



STATE OF NEVADA
DEPARTMENT OF HEALTH AND HUMAN SERVICES
AGING AND DISABILITY SERVICES DIVISION

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Minutes

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

Date and Time of Meeting: November 19, 2014
10:00 a.m.

Las Vegas: Touro University Nevada
Active Aging Center
874 American Pacific Drive
Henderson, NV 89014

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

Members Present: Tina Gerber-Winn, Gini Cunningham, Dr. Peter Reed, PhD., Senator Valerie Wiener (Ret.), Albert Chavez, Wendy Simons, Dr. Jane Fisher, PhD., Jeff Duncan (Alternate Member); Dr. Charles Bernick and Lee Ann Mandarino (Alternate Member) joined by phone.

Members Absent: Senator Joe Hardy, Assemblywoman Heidi Swank

Staff: Dale Ann Luzzi, Sunadda Woodbury

II. Public Comment (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.

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

Senator Wiener welcomed all in attendance and thanked them for coming, especially those who traveled some distance for the meeting.

IV. Approval of the Minutes from September 24, 2014 meeting **(For Possible Action)**
Senator Valerie Wiener (Ret.), Chair

Dr. Reed motioned for approval of the minutes from September 24, 2014 as written. Ms. Wendy Simons seconded. Minutes approved unanimously.

V. Review and Discussion on Possible Updates to the State Plan on Alzheimer's Disease

Senator Valerie Wiener (Ret.), Chair

Senator Wiener commented that she has reviewed the modifications made to the State Plan, which were provided by input from committee members overseeing specific recommendations. She proposed addressing each section in the State Plan and emphasized the need to update statistics to be current.

Discussion on the Executive Summary in the State Plan comprised the following:

Recommendation 1, 2, and 3: Statewide Information and Referral System, Nurse Practitioners, and Health Funding Streams

Senator Wiener remarked that Recommendation 1 and 3 were fine. She noted changes to be made in Recommendation 2 to remove redundant language.

Recommendation 4: Remove Age Barriers

Senator Wiener was concerned in particular about Recommendation 4. She emphasized the need to add an accurate description of the CARE Act. Ms. Tina Gerber-Winn asked if changes are to be made in the body of the State Plan as well as the Executive Summary section. Senator Wiener pointed out that the language in the Executive Summary and the recommendations within the State Plan should mirror each other. Ms. Gerber-Winn then suggested that an attachment with information on the CARE Act that she received from Mr. Barry Gold, AARP, after the last Task Force on Alzheimer's Disease (TFAD) meeting could be included. Ms. Simons also commented that "The CARE Act" with "CARE" in upper case is the correct reference that should be used for the Caregiver Advise, Record, Enable (CARE) Act developed by the AARP, not to be confused with the Affordable Care Act (ACA).

Senator Wiener remarked that there needs to be consistency in the use of terms throughout the State Plan. She noted in particular that a lower case "s" as in the state of Nevada means Nevada as a whole geographically. On the other hand, a capitalized "S" as in the State of Nevada means Nevada as a government entity.

Senator Wiener added that the original Task Force spent a lot of time on how to reference what they were working on because there were many authors involved. Sometimes “Alzheimer’s” was used, but typically “Alzheimer’s and other related disorders” was used throughout the document. The TFAD needs to decide which reference they will use going forward. Senator Wiener noted that Dr. Bernick had previously discussed how these terms were used nationally. Mr. Chavez remembered the Task Force talking about using “related disorders” but felt this should be confirmed with Dr. Bernick. Ms. Gerber-Winn remarked that it is important to include “dementia” because sometimes people think “Alzheimer’s” doesn’t apply to them. Ms. Gini Cunningham agreed that “dementia” is too important to dismiss and suggested “related dementias” instead of “related disorders”.

Ms. Cunningham further submitted that attention should be paid to verbiage such as “support” and “explore”. She inquired about what that actually means and what next step the TFAD will take. She suggested using more action words like “examine, identify, etc.” Senator Wiener cautioned that the TFAD needs to remember what our resources are when we pick words like “support” or “examine”. We need to determine what our capabilities are. She advised that these items can be part of our continuing discussion as we review the State Plan, item by item.

Ms. Simons proposed that a glossary of terms could be included to provide further clarification. Senator Wiener proposed that the glossary could also include an explanation of what might be involved when certain words like “support, establish, improve, etc.” are used.

