



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: January 7, 2015
10:00 am

Location: The Keep Memory Alive Event Center
The Cleveland Clinic
Lou Ruvo Center for Brain Health Campus
888 W. Bonneville Avenue
Las Vegas, NV 89106
(702) 483-6000

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

Members present: Sen. Valerie Wiener (Ret.), Peter Reed, Ph.D., Wendy Simons, Gini Cunningham, Charles Bernick, M.D., Julie Kotchevar, Lee Ann Mandarino (Alternate member), Jeff Duncan (Alternate member).

Sen. Joe Hardy and Albert Chavez joined the meeting by telephone.

Staff: 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 to the meeting at the Cleveland Clinic Lou Ruvo Center for Brain Health, Las Vegas. She expressed appreciation for the

members' ongoing contributions to the Task Force on Alzheimer's Disease (TFAD).

- IV. Approval of the Minutes from November 19, 2014 Meeting (For Possible Action)
Senator Valerie Wiener (Ret.), Chair

Dr. Peter Reed motioned for the approval of the minutes from the November 19, 2014 meeting. Wendy Simons seconded. Minutes were approved unanimously.

- V. Review and Discuss Recommendations 16-20 in the State Plan on Alzheimer's Disease
Senator Valerie Wiener (Ret.), Chair

Discussion on Recommendations 16-20 include:

Recommendation 16: Volunteers

Jeff Duncan reported that ADSD is implementing a volunteer-based respite program, through a federal grant, which will be much more formal than other volunteers programs that existed previously. Background checks will be conducted and a faith-based model will be used. Training will be provided to an individual within a church who then can go out to train individuals in their congregations who are already working in respite care with families. The plan will strive to empower families to select individual caregivers of their choice to receive the additional training that will be available to them. This would likely prevent liability issues that could occur with less formal volunteer programs.

Julie Kotchevar added that, in building the capacity of community-based organizations, it's important to understand how to appropriately recruit and manage volunteers. Dr. Reed suggested the idea of encouraging organizations to partner with the Retired Senior Volunteer Program (RSVP), which can provide background checks, as well as liability insurance. The RSVP can act as a facilitator to help other organizations build their capacity. Wording for Recommendation 16 was modified.

Recommendation 17: Small Estates

Sen. Wiener remarked that there is no update as to whether the letter to the Legislature requesting close supervision of all guardians whose wards live with dementia, mentioned in this recommendation, has been sent or not. She asked Ms. Kotchevar to check with Marsheilah Lyons, Legislative staff to the interim Health Committee, whether this has been accomplished. Ms. Kotchevar commented that, to her knowledge, not all letters requested by the TFAD were sent. The previous Chair of the Health Committee was not reelected, so several bills might not have moved forward. Sen. Wiener remarked that the group may have an opportunity to pursue these again in future legislative sessions.

Dr. Reed noted that throughout the document, instead of saying “suffering with”, use “living with” dementia to avoid stigma and focus more on raising awareness and on the person.

Ms. Simons inquired if there was a Bill Draft Request (BDR) for this, and Sen. Wiener said, to her knowledge, there wasn't. It didn't come to fruition in the last session, but can be pursued in future sessions. Ms. Simons commented that many BDRs involve guardianship and asked if the TFAD's proposal could be tagged on to one of those. Ms. Kotchevar remarked that those pertain to regulating public guardians and the TFAD's proposal might not be relevant. Sen. Wiener reiterated that, though we know we will need legislative appropriation on this, we should continue to cultivate support and generate public awareness in the meantime.

Recommendation 18: Hospital Transitional Care Programs

The group discussed whether this recommendation would be the best place to incorporate the CARE Act, which pertains to in-hospital care as well as post-discharge care of patients with cognitive impairments. The TFAD decided to reference the CARE Act in Recommendation 8, where it would be most relevant.

Ms. Kotchevar asked if there was a best-practice model that would reference all of the particulars of an effective discharge plan with up-to-date information, which we can address in the recommendation, rather than listing every detail. Ms. Simons and Dr. Reed mentioned a few resources that may be useful, including the Hospital Association and the Hartford Institute for Geriatric Nursing. There may be a best-practice discharge plan already established in Nevada.

