

Task Force on Alzheimer's Disease Annual Report



January 2020

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

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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 (2019) estimates that there are approximately 47,000 people in Nevada living with Alzheimer’s disease and other forms of dementia. According to the Alzheimer’s Association, the prevalence of Alzheimer’s disease for people ages 65 and older, will grow more than 36% in just six years between 2019 and 2025 to 64,000 Nevadans affected. During 2019, Nevada ranked as the state with the third fastest growing population of residents living with dementia.

Between now and 2025, the financial cost of Alzheimer’s disease and other forms of dementia to Medicaid in Nevada will increase 49%, from \$185 million to \$275 million. Again, Nevada is experiencing the third highest percent of increase in the US.

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. Currently, this directly or indirectly affects hundreds of thousands of Nevadans. And, these numbers continue to climb and . . . climb. The Alzheimer’s Association estimates that there are approximately 151,000 caregivers in Nevada, offering a total of 172 million hours of unpaid care per year.

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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.

TFAD adopted the 2019 State Plan in January 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).

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

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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.

Alzheimer’s-related bills tracked by TFAD during 2019 Legislative Session

Assembly Bill 65 – Assembly Bill 65 was an agency bill brought by the Nevada Secretary of State’s Office. The intention was to “clean up” notarial language on forms such as the Guardianship Nomination form. In the 2017 session at the Nevada Legislature, a form was created whereby individuals could nominate the guardian of their choice, should they ever be in guardianship proceedings. The law made provision for placement of the nomination form in a “lockbox” with the Nevada Secretary of State that could be accessed by certain limited parties, such as the guardianship court, to verify compliance with the wishes of an individual prior to alleged incapacity. The form as provided for originally included certifications by notaries that went outside the scope of what was

allowed in their role and AB65 sought to correct that. Other bills also ultimately mimicked this correction. People who already have nominations on file with the Secretary of State should not have to re-do them but the law will affect the form in future.

Assembly Bill 91 – Assembly Bill 91 relates to procedures in Guardianship matters regarding sterilization of protected persons. For possibly older adults who are under guardianship, this means changes to the burden of proof should a guardian seek authority to authorize sterilization. The law in NRS 159 does not define sterilization, nor does this bill, but there are no limitations on age or condition which would not trigger the heightened requirements. This could impact caregivers in their role as guardians if they are seeking court authority for, say, a hysterectomy for a protected person, no matter the actual likelihood of the person exercising their reproductive rights.

Assembly Bill 170 – Senate Bill 170 is included here as it aims to place pre-existing condition protections from the Affordable Care Act into Nevada law and also for its provisions related to the Office of Consumer Health Assistance having information from insurance companies that it can then use to make more direct communication with those companies possible in the course of their advocacy for Nevadans.

Assembly Bill 228 – Originally conceived as a renewal of the 2017 attempt to expand the role of the State Long Term Care Ombudsman, Assembly Bill 228 was amended to allow for permissive authority of the Administrator of the Aging and Disability Services Division to direct the referral of the State Long Term Care Ombudsman into additional settings: supported living arrangements, community based living arrangements, adult day care, and facilities for long-term rehabilitation. In a way, this was a return to the pre-2017 discretion of the Administrator of ADSD to have such discretion, but which was amended out in 2017 when the State Long Term Care Ombudsman ceased to only serve those over 60 but instead included others who were in long term care, regardless of their age. The bill will allow for a better understanding, through data related to those who may opt in and request this type of individualized advocacy.

Assembly Bill 299 – One of several bills regarding powers of attorney, Assembly Bill 299 notably creates a specific provision in the advance directive component of a power of attorney for healthcare decisions that relates to Alzheimer’s Disease. The new form language would include the following:

“6. If I have an incurable or terminal condition, including late stage dementia, or illness and no reasonable hope of long-term recovery or survival, I desire my attending physician to administer any medication to alleviate suffering without regard that the medication is likely to cause addiction or reduce the extension of my life. [.....]”

The bill also distinguishes between “durable” and “nondurable” powers of attorney such that if a Guardianship terminates a power of attorney and the individual is later restored to their rights and exited from the Guardianship, the power of attorney may revive in effectiveness.

Assembly Bill 480 – Dubbed “The Supported Decision-Making Act,” Assembly Bill 480 provides an alternative to Guardianship which could be beneficial to individuals with early stage Dementia as they may wish to have support in making informed decisions without the use of a decision making proxy. This may not be an option for all (see also Senate Bill 121 below) and even nationally much of the dialogue regarding Supported Decision Making does focus on its use by individuals with other disabilities.

Supported Decision Making is, simply put, where an individual selects one or more supporters to assist them regarding specific decisions they may wish to make (for example, consenting to medical treatment). The existence of the agreement cannot be used to argue that the individual being supported needs a guardian and the individual at all times retains the final say on the choice they make. The supporter may assist with communicating that choice, informing the individual of their options, or the like, but they have no actual authority to make the decision for the individual. The law also provides some protection from liability for those who rely on an individual’s decision made in accordance with the agreement.