Mr. Albert Chavez stated the full title for the Alzheimer’s Association is actually the Alzheimer’s Disease and Related Disorders Association.

The group agreed that the State Plan needs to be changed substantively and stylistically. Senator Wiener suggested skipping the Executive Summary and moving on to address each recommendation in detail. The group concurred.

Review and modifications to the State Plan content comprised the following:

- Changing the heading of Chapter 1 to “History of the Task Force on Alzheimer’s Disease (TFAD).
- Making the heading of Chapter 2 to be more inclusive. Originally the Task Force had used “Alzheimer’s and other related disorders” as a term of reference, but the present TFAD members feel the need to make a change to the wording to be more inclusive. Mr. Chavez pointed out that Alzheimer’s disease is most prevalent and makes up 70%, but other dementias account for 30%. Dr. Reed commented that the former usage of “other related disorders” implies that those disorders are related to Alzheimer’s, rather than

being other form of dementias. He further clarified that dementia is a set of symptoms and all forms are just causes of the symptoms.

Senator Wiener asked for a vote to change the reference throughout the document from “Alzheimer’s disease and related disorders” to “Alzheimer’s disease and other forms of dementia.” Dr. Fisher made a motion for approval. Dr. Reed seconded it. The motion passed.

- Chapter 2 heading will now read “Scope and Impact of Alzheimer’s Disease and Other Forms of Dementia”.
- Ms. Simons remarked that it’s not necessary to have a sub heading in the question form of “What is Alzheimer’s Disease”. Senator Wiener and others agreed to strike the previous sub heading and leave the paragraph following as is.
- Dr. Reed questioned whether the data under “Prevalence of Alzheimer’s Disease” is current. Senator Wiener then recommended that all members of the group should advise on the updated statistics and data in their areas of expertise, if there is new data to provide. There also needs to be updates to the citation of sources accordingly.
- For “Economic Impact” section, Mr. Chavez said that he can provide some information on current statistics on the population with Alzheimer’s as well as economic numbers.
- In the “Social Impact and Stigma” section, Dr. Fisher suggested adding a line that diagnosis has implications for the type of medical care an individual receives. She will provide language to add to this section accordingly.
- Dr. Reed suggested changing “Home-Based Services” to “Home and Community-Based Services” to be more inclusive. Sen. Wiener inquired whether resources listed were still current and Ms. Gerber-Winn confirmed that they were. No other sources are to be added at this time.
- Dr. Reed also mentioned that it would be better to use “long-term support and services” in lieu of “long term care facilities” to de-institutionalize wherever possible.
- Ms. Simons recommended capitalizing and bolding “RECOMMENDATION” throughout the document to allow for emphasis and make the recommendations stand out more and easier to locate.
- Dr. Reed also proposed adding some sort of separator between each recommendation and supporting paragraphs. Senator Wiener agreed to this

style change and asked staff to use a line, stars, Nevada flags, or something to indicate breaks between recommendations.

Recommendation 1

The TFAD discussed modifying the language to demonstrate more active involvement by changing the wording in the beginning to “Establish, fund, and sustain a statewide information and referral system...”

Dr. Fisher suggested adding the UNR Nevada Caregiver Support Center to the list of resource centers and will provide website information for it. Dr. Reed then proposed modifying the wording of the indicator to emphasize that a collaboration of resource centers already exists, and the emphasis on the indicator would be to monitor inquiries and contacts made to these programs.

In regards to potential funding, Mr. Chavez submitted the need to move the free public service announcement, appearances, etc. as these should be included in Recommendation 20 instead. Wording was modified to reflect the change.

Rural Services

Senator Wiener noted that information from the *Nevada Rural and Frontier Health Data Book* needs to be updated to show current data. Ms. Simons said that there’s a 2013 edition wherein we can find this material.

Recommendation 2

The paragraph leading into this recommendation was taken out as the information appeared redundant. Senator Wiener commented that the language was modified previously with suggestions from Dr. Andy Eisen. Ms. Simons also added an additional piece for the TFAD to continue to monitor the progress that has occurred with the passage of AB170.