The indicator was changed to “Monitor the number of hospital transitional care programs employing best-practice discharge policies.” The TFAD can ask the Bureau of Health Care and Quality Compliance (BHCQC) to help with this, as they already visit the sites. Also the Division of Public and Behavioral Health (DPBH) was added to the potential funding source.

Recommendation 19: Collaborations and Partnerships on Education and Training for Caregivers

Dr. Reed suggested being more inclusive in the wording to present the idea that not just caregivers would receive education and training, but all those who may be ‘employees’ in the business community, i.e. pharmacists, government officials, etc., along with those serving as caregivers.

Lee Ann Mandarino raised current concerns regarding incidents when people with dementia are arrested and immediately put into psychiatric wards. She explained that there are cognitive assessments that could be given to prevent

this outcome. She inquired if there could be a best-practice procedure for such instances with public safety to determine appropriate actions. She suggested that there could be better training for first responders to improve methods to make the distinction between individuals with dementia or those with psychiatric illnesses.

The group discussed areas where this could be addressed in the TFAD State Plan and whether this concern could be addressed in Recommendation 19. Upon further review, it was decided that recommendation 14 is the most appropriate place since it pertains to training for first responders. Albert Chavez emphasized that the idea of making proper analysis could be embedded in this recommendation. He mentioned that the Alzheimer's Association is currently working on creating a quick hand-reference for first responders for use in assessing and deciphering the needs of individuals who may exhibit signs of dementia. Sen. Wiener commented that perhaps recommendation 14 could be expanded to include training on administering the assessments, but potential costs would have to be considered. The group concurred that the emphasis of the training could be on the initial screening at the entry point by trained personnel.

Recommendation 20: Public Awareness Campaigns

Sen. Wiener stated that promoting public awareness through "television and radio advertisements" would incur cost, so it would be best to take out those methods. Mr. Duncan mentioned that ADSD does have funding in the discretionary grants for Alzheimer's and respite care to do some advertising, but it is very limited. However, the agency is working with some television stations on free public service announcements (PSAs). Many stations are looking for things to promote. ADSD also has some funding in the current Alzheimer's Disease Supportive Services Program (ADSSP) Grant that can be used to create an Alzheimer's web page under the existing Aging and Disability Resource Center (ADRC) website.

The TFAD discussed many avenues of promoting public awareness. Many promising ideas were presented. The indicator for this recommendation was modified to include monitoring the instances of media attention through different sources. For potential funding, Sen. Wiener stated that ADSD could work with the State Grants Office and the Department of Health and Human Services (DHHS) Outreach Services to explore potential resources and additional funding streams. Another possibility to investigate is funding through gifts, grants, and donations.

After discussing recommendations 19 & 20, Dr. Reed suggested switching the order of these around to enhance the flow of the information presented. He felt the information leading up to these recommendations would blend better. The language would remain as discussed previously.

- VI. Tour of the Cleveland Clinic Lou Ruvo Center for Brain Health
(Arranged and conducted by Lee Ann Mandarin)
- VII. Review and Discuss final modifications to the State Plan on Alzheimer's Disease
(including Recommendations 1-15 again)

Introduction and Chapter 1

Sen. Wiener suggested building up the history of the TFAD and adding information to reflect the recent activities of the TFAD. The list of members would also need to be updated.

The group also discussed the term of appointment of the task force members. Upon review of the statutes, Ms. Kotchevar confirmed that there is a sunset date of June 30, 2017. Sen. Wiener remarked that in the 2017 Legislative Session, we would need to present a bill to extend the work of the TFAD. We have legislative successes and annual reports that would demonstrate the value of the TFAD.

Chapter 2

After discussion among the group members, it was decided that although "younger-onset" and "early-onset" are often used interchangeably, it would be more appropriate, for consistency, to use "younger-onset."

Social Stigma

Language for this section had been revised by Dr. Jane Fisher. Dr. Reed commented that he feels her intent was to move us away from the language of behavioral problems to the language of responsive behaviors, recognizing that these behaviors are not in and of themselves a result of the disease. The people who exhibit these behaviors have difficulty communicating because of the disease. They often have unmet needs that they're manifesting in their behavioral expressions.

