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## **MINUTES**

Name of Organization: Task Force on Alzheimer's Disease (TFAD)

Date and Time of Meeting: October 5, 2016  
10:00 a.m.

Carson City: Legislative Counsel Bureau  
401 S Carson Street  
Room 2135  
Carson City, NV 89701

Las Vegas: Grant Sawyer Building  
555 E. Washington Avenue  
Room 4401  
Las Vegas, NV 89101

To Join the Telephone Conference Call-in Number: 877-336-1831  
Access Number: 9186101

## **Agenda**

- I. Call to Order/Roll Call  
Senator Valerie Wiener (Ret.), Chair

Members present: Dr. Charles Bernick, Jacob Harmon, Julie Kotchevar, Wendy Simons, Sen. Valerie Wiener (Ret.), and Sen. Joe Hardy (joined later in meeting.)

Members participating by telephone: Gini Cunningham and Dr. Jane Fisher

Members absent: Assemblyman James Oscarson and Dr. Peter Reed

Alternates present: LeeAnn Mandarin

Staff present: Sunadda Woodbury

A quorum was declared.

- II. **Public Comment** (This item is to receive comments, limited to three (3) minutes, on any issue and any discussion of those items. However, no action may be taken upon a matter raised under public comment period unless the matter itself has been specifically included on an agenda as an action item.)

Kris Kingery submitted a written statement, which Sen. Wiener directed staff to attach to file. See Attachment A.

Gregory Martin, residing at 2900 South Valley View, Las Vegas, NV 89102, provided comments regarding Dementia Friendly America initiative. He expressed appreciation to several TFAD members and alternates who are involved in this ongoing work. He remarked that he has been working with Chris Brooks who is running for Assembly District 10, and explained that Mr. Brooks gained valuable insight on Alzheimer's disease and other forms of dementia through these recent efforts. He commended the collaborative efforts of the Alzheimer's Association and other organizations.

Mr. Martin commented that there has been wonderful response from several legislators, in support of legislation being proposed by the Alzheimer's Association, but would like TFAD to encourage other lawmakers, particularly Congressman Crescent Hardy, to back this legislative work. Mr. Martin cited that there is much work to be done, including working with the Center for Medicare and Medicaid Services (CMS), to approve valuable medical testing for Alzheimer's disease.

- III. **Welcoming Remarks**  
Senator Valerie Wiener (Ret.), Chair

Sen. Wiener stated that TFAD has been diligently working on the State Plan, hearing presentations that lend to it, and working with decision makers to make things happen. TFAD will be working on additional refinements today.

Sen. Wiener thanked everyone present who has made contributions to TFAD's work.

- IV. **Approval of the Minutes from August 5, 2016 Meeting (For Possible Action)**  
Senator Valerie Wiener (Ret.), Chair

Ms. Simons moved to approve the minutes from the August 5, 2016 meeting. Ms. Kotchevar seconded the motion. Minutes were approved unanimously.

V. Discuss and Make Recommendations on Bill Draft Request (BDR) 270 to Repeal Sunset Date (For Possible Action)  
Sen. Valerie Wiener (Ret.), Chair

Sen. Wiener commented that TFAD needs to review the existing language in Assembly Bill 80 (AB 80), under which TFAD operates at this time, in preparation to submit language changes for Bill Draft Request 270 (BDR 270) to repeal the sunset date. She stated that because of the legislative changes that will be proposed, the Legislative Counsel's Digest will be revised accordingly. She presented the following suggestions for the revisions of the text:

1. The composition of TFAD, as listed in Section 5 of AB 80, remains effective and has been effective since the passage of AB 80.
2. The end of Section 5, pertaining to appointment of alternates, may be amended to include a sentence that states, "Alternate members shall represent the category, see 2(a) through (g), which the appointed members represent." This would provide clarification that any alternate should represent the same category that the actual appointee represents. By practice, this had been done, but to ensure clarity for the future this language should be specified in statute.
3. Section 7(c) states "Review and revise the State Plan as necessary." Suggested revision would be to change "as necessary" to "biannually" to establish a more specific guideline to ensure that the State Plan is revised in a timely manner and presented to the Governor before the respective legislative session in odd-numbered years.
4. Section 8, change "2013" to "2017" for the proposed law to take effect then.
5. Section 8(a), pertaining to effective dates for terms of membership, change "2014" to "2018"; and Section 8(b), change "2015" to "2019".
6. Section 8(2.), pertaining to Legislative Commission appointments, propose that since these legislative members will serve 2-yr terms, could they not be appointed at the same time in 2017?
7. Section 9 can be deleted as language is no longer relevant.
8. Section 10, change the year the act will become effective from "2013" to "2017" and remove the sunset date indefinitely.

