

Task Force on Alzheimer's Disease Annual Report



January 2022

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

Peter Reed, Ph.D., Chair

Director, Sanford Center for Aging, University of Nevada, Reno School of Medicine

Tina Dortch, Vice Chair

Office of Minority Health and Equity, Program Manager, Nevada Department of Health,
and Human Services

Members

Assemblywoman Lesley Cohen

Nevada State Legislature

Dylan Wint, MD

Cleveland Clinic Lou Ruvo Center for Brain Health

Virginia (Gini) L. Cunningham, M.Ed.

Volunteer and Support Group Facilitator, Humboldt Volunteer Hospice and Alzheimer's
Association in Northern Nevada

Jennifer Carson, Ph.D.

Director, Dementia Engagement, Education & Research Program, University of Nevada,
Reno School of Public Health

Chuck Duarte

Nevada Director of Public Policy and Advocacy, Alzheimer's Association

Wendy Knorr

Deputy Director of Wellness, Nevada Department of Veterans Services

Senator Marilyn Dondero Loop

Nevada State Legislature

Susan Hirsch

Member at Large

Introduction

Alzheimer's disease, and other causes 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 caregivers, 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 (2021) estimates that there are approximately 49,000 people in Nevada living with Alzheimer's disease and other forms of dementia, though many do not have a formal diagnosis. According to the Alzheimer's Association, the prevalence of Alzheimer's disease 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.

It is also important to note that the COVID-19 pandemic had a disproportionate impact on mortality among people living with dementia due to its direct health effects as well as the burden of increased social isolation. According to the Alzheimer's Association, among people living with dementia in Nevada, there were 486 *more* deaths than expected in 2020, representing nearly 30% higher mortality than typical annual averages.

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 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 caregivers, 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 Alzheimer's on Nevada is going to continue to grow in coming years and ensuring quality of life for all Nevadans means tackling the issue of Alzheimer's disease head on. The purpose of TFAD is to do just that, through presenting its recommendations in the state plan and monitoring their implementation.

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 quality and comprehensive support system for individuals affected by Alzheimer's disease.

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, caregivers, 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 the 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 includes 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 on older adults and people living with dementia, but is framed more generally to provide guidance in managing future crises of any nature.

In terms of leadership, in mid-2019, Senator Valerie Wiener (ret.) stepped down as Chair of TFAD (July 2019) and Dr. Peter Reed was elected as Chair. In September 2019, Tina Dortch was elected Vice-Chair.

Legislative Successes

Though TFAD has no authority to introduce legislation, 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 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 proposed the ACR 10 Task Force did not proceed, *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 AB 170, 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. Below is a complete review of Alzheimer’s-related bills created for TFAD by Homa Woodrum, 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 A.B. 216: Medicaid coverage for CPT code 99483. In addition, other policy-related successes noted by TFAD include 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.

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

In January, 2021, TFAD approved the final draft of the “State Plan to Address Alzheimer’s Disease” (2021). As previously noted, the 2021 State Plan includes 15 recommendations; each of these are continuing recommendations from the 2019 State Plan. Each recommendation includes indicators and potential funding sources. Also, the 2021 State Plan includes Appendix A listing ‘retired’ recommendations (two recommendations retired from the 2019 State Plan) and Appendix B (Resources).

During 2022, TFAD will be drafting a new 2023 State Plan. The process will include a review of all current recommendations in the 2021 State Plan to determine their status in terms of progress and/or completion. Recommendations that have been fully met will be retired to the State Plan Appendix. Recommendations that are deemed to be in a stage of continuation will be reviewed for

any relevant updates or revisions. TFAD will also consider the adoption of new recommendations identified by members or other stakeholders.