Several members expressed confusion over the writing in this section and felt it was too academic, like a research paper, and would be hard to for a lay person to grasp. Sen. Wiener commented that stylistically it's not consistent with the population-friendly language of the rest of the document, and non-medical people might have difficulty understanding it. Dr. Reed offered to revise the wording for clarity, without losing the intent.

Dr. Charles Bernick recommended adding a new section heading to separate the ideas presented in this section. Dr. Reed suggested adding a new heading with a focus on behavior and communication, which would differentiate from social impact and stigma. He accepted the assignment to rework this entire section.

Chapter 3 Access to Services

Sen. Wiener recognized the work of the TFAD Subcommittee who met and reviewed this piece. She expressed appreciation for the work done.

Recommendation 1: Information Referral System

The TFAD discussed whether it would be appropriate to include Trial Match opportunities here. Ms. Mandarino had raised the idea previously. Dr. Reed explained that Trial Match is an actual program that was created by the Alzheimer's Association for researchers to submit the studies that they're offering and for people, who are interested in participating, to find ones in their area for which they are eligible. The question is whether or not it really meets the needs of this area. Ms. Mandarino expressed concern over the cost effectiveness of the Cleveland Clinic providing resources on clinical trials for the ADSD website. Ms. Kotchevar assured her that the ADSD website already has funding for its maintenance, and receiving additional information would not be a problem.

Dr. Bernick pointed out that perhaps Trial Match opportunities would fit better in recommendation 7, which focuses on research. Dr. Reed supported the idea, citing that recommendation 1 involves an information referral system, which may include research participation, but also includes all of the other community support and services and clinical services.

Ms. Simons asked what "Establish and fund" really means in this recommendation. Sen. Wiener remarked that it would be better to just say "Sustain" since the information referral system has already been established. This would demonstrate that the TFAD will continue to support it.

In the indicator, ADSD will be the agency monitoring the number of contacts made by the outreach program.

Recommendation 2: Advanced Practice Registered Nurses (APRNs)

In the indicator, ADSD will contact the State Board of Nursing annually to monitor the number of applicants who file to practice independently.

Telehealth

Sen. Wiener asked staff to find out what year the Nevada Hospital Association received the \$19.6 million grant from the National Telecommunications and Information Administration. She also wanted to know the status of the Nevada Broadband Telemedicine Initiative (NBTI). Has it been created? Sen. Wiener would like this information to be updated in the State Plan.

Dr. Reed added that we should also incorporate information on Project ECHO (Extension for Community Health Outcome) into this section, as well as into recommendation 3, to demonstrate support for various Telehealth initiatives, such as Project ECHO. Dr. Bernick commented that the Cleveland Clinic Lou Ruvo Center for Brain Health is also involved in Telehealth, so it would be good to mention several programs to be more inclusive in our statement. Ms. Kotchevar also mentioned that ADSD has also been partnering with Project ECHO, using secured HIPAA-compliant Skype services for in-home client services.

Recommendation 3: Telehealth and Telemedicine

Wording was expanded to include the TFAD working with several initiatives, such as Project ECHO Nevada, Renown Medical Center, and the Cleveland Clinic Lou Ruvo Center for Brain Health, to improve access to quality Telehealth Services.

Recommendation 4: Remove Age Barriers

The group decided to remove the language on CARE Act from this recommendation (better fit elsewhere).

In the indicator, the DHHS will monitor the progress of respite services for the “younger-onset” population living with Alzheimer’s or other forms of dementia.

Recommendation 5: Outreach to Cultural Communities

The recommendation was broadened to support efforts to develop toolkits to assist public and private organizations in their outreach to different cultural communities. The focus would be more action-oriented than just conducting a needs assessments. However, the results from the needs assessments could be used to create the appropriate tool kits.

