

Task Force on Alzheimer's Disease Annual Report



January 2019

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

Senator Valerie Wiener (Ret.), Chair
Founder and President, PublicServiceNV

Peter Reed, Ph.D., Vice Chair
Director, Sanford Center for Aging, University of Nevada

Members

Charles Bernick, M.D., Associate Medical Director,
Cleveland Clinic Lou Ruvo Center for Brain Health

Jill Berntson, Deputy Administrator, Department of Health and Human Services
(Retired on June 14, 2018)

Assemblywoman Lesley Cohen, Nevada State Legislature

Virginia (Gini) L. Cunningham, M.Ed., Volunteer and Support Group Facilitator,
Humboldt Volunteer Hospice and Alzheimer's Association in Northern Nevada

Jeff Duncan, Social Services Chief II, State of Nevada Aging and Disability Services

Jane Fisher, Ph.D., Department of Psychology, University of Nevada Reno
(Term ended June 30, 2018)

Senator Joseph Hardy, Nevada State Legislature

Nikki Rubarth, Regional Director, Alzheimer's Association of Northern Nevada

Wendy Simons, Deputy Director of Wellness, Nevada Department of Veterans Services

Introduction

Alzheimer's disease and other forms of dementia dramatically and uniquely impact individuals, who have been diagnosed with the disease, and ALL those who support them, including, without limitation, family, friends, caregivers, health care providers, first responders, legal representatives, and others. Approximately 50 forms of dementia have been identified. Alzheimer's disease is just one form of dementia and comprises about 70 percent of all dementia diagnoses.

More than 45,000 people in Nevada have been diagnosed with Alzheimer's disease and other forms of dementia. According to the Alzheimer's Association, the prevalence of Alzheimer's disease for people, age 65 and older, will grow more than 42 percent, between 2018 and 2025, to 64,000 Nevadans affected. Nevada now ranks as the state with the second highest percentage of increased diagnoses.

Between now and 2025, the financial cost of Alzheimer's disease and other forms of dementia to Medicaid in Nevada will increase 71 percent, from \$158 million to \$270 million. Again, Nevada is experiencing the second highest percent of increase of all the 50 states.

There are other, immeasurable costs, as well, which address the multiplier effect. These "costs" relate to the engagement of, as well physical, emotional, financial, psychological, social, and other effects on, those who provide constant uncompensated support and care. Currently, this directly or indirectly affects hundreds of thousands of Nevadans. And, these numbers continue to climb and . . . climb.

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. This included the scheduling of timely and meaningful presentations to determine new recommendations, as well as updates to refine the language of ongoing recommendations included in the 2017 State Plan. TFAD also reviewed and evaluated which recommendations from the 2017 State Plan should be "retired" to the Appendix, because they have been—or are being—addressed. Again, between 2017 and 2018, TFAD reviewed the 2017 State Plan to determine which recommendations should be retained or retired to the Appendix and which new recommendations should be added.

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!

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

On January 23, 2019, TFAD approved the final draft of the “State Plan to Address Alzheimer’s Disease” (2019). The 2019 State Plan includes 17 recommendations; four of these are new

recommendations. Each recommendation includes indicators and potential funding sources. Also, the 2019 State Plan includes Appendix A (three recommendations retired from the 2017 State Plan) and Appendix B (Resources).

TFAD Activities--2018

Meetings

TFAD met six times in 2018: January 10, March 9, May 9, July 6, September 5, and November 2. The primary focus of each meeting involved review, assessment, refinement, and/or retirement of recommendations included in the “State Plan to Address Alzheimer’s Disease” (2017). The 2017 State Plan comprised 16 recommendations, which are categorically included in one of three focus areas: 1) Access to Care, 2) Quality of Care and Quality of Life, and 3) Public Awareness.

Throughout the year, TFAD members facilitated the recommendations in the State Plan that involved their areas of expertise. Each member was charged with determining if his or her assigned recommendations were still timely and relevant. If TFAD agreed that a recommendation should be retained, the assigned member was responsible for refreshing substantive information, including: medical updates; data and statistical revisions; and funding resources.

Maximizing Resources and Collaborations

Making information about resources and services readily accessible to people with Alzheimer’s disease and other forms of dementia, their families, their caregivers, and others is very important to TFAD. This is why TFAD received regular progress reports from Dementia Friendly Nevada and Dementia Friendly Southern Nevada Champions.