Ms. Gerber-Winn pointed out there needs to be a statement from the TFAD to clarify in the indicator part who is actually going to be doing the “monitoring” and other related activities. If the Aging and Disability Services Division (ADSD) is expected to perform certain duties, it should be stated here. Senator Wiener emphasized that the relationship between the TFAD and the ADSD needs to be clearly demonstrated. We need to show the connection between the TFAD and the agency and define appropriate roles. She reviewed how the original Task Force was formed and how it has evolved since then. It was agreed at one point that the Department of Health and Human Services (DHHS) could absorb the Task Force and provide the administrative support. The question now is if the desire of the TFAD is for the ADSD to do more substantive work, including monitoring certain activities

and seeking grants, there needs to be a definitive ongoing statement clearly stating the collaboration between the TFAD and the ADSD.

Dr. Reed commented that we need to be careful not to take on an 'oversight' role and create the perception of a regulatory function. We need to carefully consider the actions we choose for the indicators for each recommendation. Senator Wiener agreed and said that statutorily we don't have the authority to do that anyway. Ms. Gerber-Winn proposed that as a work assignment, the ADSD could collect data from pertinent sources for the TFAD to review. Senator Wiener suggested the idea of including an explanatory provision in the section that pertains to the functions of the TFAD to indicate that the ADSD will perform tasks as recommended in the State Plan and reviewed by the TFAD. Senator Wiener urged the group to come up with clear and concise language to fortify the relationship between the TFAD and the ADSD. Ms. Gerber-Winn further affirmed that the ADSD can provide information and obtain reports for the TFAD, which can be used to mark progress of the recommendations in the State Plan. Senator Wiener also remarked that this knowledge will enable the group to better support certain legislation that may be pertinent to the State Plan.

Telehealth

Senator Wiener inquired whether there is an update on the money the Nevada Hospital Association has received in grants for Telehealth and how Nevada has been affected by this. An update needs to be added here.

Dr. Reed suggested adding content on Project Echo, which is a Telehealth initiative. Nevada is one of the first states to be funded for this.

Recommendation 3

Senator Wiener proposed that the TFAD's role is to support this legislation, while the ADSD's assignment is to identify funding streams. Ms. Cunningham asked how the TFAD can actually "improve access". Senator Wiener advised that this is done by supporting the legislation. Ms. Gerber-Winn submitted that there will be at least one bill on Telehealth in this upcoming legislative session. The TFAD can testify to the importance of the proposed legislation.

Ms. Simons remarked that she found valuable information from the Nevada Hospital Association (NHA) as to the grant money for Telehealth and what it has been used for along with current projects through the University of Nevada School of Medicine. Advances in Telehealth and Telemedicine will accelerate in the coming years. Ms. Cunningham suggested looking at insight from patients collected by the NHA as well. Ms. Gerber-Winn said the TFAD can use this information as an advisory board in making recommendations to the Governor to support issues that are beneficial to the

people of Nevada. Senator Wiener emphasized that the TFAD has a very important role to do the screening and the advising on these issues, as well as providing information to the public.

In regards to potential funding, Dr. Reed pointed out that the Alzheimer's Disease Demonstration Grants to States is now called the Alzheimer's Disease Supportive Services Program (ADSSP).

Early-Stage and Younger/Early-Onset

Dr. Reed, Dr. Fisher, and Mr. Chavez discussed language and all agreed on changing the headings in these sections to "Early-Stage/Mildly Impaired" and "Younger-Onset" to align with current phraseology.

Dr. Reed also advocated replacing the term "caretakers" with "caregivers" throughout the document.

Recommendation 4

Senator Wiener proposed additional language to "expand" upon AB86 allowing for a more active statement. This may not happen during the upcoming legislative session, but it may happen in the one following. We are just setting this up as a priority. Ms. Gerber-Winn expressed her concern about what 'disability services' actually means (too vague). Dr. Fisher suggested "social services" would be more appropriate. Dr. Reed asked to move the sentence with the CARE Act to recommendation 8 as it is more relevant in that section.

The indicator was changed to indicate that the ADSD will annually review the statutes and regulations regarding funding for younger-onset individuals with Alzheimer's and related forms of dementia.

Recommendation 5

Dr. Reed recommended modifying the language regarding the needs assessment to specifically state this pertains to Alzheimer's experiences and needs.

Discussion followed concerning who would actually put together and administer the needs assessment. Ms. Gerber-Winn commented that we have funding to hire a contractor if needed. Ms. Cunningham also added that some of the assessment can be done through volunteers doing informal evaluations, and many of the Hispanics just want some tips on caregiving in English and Spanish. Senator Wiener pointed out that perhaps we don't need a needs assessment, but rather we can provide access to multicultural information (which can be part of the public information campaign in

recommendation 20) and work with Hispanic Organizations to accomplish this.