In the indicator, ADSD will only be able to monitor the ADSD grant-funded partners and their efforts to accommodate different cultural needs. Dr. Reed asked if there could be specifications in any Alzheimer’s-related grants to make them more culturally competent. Mr. Duncan and Ms. Kotchevar both remarked that it would be entirely appropriate to require that specification within the ADSD-funded programs. Dr. Reed then proposed if this could be extended to other programs outside ADSD. Ms. Kotchevar said she will ask Richard Whitley, the DHHS Director, if these efforts can be incorporated into other DHHS programs as well.

Recommendation 6: Affordability of Services

Ms. Simons commented that we would like to know why providers are not accommodating people living with Alzheimer’s disease or other forms of

dementia at the current Medicaid rate. Ms. Kotchevar stated that a lot of national and state data already exist and can be used to assess affordability. All the rates are published for long-term services and support. The concern may be to use the information to make recommendations if the group feels that the reimbursement rates are too low. Sen. Wiener then summarized that what we can do is support more equitable reimbursement rates for providers of care for this population.

Recommendation 16 was modified to include assessing affordability of services by using national data and exploring other cost-sharing mechanisms. In the indicator, ADSD will track and analyze national data and make a recommendation of equitable reimbursement rates based on that analysis.

Chapter 4: Quality of Care

Ms. Kotchevar pointed out that there is a distinction between quality of care and quality of life. People who are going through degenerative conditions, like Alzheimer's disease and other forms of dementia, can have high quality of care, and yet their quality of life is not so great. Quality of life during treatment is very important.

The committee members discussed the definition of quality of care and quality of life at length. The information in the State Plan was provided by Dr. Fisher who referenced data from a workgroup comprising the American Academy of Neurology, the American Geriatric Society, the American Medical Association, and the American Medical Directors Association. Suggestions were made to modify wording in this section to provide more clarity and focus on desired outcomes in dementia care.

Research

Sen. Wiener said to specify the date the National Plan to Address Alzheimer's Disease was produced by the U.S. Department of Health and Human Services. Ms. Kotchevar indicated that it was done in 2011.

Mr. Duncan had provided updated information on research funding in the State Plan. Sen. Wiener asked for a timeline regarding particular programs mentioned in this piece. Ms. Simons posed questions on who exactly received funding and what exactly Single Entry Point (SEP) access means. Mr. Duncan commented that he can expand on that and provide additional clarification.

Dr. Bernick also recommended updating the statement involving the Cleveland Clinic Lou Ruvo Center for Brain Health's efforts in national studies of brain imaging to include mention of other methods for early detection of Alzheimer's disease, not just a blood test.

Recommendation 7: Establishing a Nevada Consortium to Promote Current and Future Research

Ms. Mandarino expressed the need to ensure that the information on current research projects is being kept up to date and available to the public. Dr. Bernick commented that most people will look at a variety of resources for information, i.e., the Trial Match Site and the ADRC website. Ms. Mandarino wanted to know who was going to monitor the website and whether the information can be linked to various research centers' sites. Mr. Duncan informed the group that ADSD's plan is to create an Alzheimer's-specific page within the ADRC website, and on that page there could be links provided to the research centers. ADSD can then monitor the 'hits' to those links from the ADRC page, which would allow us to receive valuable information regarding the public's interest. This could represent the indicator for this recommendation.

Dr. Bernick offered that the Cleveland Clinic Lou Ruvo Center for Brain Health can spearhead establishing a Nevada consortium to promote current and future research. The TFAD enthusiastically accepted this offer. Language for recommendation 7 was changed to reflect this. Dr. Reed remarked that the consortium, which would include the Alzheimer's Association, could help create a page within the ADRC website, which could include a link back to trial data base and Trial Match.

Recommendation 8: Specialized Care Pathways

Information on the Caregiver Advise, Record, Enable Act (CARE Act) will be added to the paragraph leading into recommendation 8. Dr. Reed stated that the relevance of the CARE Act here is that once someone is diagnosed and a support plan is developed, it needs to be communicated to the caregiver.

In the indicator, discussion involved who exactly will be monitoring how many hospitals establish a best-practices care plan. It was proposed that the TFAD can ask the Bureau of Health Care and Quality Compliance (BHCQC), the Nevada Hospital Association (NHA) or the Nevada Rural Hospitals Partners (NRHP) to do this.