Sen. Wiener remarked that these changes would be proposed to Sen. Hardy, who submitted the BDR, as well as the bill drafters. The changes discussed are highlighted in a document attached to file. See Attachment B.

Ms. Simons expressed support for all of the recommended changes and moved to approve the suggested revisions as discussed. Dr. Bernick seconded the motion. The motion carried with unanimous support.

VI. Presentation on the No Wrong Door (NWD) Program and Updates on the ADRC Website

Cheyenne Pasquale  
NWD Coordinator  
Aging and Disability Services Division

Ms. Pasquale presented an overview of Nevada's 3-yr plan to improve access to Long-Term Services and Support System (LTSS), through a No Wrong Door (NWD) Approach, regardless of age, income, or disability. She stated today's presentation will provide a brief history of how the program was created and how the plan intersects with some of the ADSD programs, as well as recommendations in the State Plan to Address Alzheimer's disease.

Ms. Pasquale explained that the purpose of the NWD program is to develop a coordinated system of care for people needing LTSS. LTSS includes services that assist individuals with activities of daily living (ADLs) and their individual activities of daily living (IADLs). The target population is all LTSS populations across the lifespan of consumers. NWD is not a new program, but a new philosophy—a better way to improve access to services which has potentially positive implications throughout the system.

Ms. Pasquale shared a PowerPoint presentation highlighting the following the areas:

- Purpose of the NWD program
- Overview of LTSS in Nevada
- History and background of State/Federal initiatives on long-term care
- Why NWD is needed
- Nevada's NWD Plan mission and vision
- NWD Key Elements
  - Public Outreach and Linkage to Key Referral Sources
  - Person-Centered Counseling
  - Streamlined Access to Public Programs
  - Governance and Administration

In addition, the goals of NWD were presented along with their intersection with TFAD recommendations, including:

Goal 1

Engage and inform consumers, caregivers and providers in the NWD system to develop support for the initiative and increase access to care.

Intersection with TFAD Recommendation #1, #5, and #9

## Goal 2

Implement high-quality, person-centered counseling across agencies with established standards.

Intersection with TFAD Recommendation #7, #10, and #13

## Goal 3

Improve access and availability of LTSS.

## Goal 4

Develop an integrated IT system to improve access and efficiencies.

Intersection with TFAD Recommendation #7, #8, #10, and #12

## Goal 5

Establish a governing board to guide, promote, and ensure success of NWD in Nevada.

In conclusion, TFAD members were invited to advocate and support NWD efforts, as well as provide feedback.

The complete PowerPoint presentation, presented by Ms. Pasquale, is attached to file. See Attachment C.

Ms. Pasquale also gave an update on the Nevada ADRC.com website, highlighting the following:

- More positive language will be presented in the general information.
- Testimonials have been received from the Alzheimer's Association of southern Nevada, but she is seeking more interviews with people with dementia to incorporate more positive outlook into the site.
- Development of Nevada Consortium on Dementia Research (NCDR) registry page is underway.
- Collaboration opportunity with Nevada 2-1-1 to combine resource directories to potentially have one statewide resource directory.
- Assess My Needs screening tool, with a specific field for memory loss, will trigger referral to the local Aging and Disability Resource Center (ADRC) programs.

Sen. Wiener remarked that there may be other TFAD State Plan recommendations that would mirror the elements of the NWD program, and Ms.

Pasquale encouraged members to provide additional feedback should they find that other recommendations are also relevant to those key elements.

Discussion took place regarding the vetting process of projects to be included in the registry under NCDR. Dr. Bernick commented that consortium members are considering establishing a committee to review the postings to ensure they are vetted before they are included on the website.

Dr. Bernick also remarked that it would also be beneficial to improve access to electronic medical records (EMRs) from different entities (nursing homes, etc.) to allow physicians easier access to essential information and provide timely care to meet their patients' needs.