Senate Bill 20 – Senate Bill 20 covers multiple Guardianship specific areas. Guardianship is a court process by which an individual is deemed legally incapacitated and a guardian is appointed to make decisions in their best interests while also taking into consideration their wishes to the greatest extent possible (see, for example, the provisions of 2017’s Senate Bill 360, creating the Protected Person’s Bill of Rights). While there were numerous Guardianship reforms in the 2017 session, Senate Bill 20 sought in 2019 to adjust some areas of those reforms and address other gaps. This included:

- Addressing the issue of successor guardianships. This involves planning for when/if an existing guardian is no longer able to serve in their role.
- Including provision for use of Temporary Guardianships (also known as emergency or expedited guardianships) related to transfer and discharge concerns for an individual. Temporary Guardianships can be of concern because of the suspension of certain important procedural protections in service of emergency authority over another person.

- Referencing Temporary Guardianship authority to possibly include application for assistance or Medicaid and adding requirements related to the Temporary Guardian showing what actions were taken during their authorized temporary role when considering future requests for authority (meant to combat use of these guardianships based on stated emergencies which are then not addressed in the initial maximum ten day window).
- Allowance of certain appearance waivers and alternate appearance methods such as audio or video appearances. This can be helpful if presence in person at court is contraindicated by a physician.
- Clarification as to notification by guardians to interested persons for changes of residence for the protected person in certain emergency situations.
- Correction of the term "Supported Living Arrangement Services" to correct a prior error in statute that was being strictly construed by judges.
- Changes to the rights of refusal rules as to personal property sales (how offers to family members are handled).
- Elimination of requirements to include receipts unless court ordered.
- Recording fee increase to provide additional funding for mandated counsel, for investigators, and for self-help assistance in minor guardianship.

Senate Bill 121 – Senate Bill 121 provides for a Power of Attorney for Dementia. This is meant to address the unnecessary use of Guardianship where a person with a diagnosis of Dementia is denied services because of their diagnosis but without an actual judicial determination of incapacity. Put another way, where a person maybe failed to make their plans known prior to diagnosis, they are afforded a window of opportunity to have assistance in their healthcare decisions from their designated agent.

The bill also provides an explicit affirmation of the role the principal in any power of attorney arrangement continues to play. This means that where an agent is attempting to take action over the objection of the principal, the burden is on the agent to argue the appropriateness of their actions, not on the principal to initiate action to fight the agent's conduct.

Finally, Senate Bill 121 provides, in counties of under 100,000 residents (all counties except Washoe and Clark), certain information *can* be provided to Public Guardians prior to the appointment of a guardian if that information originates from the court, law enforcement, or the Aging and Disability Services Division. This is meant to encourage collaboration regarding referrals of cases to public guardians for possible filing.

Senate Bill 223 – Senate Bill 223 amended provisions relating to powers of attorney and touches upon transfers and discharges and notifications related thereto. Notification of the State Long Term Care Ombudsman and the patient is included. It was amended in part by Senate Bill 540.

Senate Bill 312 – Senate Bill 312 could represent a benefit to caregivers of those with Dementia as it creates a requirement for paid leave to be provided by employers with over 50 employees. Employees are not required to provide a reason for the use of their leave.

Senate Bill 362 – Senate Bill 362 requires certain assessments related to the condition and daily activities of residents be undertaken at various points in time, including upon admission, annually, and upon observed changes in condition. Placement in a residential facility for groups remains appropriate upon certain determinations relating to dementia while other determinations may result in the requirement that placement be at such a location that is certified to care for that individual under NRS 449.0302(2).

Senate Bill 540 – Senate Bill 540 was an agency budget bill draft from the Aging and Disability Services Division aimed at addressing a gap in protective services provision for those 18-59 who are vulnerable under NRS 200. This means an individual with early onset Dementia under the age of 60 can, as of July 1, 2019, avail themselves of protective services previously reserved for those 60 and older. The bill contemplates collaboration between law enforcement and protective services as well as adjusting some confidentiality provisions to reflect the involvement of protected person's counsel in guardianship. *Note: Contact information for Adult Protective Services remains the same as the prior Elder Protective Services. See adsd.nv.gov for more information.*

The bill also provides for amendments to the power of attorney form related to transfer and placement authority of an agent to phrase such options in a manner which informs an individual that if authority of their agent to make placement decisions is not granted, guardianship may be necessary.

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). As previously noted, 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).

During 2020, TFAD will be drafting a new 2021 State Plan. The process will include a review of all current recommendations in the 2019 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.

TFAD Activities—2019

TFAD met six times in 2019: January 23, March 15, May 15, July 12, September 11, and November 15. The primary focus of each meeting involved monitoring progress on the 17 recommendations included in the *2019 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.

Two key initiatives that TFAD received regular reports from included: 1) an Inter-Agency Collaboration to Address Adequacy of Dementia Care in Residential Facilities and 2) the Dementia Friendly Nevada initiative led by ADSD. Both of these efforts offered regular reports to TFAD.

Dementia Friendly Nevada in particular was a major three-year initiative that was supported by leveraging a \$1 million federal grant to ADSD in supporting six community action groups across the state (Elko, Pahrump, Pyramid Lake Paiute Tribe, Southern NV Urban, Washoe County and Winnemucca). These action groups, offered wide-ranging education and awareness programs, and connected people living with dementia and their caregivers to the valuable care and support resources offered in ADSD's Dementia Supports Toolbox. During the course of this funded initiative, there was an 892% increase in dementia-related service utilization statewide, representing a major impact by this initiative. While the federally-funded aspect of this initiative ended on September 30, 2019, these efforts are being sustained with leadership of the program being transferred to the Dementia Engagement, Education and Research (DEER) Program at the UNR School of Community Health Sciences.

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.