Long-Term Care

Ms. Simons confirmed that the State Ombudsman will advocate for persons who reside in long-term care settings, without any age requirements. It should also be noted that the updated data on the number of available beds for Alzheimer's patients was provided by the BHCQC in December 2014.

Recommendation 9: Quality Long-Term Care

Dr. Reed commented that wording for this recommendation had been reworked in the Subcommittee Meeting and submitted the modified language to the group.

Promoting Behavioral Health

Title for this section was shortened. Ms. Simons also confirmed that the data received from the Nevada Healthcare Association on the number of skilled nursing facilities with special Alzheimer's units in Nevada is current and was received in December 2014. There are now only three such facilities in Nevada and all are located in southern Nevada.

Recommendation 10: Reducing Out-of-State Placement

Dr. Reed provided additional edits for recommendation 10. He also mentioned that the Subcommittee had reworked this recommendation and made some substantive changes. The TFAD reviewed the entire recommendation again, along with the indicator, and potential funding. Dr. Reed explained that the Civil Monetary Penalties Grant comes from nursing home fines when they get deficiencies. The State can provide a grant out of that fund for quality improvement efforts.

Recommendation 11: Awareness and Education for Health Care Providers

No modifications were made.

Recommendation 12: Continuing Education Opportunities for Nurses and Other Health Care Professionals

No modifications were made.

Recommendation 13: Training for Hospital Personnel

Ms. Mandarino had brought up concerns about people being mis-diagnosed when they are arrested. (See notes from discussion in Recommendation 19). She felt that it is important to educate both first responders and medical personnel to distinguish between dementia and other psychiatric illnesses. Dr. Bernick felt that this would require a higher level of training, which might not be practical. Dr. Reed suggested adding a few words to increase awareness and understanding of Alzheimer's disease and other forms of dementia may be sufficient to call attention to this matter.

Recommendation 14: Training Hours for First Responders

Dr. Bernick felt that we should leave wording for this recommendation as is.

In the indicators, the wording was changed from “Monitor” to “Work with the Division of Public and Behavioral Health Office of Health Preparedness to monitor...” Sen. Wiener will speak with Richard Whitley about this.

Recommendation 15: Respite Services

Concern was expressed over the complex clinical language in this recommendation. Dr. Reed suggested modified language and worked with the group to come up with new wording and eliminated unnecessary information.

- VIII. Determine Items and Updates to Include in the Annual Report Due January 2015 **(For Possible Action)**
Senator Valerie Wiener (Ret.), Chair

Sen. Wiener stated that it is a statutory requirement for the TFAD to submit an annual report to the Governor and the Legislature. She asked for permission from the TFAD members to work with staff to update the information from last year’s report and provide an overview of what has been accomplished in 2014. Ms. Simons moved to approve this action, and Dr. Reed seconded the motion. The vote was unanimous.

- IX. Discuss Potentials Activities for 2015 Legislative Session, Including Testifying, Bill Draft Requests (BDR) and Alzheimer’s Day **(For Possible Action)**
Senator Valerie Wiener (Ret.), Chair

Sen. Wiener commented that the Alzheimer’s Day at the Legislature will be March 16, 2015, and we may want to have at least one of the bills that we’re tracking heard on that day when advocates will be present. Albert Chavez, who joined the meeting by telephone, confirmed the date and outlined the plan for the Alzheimer’s Advocacy Day at the Legislature as follows:

- Early morning meet and greet for lawmakers and advocates starting at about 7:00 a.m.
- Education, presentations, and training for advocates and ambassadors from throughout the state of Nevada in the morning
- Pairing up in teams and meeting with their respective state legislators in the afternoon to discuss issues we see in the state and ask for support of the dementia-related legislation

This will be a great opportunity for the TFAD members to participate in person, if able. Mr. Chavez asked that the TFAD informs him what we would like to support, and that message can be conveyed to the advocates and ambassadors on that day so they can make an impact when meeting face to face with their State lawmakers.