In the planning process to date, TFAD has approved the development of five new recommendations for inclusion in the 2023 State Plan. The five proposed new recommendations include:

- Dementia Crisis Response in Community and Residential Care
- Healthy Brain Initiative Roadmap Priorities
- Dementia Inclusion in Memory Care
- Advance Care Planning
- Cognitive Assessment and Diagnosis

TFAD Activities—2021

TFAD met six times in 2021: January 13, March 10, May 12, July 14, September 8 and November 10. The primary focus of each meeting involved monitoring progress on the 15 recommendations included in the *2021 State Plan to Address Alzheimer's Disease*, as well as receiving reports from a range of Alzheimer's-related efforts from state and community-based groups across Nevada.

One key concern that TFAD received regular reports on was the COVID-related, federal relief funding coming into Nevada, including Older Americans Act funds in the CARES Act and American Rescue Plan Act. TFAD received regular reports from ADSD, DPBH and Medicaid to fully understand how the funds were being distributed, and where there may be opportunities for increasing support of people living with dementia throughout the state.

Additionally, in its role of monitoring Alzheimer's- related activities and relevant initiatives and agencies, TFAD received numerous key updates and presentations during its 2021 meetings. These included the following presentations and presenters:

March 10:

- Nevada Aging and Disability Services Division (ADSD) Budget
 - Rique Robb, Deputy Administrator, ADSD
 - Jessica Adams, Deputy Administrator, ADSD
- Aging and Disability Resource Centers (ADRC) / Nevada Care Connections: Statewide Information and Referral (I&R) Systems
 - Jamie Ahumada, Social Service Program Specialist, ADSD
- Nevada Geriatrics Telehealth Collaborative
 - Dr. Peter Reed, Director, Sanford Center for Aging, UNR Med

May 12:

- ADSD Budget / Economic Reform & Relevant Medicaid Budget
 - Rique Robb, Deputy Administrator, ADSD
 - Jessica Adams, Deputy Administrator, ADSD
 - DuAne Young, Deputy Administrator, Health Care Finance and Policy
- Nevada Ensures Support Together (NEST) Collaborative
 - Dr. Jennifer Carson, Director, Dementia Engagement, Education and Research (DEER) Program, UNR School of Public Health

July 14:

- Medical and Dementia Holds
 - Jessica Flood Abrass, Northern Regional Behavioral Health Coordinator
- Outreach to Physicians
 - Charles Duarte, Nevada Director of Public Policy and Advocacy, Alzheimer's Association
 - Kate Ingalsby, Program Manager, Cleveland Clinic, Lou Ruvo Center for Brain Health
 - Dr. Peter Reed, Director, Sanford Center for Aging, UNR Med

September 8:

- Cultural Competency
 - Tina Dortch, Program Manager, Nevada Office of Minority Health and Equity
- Healthy Brain Initiative / CDC Roadmap for Brain Health
 - Dr. Jennifer Carson, Director, Dementia Engagement, Education and Research (DEER) Program, UNR School of Public Health

November 10:

- American Rescue Plan Act (ARPA) activities
 - Kirsten Coulombe, Social Service Chief, Health Care Finance and Policy

- ADSD Olmstead Planning Survey
 - Nikki Haag, Public Information Officer, ADSD
 - Cheyenne Pasquale, Chief, Planning, ADSD

- Nevada Dementia Supports Toolbox, Caregiver Support Grant Funds and Dementia Care Connection Responses
 - Cheyenne Pasquale, Chief, Planning, ADSD
 - Jamie Ahumada, No Wrong Door Coordinator, ADSD

Conclusion

The members of the 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” (2013, 2015, 2017, 2019, 2021) 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 2021 State Plan, as well as during every bi-monthly meeting, TFAD has monitored the impact of the COVID pandemic and explored opportunities for those with Alzheimer’s disease and other forms of dementia, along with their families and caregivers, to feel and experience respect, dignity, support, value, and inclusion in everyday community life. We have also explored key needs among Nevada’s healthcare providers in gaining the knowledge, skills and tools needed to better support people living with dementia. Nevada should take pride in its proactive efforts to plan for the care, comfort, and respect of these individuals.

In the 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.