Richards, Esq., Chief Rights Attorney, David Godfrey, JD Director, American Bar Association, Dylan Wint, MD, Director Cleveland Clinic Nevada.

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 caregivers.

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 caregivers. The 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*.

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