Sen. Hardy reported that he will be chairing the Senate Health and Human Services Committee. He hoped that his bill, which addresses Recommendations 11-14 in the State Plan, could move quickly to the Assembly and back to the Senate, and to the Governor. Sen. Wiener noted that since the Alzheimer's Day will be occurring late, six weeks into the session, it would be best to allow the bill to move along as quickly as possible and perhaps celebrate the bill on Alzheimer's Day. Sen. Hardy mentioned that Assemblyman James Oscarson will be the Assembly Health and Human Services Chair, and felt that he would be supportive of the TFAD's efforts. Dr. Reed inquired about the status of the BDR at present. Sen. Hardy indicated that it is now designated as Bill Draft Request (BDR) 237, but the number will change once it becomes a Senate Bill (SB).

Sen. Wiener stated that there is also another bill supporting the CARE Act, which has been referenced in the TFAD State Plan. Her understanding is that the AARP is advocating for legislation that includes the CARE Act in the Nevada Legislature and nationally. She proposed that perhaps this bill could be presented at the same time as the other previously mentioned, since the TFAD desires to support both. The AARP Care Act bill is BDR 512, which has been assigned to the Senate. Sen. Wiener asked that Sen. Hardy keep an eye on both bills' progress.

Sen. Wiener further remarked that whether or not there will be a bill that pertains to Alzheimer's heard on Monday, March 16 (Alzheimer's Day), it would be nice to have an agenda item, such as a presentation, as to what the TFAD is doing and again present the Legislature with a copy of the State Plan, highlighting our priorities. She feels confident that the Senate Committee on Health and Human Services, chaired by TFAD member Sen. Hardy, will be accommodating. We can deliver a presentation, even though we won't be testifying on a specific bill. Sen. Wiener would also like to know when the Assembly Committee on Health and Human Services will meet and, if possible, if we can get on the agenda there too.

Ms. Simons asked if all legislators will receive a copy of the TFAD State Plan and Ms. Kotchevar confirmed as such. Sen. Wiener commented that most legislators will only have the opportunity to peruse the document. Dr. Reed then suggested the possibility of putting together a synopsis, a one-page consolidation of the Executive Summary of the TFAD State Plan, which could be given as a takeaway for the lawmakers and any other attendees. Mr. Chavez agreed that it would be a good idea and offered the services of his director of development to put it together with input from the TFAD. Sen. Wiener stated that it could be a statement with 20 bullet points, along with titles for each recommendation, and this could be a project that can be undertaken by ADSD staff.

Mr. Chavez confirmed that the Alzheimer's Day has been put on the legislative calendar in both houses. Room 3100 has been reserved at the Legislative

Building. Sen. Wiener recommended that Mr. Chavez make sure to indicate the Legislative Building and not the Capitol to avoid confusion.

- X. Establish Work Groups to Plan and Carry Out Recommendations in State Plan **(For Possible Action)**
Senator Valerie Wiener (Ret.), Chair

Ms. Kotchevar suggested that, rather than 'establishing' work groups, the TFAD could have a discussion on how to implement and monitor the recommendations in the State Plan. Sen. Wiener expressed that this agenda item could be modified and presented at the next Quarterly Meeting, which will likely be scheduled for April, not the teleconference in February.

- XI. Consider Agenda Items for Next Meeting **(For Possible Action)**
Senator Valerie Wiener (Ret.), Chair

Agenda items would include:

- 1) Preparing for Alzheimer's Advocacy Day at the Legislature. Dr. Reed suggested inviting Mr. Albert Chavez and Mr. Jacob Harmon of the Northern and Southern Alzheimer's Association to give us an outline of what the plans will be for the day's activities.
- 2) Hearing legislative update on Dr. Hardy's BDR and the CARE Act, and other legislative items relevant to the TFAD.
- 3) Discussing other matters (for possible action).

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

Ms. Kotchevar proposed a teleconference meeting to discuss the details of the upcoming Alzheimer's Day at the Legislature on March 16, 2015. The group agreed to hold a teleconference meeting on February 25, 2015 at 10:00 a.m. The TFAD will determine the next Quarterly Meeting Date at that time.

- XIII. 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.

- XIV. Adjournment

The meeting was adjourned at 3:34 p.m.