Dr. Fisher indicated she has been working with doctoral students on a pilot project which involved translating standardized measures of caregiver needs into Spanish for some of the most widely used measures, and changed the language to eliminate the pathology (stigmatizing element) in order to overcome cultural concerns.

Senator Wiener then suggested that we could indicate our support of this project in Recommendation 5 and the indicator could be the results of these measurements being conducted. She asked Dr. Fisher to revise the language, the indicator, and the potential funding for this recommendation.

Recommendation 6

Ms. Simons indicated that this recommendation has been streamlined by removing the sliding scale funding streams. She also pointed out that the survey of providers mentioned in the indicator could be put together by the ADSD staff using Survey Monkey. Committee members/experts could help suggest ideas for what questions to include that would have the greatest value. Senator Wiener proposed that the survey be included in the recommendation part, and change the indicator to be the tracking and analyzing of survey results.

Dr. Reed suggested using “Assess” instead of “Address” affordability of services and all agreed.

Chapter 4: Quality of Care

Senator Wiener recommended moving the Research Section ahead of the Diagnostic Section.

Dr. Fisher commented that she can provide a better source for definition of quality care specific to people with dementia. She said she can get the information from the American Geriatric Society (AGS) to use in place of the existing piece because the American Medical Association (AMA) data from 1984 is outdated.

Data tables for the Research Section need to be updated to show current numbers, if possible.

Ms. Gerber-Winn and Dr. Reed suggested removing the segment on early detection tests since the information may appear too technical and narrowed to one study instead of providing a broad spectrum of information that is

needed here. Ms. Simons and Senator Wiener noted other wording changes and proposed redoing the bulleted segments into a new paragraph.

Dr. Fisher brought up challenges in enrolling enough people, including limitations for those under guardianship. She will offer additional language here to be included in the issues limiting research.

Recommendation 7

Lee Ann Mandarino from the Cleveland Clinic Lou Ruvo Center for Brain Health joined the meeting on the phone. Ms. Mandarino questioned whether recommendation 1 and 7 are related and should be combined. Mr. Chavez stated that there is a distinction between the two, with recommendation 1 centered mostly on the website that would allow for an information referral system for patients with Alzheimer's and other dementias, whereas recommendation 7 would focus more on research and a registry for research participants.

Dr. Fisher commented that the ongoing research at UNR, UNLV, and other locations would benefit tremendously from more public recruitment and support. This exposure would be a huge advance and also reflect positively on the State of Nevada and allow the public to become more aware of the research efforts here. Dr. Reed asked whether the intent is to recommend creating a website as clearinghouse for research in Nevada. Senator Wiener presented the idea of adding information to recommendation 1 to reflect the promotion of access to research and trial match opportunities that could be included on the ADRC website.

Mr. Jeff Duncan confirmed that presently there are several sub-sites on the ADRC page. A stand-alone page could be added to house information for Alzheimer's and other forms of dementias, or a link could be added under the existing resource directory page on the ADRC website to display this information along with a list of research opportunities and a patient registry. The latter option might be best because it would allow easy access. Everything is already on one page on the resource directory page. Mr. Duncan remarked that funding for these tasks would have to be carefully considered. The group decided to modify the language of recommendation 7 to incorporate expanding the ADRC website to specifically include information on current Alzheimer's research and information on a registry that allows individuals to register to participate in clinical research.

The indicator and potential funding sections were also modified.

Recommendation 8

Ms. Gerber-Winn reported that after consulting with Dr. Charles Bernick, the previous recommendation 7 & 8 were combined and a new recommendation 8 was created. Dr. Bernick stated that the emphasis of this recommendation would be to encourage hospitals to adopt specialized care pathways for treatment of patients with Alzheimer's. Ms. Gerber-Winn suggested seeking collaboration from others as well, and not relying solely on hospitals. A combined effort by the hospital as well as experts from various organizations to develop and implement a best practices care plan would be ideal. The TFAD also supports the AARP-sponsored CARE Act, which is a mandate relating to hospital care and services which are given to caregivers at the time of patient discharge.

Long-Term Care Facilities

Ms. Simons will contact the Bureau of Health Care Quality and Compliance (BHCQC) and update the data in this section.