## VII. Presentations on Dementia Friendly Nevada

### A. Jeff Doucet, Aging and Disability Services Division (ADSD)

Jeff Doucet provided an overview of the current Dementia Friendly Nevada grant that was recently awarded, beginning October 1, 2016. He presented highlights, including:

- The grant is a 3-yr grant of \$1,000,000.
- There is a 25% State match, which is being met through program partners, in-kind contributions, and some in-kind and cash from ADSD, totaling about \$333,000 in match.
- The funding source is the Alzheimer's Disease Supportive Services Program (ADSSP), Alzheimer's Disease Initiative (ADI) –Specialized Supportive Services (SSS) Program.
- Grant partners and their roles are listed in the Project Summary.

Mr. Doucet also shared the goals and objectives of Dementia Friendly Nevada, which are:

- Enhance the quality of life of people living with dementia and their family caregivers through coordination of services and community- driven systemic community improvements.
- Engage seven Nevada communities, including people living with dementia, their family caregivers, health care professionals, and broader community partners/stakeholders, in dialogue about Alzheimer's disease and other forms of dementia in ways that will foster adoption of evidence-based supportive services at the local level.

A copy of Mr. Doucet's Project Summary is attached to file. See Attachment D.

Discussion took place about the development of Dementia-Friendly communities in Nevada, and the requirements for participation in this initiative. Jacob

Harmon of the Alzheimer's Association explained that there are existing Dementia Friendly America models that can be adapted to the unique situations of communities in Nevada. He noted that different communities have different needs that must be addressed individually. Dementia Friendly is about a community—all stakeholders, from the medical side to the retail side, transportation side, patient side, the faith-based side, etc.—coming together to talk about what the community needs. Then the information can be relayed to service providers, such as the Alzheimer's Association, so they can formulate services to meet the unique needs of that particular community. He anticipates and hopes that in the future, more than seven communities could become involved.

B. Lee Ann Mandarino, Cleveland Clinic Lou Ruvo Center for Brain Health;  
Nicole Anderson, Alzheimer's Association;  
and Susan Hirsch, Nevada Senior Services

Lee Ann Mandarino, Nicole Anderson, and Susan Hirsch gave a joint presentation on Dementia Friendly Nevada.

Ms. Mandarino commented that there was a kick-off event on September 21, 2016, in Las Vegas for Dementia Friendly Nevada. She explained that efforts to convene, according to the Dementia Friendly America plan, started in May 2016 and there has been good engagement at the monthly meeting since then. Around 30-50 people have participated and held productive discussions to outline ideas for Nevada. The kick-off event was the culmination of the first phase of work.

Ms. Mandarino remarked that the next step is to garner input from various communities regarding their particular needs. It will be a bottom-up process to get feedback from communities throughout Nevada to assess what they're lacking.

Ms. Mandarino presented an overview of Dementia Friendly America (DFA), a grass-roots movement, which aims to foster a more fulfilling life for individuals affected by dementia, their families, and care-partners. The goal is to go beyond just meeting the health care needs of people with dementia, with the intention to support their abilities to sustain the best quality of life possible and to continue to live their lives purposefully in their community. Additionally, increasing awareness and involving community partners will also be key factors.

Various components of the mission of DFA were highlighted. This information is attached to file. See Attachment E.

Ms. Anderson stated that Phase 1 of the strategic plan, based on the model established by Dementia Friendly America, has been accomplished. Steps completed include:

1. Convene.
2. Determine community readiness.
3. Generate awareness.
4. Build an action team.
5. Hold a community kick-off event and publicize.

She further outlined the activities and meetings that have taken place since May 2016 in southern Nevada to move forward the Dementia Friendly Nevada initiative. She noted, in particular, that participation grew immensely as meetings progressed, and the number of participants had almost tripled, reflecting great interest from the public.

Ms. Anderson highlighted the alignment of the initiative in Nevada, beginning at the state level, which consists of a steering committee, comprising ADSD, AARP, and the Alzheimer's Association. Using the DFA model, a Champions Team was formed to plan meetings and coordinate sector meetings. The four sectors are:

1. Healthcare
2. Government
3. Community Services
4. Care Partner

She explained that participants can chose to be involved in the sector(s) of their choice. They will be working on modifying questionnaires, derived from the DFA model, and discussing how to make these questionnaires more specific to Nevada. Once the questionnaires are approved, the goal will be for representatives from each sector to distribute them to their colleagues and solicit feedback.

