

# **TASK FORCE ON ALZHEIMER'S DISEASE ANNUAL REPORT**



**January 2017**

## **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)

## **Task Force on Alzheimer's Disease**

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## **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 family, friends, caregivers, health care providers, first responders, 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 40,000 people in Nevada have been diagnosed with Alzheimer's disease or another form of dementia. With the multiplier effect that includes those who provide constant support and care, this means that hundreds of thousands of Nevadans are directly or indirectly affected by Alzheimer's disease and other forms of dementia.

## **Legislative 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 both Governor Brian Sandoval and State Legislators in January 2015. This State Plan included 20 recommendations, including suggested indicators and potential funding sources.

In the Fall of 2015, TFAD began its work on the “State Plan to Address Alzheimer’s Disease” (2017). This included the scheduling of timely and meaningful presentations and updates to refine the language of ongoing recommendations included in the 2015 State Plan. However, since the 2015 Legislative Session, TFAD also reviewed and evaluated which recommendations from the 2015 State Plan should be “retired” to an appendix, because they have been—or are being—addressed. In addition, TFAD considered vital and emerging issues that should be included in the 2017 State Plan. The 2013, 2015, and 2017 State Plan are available to the public on the ADSD website at <http://adsd.nv.gov/Boards/TaskForceAlz/TFAD/>.

### **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 by 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 has 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.

### **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 November 4, 2016, TFAD approved the final draft of the “State Plan to Address Alzheimer’s Disease” (2017). This State Plan includes 16 recommendations, five of which are new recommendations. Each recommendation includes indicators and potential funding sources. Also, the 2017 State Plan has been expanded to include Appendix A (nine recommendations retired from the 2015 State Plan) and Appendix B (Resources).

### **TFAD Activities--2016**

#### **Meetings**

TFAD met six times in 2016: February 3, April 1, June 1, August 5, October 5, and November 4. 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” (2015). The 2015 State Plan comprised 20 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 the Task Force worked regularly and closely with Cheyenne Pasquale, Aging and Disability Resource Center (ADRC) Project Manager, as well as ADSD's "No Wrong Door" Coordinator, to ensure that people could easily access the most current and applicable information on the ADRC web site.

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 executive assistant who provides a full-range of clerical support to TFAD. Sunadda Woodbury substantially assists TFAD with the revision and updates for both the State Plan and the Annual Report. In addition to addressing the ongoing needs of TFAD, during 2016, Ms. Woodbury provided full staff support to TFAD's Subcommittee on Dementia and Driving, which held multiple meetings in Washoe, Clark, and several rural counties.

In the third year of Alzheimer's Dementia Capability Grant of \$450,000 (federal grant), with a required \$256,000 state match (Tobacco Settlement and In-kind Match), ADSD continued to meet the grant's three goals for the program: developing screening for early identification of Alzheimer's disease and other forms of dementia, connecting individuals and their caregivers to appropriate services and resources, and establishing and improving data sets to quantify measurable outcomes. These three goals are included in the 2015 State Plan, and ADSD continued to work with TFAD to ensure that the State maximizes the outcomes of the grant.

Outreach and services delivery continued for the two programs implemented in the grant: Early Stage Partners in Care (EPIC) and Rosalynn Carter, Benjamin Rose Care Consultations Program. ADSD also reviewed and identified data collection changes to be applied in the ADSD SAMS system to better identify individuals with memory loss or Alzheimer's/ dementia, and the level of impairment. Through a completed environmental scan, 91 programs and services throughout the state of Nevada were identified that potentially serve people with Alzheimer's disease and other forms of dementia.

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 2016, 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.

### Finalization of 2017 State Plan

During the November 4, 2016, meeting, TFAD voted to approve the final draft of the “State Plan to Address Alzheimer’s Disease” (2017). This involved retiring nine recommendations (of the 20 recommendations in the 2015 State Plan) to a newly added appendix in the 2017 State Plan. Recommendations that are being moved to the appendix will be monitored at least annually to determine if they need additional attention (with a possible inclusion in the next State Plan). In addition, TFAD voted to include five new recommendations in the 2017 State Plan, which address key emerging issues and needs: caregiver support; veterans and families; outreach to physicians; driving and dementia; and guardianship.

The 2017 State Plan, with its sixteen recommendations, has added three new sections: “Statement of Support,” with a strong commitment to dementia-friendly communities; Appendix A: Nine Retired Recommendations; and Appendix B: Resources.

### 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) is an essential and viable 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 2017 State Plan, as well as during every bi-monthly meeting, TFAD strongly supports 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 caregivers, 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.

TFAD is statutorily authorized to meet through June 2017. If legislation to extend the life of the Task Force on Alzheimer’s Disease passes during the 2017 Legislative Session, 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.