Recommendation 9

Dr. Reed pointed out that the problem is not that there are people with Alzheimer's who have behavioral issues, but that these patients are not being supported properly. Therefore, they are sent out of state. Ms. Simons remarked that the regulatory pressures on the care facilities are hostile as well.

In looking at funding, Ms. Simons asked if we want to address the Home and Community-Based Waiver shift with the new revised rules from Centers for Medicare and Medicaid Services (CMS) that are now effective. Senator Wiener suggested that we can be forward thinking without being specific at this time. Ms. Simons also presented the news of the construction of the Northern Nevada Veterans home which will add beds for Alzheimer's patients. Funding for this will be deliberated in the upcoming legislative session.

Long-Term Care for Alzheimer's Disease Patients With Challenging Behaviors

Senator Wiener urged the committee members to carefully review this section because it contains a lot of data and numbers that must be accurate. Dr. Reed also expressed concern about the language in this section and offered to help to revise the wording.

Recommendation 10

A subcommittee comprising Dr. Reed, Dr. Fisher, and Ms. Simons will be formed to further discuss modifications to recommendation 9 & 10. Public notice and agenda will be posted for this meeting.

Ms. Cunningham asked whether there has been reduction in the number of out of state placements in Nevada. Ms. Simons will ask Mr. Daniel Mathis with Nevada Healthcare for this information.

Training, Education, and Professional Development

Dr. Reed stated requirements for education for caregivers of people with Alzheimer's disease on how to address behavioral symptoms are important, but it is "appropriate" education that is essential to better support the quality of life and well-being of these individuals. It is necessary to shift the focus from the disease to the people. Symptoms are not the person.

Dr. Fisher brought up concerns about reliability of information on the internet. She mentioned how people often google the information about Alzheimer's disease and use it for training without verification. Under the paragraph on education challenges, Dr. Fisher suggested adding a cautionary statement about obtaining accurate information on the internet. She'll provide phrasing for this.

Additionally, the group decided that continuing education focused on Alzheimer's disease and dementia should be provided for "healthcare professionals" rather than just "primary care physicians."

Recommendations 11, 12, 13, and 14

These recommendations focus on education and training. Senator Joe Hardy has been working to put forward a Bill Draft Request (BDR) that addresses all four recommendations and will let us know the BDR number.

Ms. Cunningham wanted to know if we could provide information directly to the public in some manner to help with the efforts to promote better education and training on Alzheimer's disease and other dementias.

Discussion centered on whether there were better wording than "encourage" to make a stronger emphasis in these recommendations. It was mentioned that Senator Hardy had previously advised that we cannot mandate actions, and that is why "encourage" is used. Dr. Bernick and LeeAnn Mandarino submitted the idea of adding "incentivize" as well. The group considered

these options and agreed to modify several parts of these recommendations accordingly.

Recommendation 15

Dr. Fisher recommended changing “neurocognitive disorders” to “Alzheimer’s and other forms of dementia” to be consistent with the other references to the disease.

Discussion about the indicator included assigning the ADSD to monitor the number of consumers and hours of caregiver support services. Mr. Duncan stated he has data only for the ADSD supported programs that he controls the funding for. Senator Wiener asked Mr. Duncan to work on the wording of the indicator again to present the breakdown of data for different services the ADSD provides.

Recommendation 16

Ms. Cunningham expressed the desire to pursue active recruitment of volunteers. Senator Wiener commented that the TFAD can only “encourage” the recruitment of volunteers. Mr. Duncan also cautioned about liability issues with volunteer recruitment and training. Who will do the background checks? Who will administer proper training?

Senator Wiener suggested tabling Recommendation 16 for more extensive discussion in the next meeting.

- VI. Tour of Touro University Active Aging Center and Lunch
Lisa Rosenberg, MD, Touro University
Primary Care, Assistant Professor

Dr. Rosenberg conducted a tour of the Active Aging Center at Touro University for the TFAD and provided an overview of the Center’s activities and services available to seniors.

- VII. Discussion and Vote on Date for Next Meeting **(For Possible Action)**
Senator Valerie Wiener (Ret.), Chair

A meeting in Las Vegas on January 7, 2015 is proposed. The TFAD will continue discussing Recommendation 16-20, review final language for the State Plan for all recommendations, as well as talk about the January 2015 Annual Report.

- VIII. Public Comment (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.

- IX. Adjournment
Senator Wiener adjourned the meeting at 4:30 p.m.