Ms. Anderson highlighted the action steps to be completed in Phase 2, which include:

1. Forming a community engagement sub-team.
2. Adopting the engagement process to each community.
3. Holding and interviewing focus group training and prep session.
4. Developing an organized flow and timeline.
5. Engaging the community in interviews and focus groups.

Discussion took place on the specifics of the analysis of the questionnaires and anticipated work plans, along with conversation about similar efforts taking place in other states. Ms. Mandarino mentioned that the timeline to complete this phase will be 3-6 months.

Ms. Hirsch explained that under the Dementia Friendly initiative, there is a model and toolkit, along with materials, that can be utilized. The challenge is how to adopt these resources to address the needs in Nevada.



She presented a Power Point, which demonstrated the goal to “ensure resources and support are available and accessible to all people regardless of where they live, their cultural background, or their economic status.” She reported Nevada Senior Services offer a continuum of resources to individuals across the spectrum of needs. She cited that a survey done by the Centers for Disease Control found that approximately 80% the individuals who attend the adult daycare center at the Jones facility have dementia. They are able to take advantage of the services and go home to their families at the end of the day.

Ms. Hirsch presented ideas on how to build a support network and described how the sectors in a community can work to implement the action plans, while continuing to focus on the persons with dementia. Furthermore, she provided an overview of Phase 3 and Phase 4: Analyze and Act.

During the third phase of becoming a Dementia Friendly City, the sectors will analyze their community’s needs based on findings of the assessments in Phase 2. Then they will determine which issue community members are motivated to act on and set community goals to achieve it.

During the fourth and final phase of becoming a Dementia Friendly city, the sectors will act together to establish implementation plans for their community goals, both short term and long term, and identify ways to measure progress. Future sectors may include, but are not limited to:

1. Business
2. Faith-Based
3. Legal/Financial
4. Rural

A copy of Ms. Hirsch’s Power Point presentation is attached to file. See Attachment F.

Discussion ensued on the designation of communities/cities to be involved, as well as how different sectors were chosen.

Mr. Harmon commented that the statewide steering committee has a participant who has early stage Alzheimer’s disease, who is an integral part of the group. Conversations followed about the importance of engaging people living with Alzheimer’s disease and other forms of dementia in the work of Dementia Friendly Nevada. Their input is an essential element to understanding the needs of this population.

Ms. Hirsch reported that there is strong engagement from not only individuals living with dementia, but also their care partners who can provide very valuable feedback.

Sen. Wiener reiterated the importance of this initiative, which aligns with the work of TFAD, to increase awareness, provide a venue to address concerns and overcome stigma, and improve the lives of many individuals living with Alzheimer's disease and other forms of dementia who have contributed much to their communities over their lifetime.

VIII. Discuss and Approve Lead-in Language for New State Plan Recommendations (For Possible Action)

Senator Valerie Wiener (Ret.), Chair

TFAD discussed lead-in language for the following new recommendations:

Recommendation #9: Caregiver Support

Statistics from the latest Facts and Figures Report from the Alzheimer's Association were added to the introduction paragraph. See Attachment G.

Ms. Simons moved to approve the background information. Dr. Bernick seconded the motion. The motion was approved unanimously.

Recommendation #13: Veterans and Families

Sen. Wiener proposed that she work with Ms. Simons and staff to condense the information provided for the lead-in language down to one or two paragraphs to fit the format of the State Plan.

Dr. Bernick moved to approve the proposal as discussed. Mr. Harmon seconded the motion. The motion was approved unanimously.

Recommendation #5: Outreach to Physicians

Background information was provided by Mr. Harmon and Albert Chavez.

Ms. Simons moved to accept the language as provided. Dr. Bernick seconded the motion. The motion was approved unanimously.

Recommendation #14: Driving and Dementia

Dr. Fisher requested that the final approval of the language for this recommendation be deferred until the November 4, 2016, meeting due to data still pending from physicians' survey.

Dr. Bernick inquired about the scope of the physicians' survey and Dr. Fisher provided a sample of the different types of physicians who have participated, citing that Dr. Reed has been primarily conducting this research. Conversations

took place about specific details of the survey, and Dr. Fisher stated that she will forward Dr. Bernick a copy of the document.

Sen. Wiener recommended that TFAD review the entirety of this recommendation and background language at the next meeting.

#### Recommendation # 11 Guardianship (replacement)

This recommendation is not new, but is a modification of a previous recommendation on guardianship. Sen. Wiener suggested that lead-in language may not be necessary as the revised recommendation is clear and concise.