DHHS, which has statutory responsibility for providing staff support to TFAD, continues to recognize the value of TFAD's work and the far-reaching impact of its contributions to the State Plan and its effect on the people of Nevada. To further support this work, ADSD staffs TFAD with an administrative assistant, who provides a full-range of clerical support to TFAD. Elizabeth Quintero assists TFAD with bi-monthly meetings, as well as revisions and updates for both the State Plan and the Annual Report. We also want to thank Jill Berntson, Deputy Administrator, Aging and Disability Services, until her retirement in June 2018, for providing leadership and support throughout her affiliation with TFAD.

ADSD’s current Alzheimer’s project is the Alzheimer’s Disease Initiative - Specialized Supportive Services (ADI-SSS) Program, awarded in September 2016. The goal of this project is to engage Nevada communities, including people living with dementia, their family caregivers, health care professionals, and broader community partners/ stakeholders, in dialogue about Alzheimer’s and other forms of dementia in ways that will foster adoption of evidence-based supportive services at the local level. This community engagement will reduce stigma and enable people living with dementia to fully engage within their communities, while also connecting families living with dementia to information, support, and evidence-based services as early as possible through multiple connection points, improving quality of life outcomes. The objectives of this project include:

- 1) Fostering the development of a ‘Dementia Friendly Nevada’ (DFNV) by initiating community action groups in seven, updated to six in 2018, targeted areas throughout the state, aimed at transforming the culture of dementia in those communities, enabling conversation and participation by all citizens, especially those living with dementia.
- 2) Facilitating/mobilizing community-driven change and decision making for local Community Action Groups.
- 3) Enhancing the reach and spread of Nevada’s Tool Box of available programs by making available for community action groups referring clients into existing Tool Box of Nevada’s Evidence-based care programs.

ADSD discussed strategies with key partners for effective program implementation and best practices in using evaluation instruments to assess community gaps and needs during multiple meetings. ADSD assisted with organizing meetings between Community Action Group (CAG) facilitators (Champions) to collaborate and communicate ideas among Dementia Friendly pilot communities, encouraging partnerships and sharing of resources to strengthen their communities, as well as raising awareness about promoting Dementia Friendly communities.

ADSD continues to work with TFAD to ensure that the State maximizes the outcomes of its three Alzheimer’s grants (Dementia Capable, Dementia Capable Expansion, and Dementia Friendly Nevada). These projects represent a federal investment in Nevada of \$1,751,108, with a required state match of \$836,619. Overall, these projects improved screening for cognitive issues related to this disease, improved connection of individuals to available resources, established improved data sets, created a “tool box” of available supports, and assisted and empowered communities to identify and address issues at the local level. Six Nevada communities are developing local resources through community engagement and embedding them within each community structure. The Dementia Friendly Nevada website (<https://dementiafriendlynevada.org/>) contains specific subsites for each community and houses training and resource materials, developed under these projects. ADSD is applying for an expansion grant to further support these initiatives in 2019, which, among other goals, will establish a Nevada resource center to connect Nevadans to available resources in support of individuals with Alzheimer’s disease and other forms of dementia and their care partners.

In addition, TFAD is working with ADSD on several of the State Plan's recommendations to monitor the indicators and secure funding, e.g. working with the State of Nevada Grants Office to locate and secure available funding.

TFAD appreciates the value of collaboration, which allows us to maximize resources that otherwise might not come together. Therefore, throughout 2018, TFAD focused on ways to create and re-enforce collaborations to address Alzheimer's disease and other forms of dementia, including the partnering of nonprofits, educational institutions, foundations, and State agencies, e.g., Cleveland Clinic Lou Ruvo Center for Brain Health, the Alzheimer's Association, the Nevada Consortium on Dementia Research, Dementia Friendly Communities, the Sanford Center for Aging, and Nevada Rural RSVP.

Finalization of 2019 State Plan

During the January 23, 2019, meeting, TFAD voted to approve the final draft of the “State Plan to Address Alzheimer’s Disease (2019),” which includes a total of seventeen recommendations. This plan includes four new recommendations, which address key emerging issues and needs: guardianship; APRN education, caregiver support, and dementia training. In addition, three recommendations (of the 16 in the 2017 State Plan) are being retired to the Appendix. All recommendations, which have been—or are being—moved to the Appendix, are monitored during the two years between State Plans to determine if they need additional attention (with a possible inclusion in the next State Plan).

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) 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 2019 State Plan, as well as during every bi-monthly meeting, TFAD has strongly supported the profound efforts of the Dementia Friendly Communities Initiative to provide opportunities for those with Alzheimer’s disease and other forms of dementia, along with their families and care givers, to feel and experience respect, dignity, support, value, and inclusion in everyday community life. 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 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.