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Governor



RICHARD WHITLEY, MS
Director

DENA SCHMIDT
Administrator

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December 20, 2017

Rick Combs
Director, Legislative Counsel Bureau
Nevada State Legislative Building
401 South Carson Street
Carson City, NV 89701

SUBJECT: Task Force on Alzheimer's Disease Annual Report

Dear Mr. Combs:

Please find enclosed the Task Force on Alzheimer's Disease Annual Report pursuant to NRS 439.5085. NRS 439.5085 (1) f. requires that on or before February 1 of each year, the task force 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. The Task Force is please to present the 2017 annual report. If you have any questions about the report please do not hesitate to contact me.

Sincerely,

A handwritten signature in blue ink that reads "Jill Berntson".

Jill Berntson
Deputy Administrator

Enclosure

Cc: Richard Whitley, Director, Department of Health and Human Services
Rick Combs, Director, Legislative Council Bureau

TASK FORCE ON ALZHEIMER'S DISEASE ANNUAL REPORT



January 2018

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

(Assembly Bill No. 80, Committee on Health and Human Services, State 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

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

Senator Joseph Hardy

Assemblywoman Lesley Cohen

Charles Bernick, M.D., Associate Medical Director, 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

Niki Rubarth, Regional Director, Northern Nevada Alzheimer's Association

Jane Fisher, Ph.D., Department of Psychology, University of Nevada Reno

Wendy Simons, Director, Assisted Living Development at Nevada Health Care
Association, Owner at Wendy Simons Consulting

Jill Berntson, Deputy Administrator, Department of Health and Human Services,
Aging and Disability Services Division

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. Alzheimer's disease is just one form of dementia and comprises about 60-80 percent of all dementia cases. In 2017, more than 43,000 Nevadans were estimated to be living with Alzheimer's disease or another form of dementia, projections estimate this number to rise to 64,000 by 2025. With the multiplier effect, which 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. The 2017 Alzheimer's Association Facts and Figures estimate Nevada has 145,000 caregivers of people with Alzheimer's or other forms of dementia contributing 165,000 hours of unpaid care valued at more than \$2 billion dollars.

Legislative and TFAD 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 (State Plan) 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,

Task Force on Alzheimer's Disease

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caregivers, service providers, legislators, educators, policy developers, and the general public. The primary role of TFAD is to create a Plan to Address Alzheimer's Disease "as needed."

TFAD is only statutorily required to meet quarterly. However, TFAD members determined that, based on the importance of these issues and needs, it is essential to meet bi-monthly. In addition, TFAD members decided to continue with the responsibility for developing, reviewing, and revising the State Plan by revising the State Plan biannually and presenting this plan to the Governor and Legislature in January of Legislative Session years. TFAD submitted its revised State Plan (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. See "State Plan to Address Alzheimer's Disease (2015)" at: <http://adsd.nv.gov/Boards/TaskForceAlz/TFAD/>

In the Fall of 2015, TFAD began its work on the next State Plan (2017). This included scheduling timely and meaningful presentations and updates to refine the language of ongoing recommendations included in the State Plan (2015). TFAD also considered vital and emerging issues that should be included in the State Plan (2017). In addition, TFAD reviewed and evaluated which recommendations from the State Plan (2015) should be "retired" to an Appendix, because they have been—or are being—addressed.

The State Plan (2017) was submitted to Governor Brian Sandoval and Legislators in January 2017. This Plan included 16 recommendations, with Appendix A, containing nine retired recommendations, and Appendix B, containing resources for persons and caregivers of persons with Alzheimer's disease and other forms of dementia. See "State Plan to Address Alzheimer's Disease (2017)" 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 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 State Plan (2017) 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 this 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.

Status of the State Plan (2017)

Throughout 2017, TFAD worked vigorously to address the growing needs of individuals living with Alzheimer's disease and other forms of dementia. TFAD discussed the status of current recommendations. In addition, members reviewed retired recommendations in the State Plan (2017) to determine whether any of these retired recommendations should be returned to the next State Plan (2019). Currently, TFAD members have determined that at least two retired recommendations should be returned to the State Plan (2019):

- 1) State Plan Recommendation #2 (2013 and 2015), which involved the availability of APRN care statewide, especially in rural and frontier Nevada.
- 2) State Plan Recommendation #10 (2013 and 2015), which addressed guardianship issues, especially as they affect persons with Alzheimer's Disease and other forms of dementia.

TFAD members continue to evaluate the current status of the recommendations they oversee, based on each member's particular area of expertise or interest. Each member also provides updates regarding available resources, potential partners to prompt completion, action plan timelines, and other details necessary to advance or modify the recommendations. TFAD will review the recommendations in the State Plan (2017) more thoroughly in 2018, as members focus on preparing the next State Plan (2019).

TFAD Activities (2017)

As prescribed by law, TFAD is required to meet at least quarterly each year. TFAD met five times in 2017: January 11, March 10, June 23, August 21, September 6, and November 17. During these meetings, TFAD explored several issues, needs, and concerns that could be addressed as new recommendations in the State Plan (2019). These include, but are not limited to:

- 1) Emergency medical services in rural and frontier Nevada.
- 2) Behaviorally Complex Care Program.
- 3) Cultural Competency/Accommodation.
- 4) No Wrong Door and the Balancing Incentive Program.
- 5) Care Transitions Project.
- 6) Dementia Friendly Nevada.
- 7) Speech Therapy and Dementia.
- 8) Telehealth/Telemedicine.
- 9) On-line Dementia Training.

In addition to hearing presentations about the issues addressed above (1-10), TFAD members reviewed the nine recommendations that were retired to Appendix A in the State Plan (2017).

TFAD appreciates the value of collaboration, which allows us to maximize resources that otherwise might not come together. Therefore, throughout 2017, TFAD supported 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. One great demonstration of this was the ongoing work of the Nevada Consortium on Dementia Research (NCDR), which was created in response to a recommendation in the State Plan (2013