Ms. Simons moved to let the recommendation stand as is, without adding lead-in language. Dr. Bernick seconded the motion. The motion was approved unanimously.

#### IX. Make Recommendations of Any Additional Changes to the State Plan (For Possible Action)

Senator Valerie Wiener (Ret.), Chair

TFAD reviewed the revised State Plan, along with Appendix A, retired recommendations, as well as Appendix B, resources.

Sen. Wiener explained the reasoning behind the abbreviated resource page, which includes only federal and state agencies, the Alzheimer's Association, and the link to the ADRC website. She emphasized that the list presents the initial gateway to additional resources within those entities, and the website will provide connections to numerous other resources. To include a comprehensive list would be a monumental task.

Dr. Fisher questioned the criteria that were used to determine what agencies to include on the resource list, and suggested that there are some statewide organizations, specific to Nevada, that should also be included. For example, the agencies in the Nevada higher education system such as the Sanford Center and the UNR Caregiver Support Center should be considered since they provide services and information specific to address the needs of families in Nevada.

Extensive discussions transpired regarding the challenges of including a comprehensive list of providers, as well as how to ensure that those resources have been vetted to be reliable for the vulnerable senior population. Sen. Wiener suggested that the link to the Nevada ADRC website will provide a connection to an extensive network of resources.

Ms. Pasquale stated that at present there is a comprehensive directory of about 600 providers of LTSS included on the ADRC page. She added that the Nevada 2-1-1 page has almost double the amount of resources in their directory, and it

would be beneficial to add that link in Appendix B. She explained that in the current efforts to establish a comprehensive statewide information and referral system in Nevada, the resource list on these websites are continually updated.

Mr. Harmon inserted that the Alzheimer's Association is required, through grant funding, to maintain a comprehensive resource directory for families of individuals living with Alzheimer's disease and other forms of dementia in Nevada. Then through the 24-hour helpline, they can provide the information and support 24 hours a day, seven days a week. He suggested removing the regional contact information for the Alzheimer's association offices, since they're now one, and keeping only the 1-800 number and the main alz.org website, which will direct people to their respective local area resources. Sen. Wiener recommended adding "24/7 Access" in that category as well.

Mr. Harmon also explained how the hotline works, particularly in response to identifying geographic locations of callers and addressing specific needs of individuals and providing referrals, as well as care consultations over the phone.

Dr. Bernick and Dr. Fisher expressed concerns that only generic information will be provided, rather than Nevada-specific information, which would be more beneficial and timely for families in times of crisis.

Ms. Kotchevar reemphasized the difficulties in including an exhaustive resource list, thus resulting in the abbreviated list, as presented, to provide an entry way to other resources.

Dr. Bernick recommended adding categories to the existing resource list on the ADRC page to improve navigation and enable easier maneuvering. Sen. Joe Hardy suggested the possibility of adding an index as well, along with a disclaimer.

Sen. Wiener suggested that TFAD members, the experts, can assist with providing key words for categories. Ms. Mandarino offered to connect Ms. Pasquale with an individual working on a similar project. Dr. Bernick inquired whether a workgroup could be formed to assist. Sen. Wiener stated an agenda item can be added to discuss this possibility further.

X. **Make Recommendations of Possible Agenda Items for Next Meeting (For Possible Action)**

Senator Valerie Wiener (Ret.), Chair

Possible agenda items may include:

1. How to improve access to information for our constituents (form a workgroup to assist Ms. Pasquale?)

2. Final review and approval of Recommendations #13 (Veterans and Families) and #14 (Driving and Dementia)
  3. Final review and approval of the State Plan, along with Appendix A and B.
  4. Discussion of January 2017 Annual Report
  5. Scheduling of meeting dates for 2017
  6. Legislative update on upcoming legislation that may pertain to TFAD
- XI. **Public Comment** (This item is to receive comments, limited to three (3) minutes, on any issue and any discussion of those items. However, no action may be taken upon a matter raised under public comment period unless the matter itself has been specifically included on an agenda as an action item.)

No public comment.

- XII. **Adjournment**

The meeting was adjourned at 12:49 p.m.

**NOTE:** Items may be considered out of order. The public body may combine two or more agenda items for consideration. The public body may remove an item from the agenda or delay discussion relating to an item on the agenda at any time. The public body may place reasonable restrictions on the time, place, and manner of public comments but may not restrict comments based upon viewpoint.