



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: June 1, 2016  
10:00 a.m.

Carson City: Legislative Counsel Bureau  
401 S Carson Street  
Room 2134  
Carson City, NV 89701

Las Vegas: Grant Sawyer Building  
555 E. Washington Avenue  
Room 4412  
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: Senator Valerie Wiener (Ret.), Senator Joe Hardy, Dr. Peter Reed

Members participating by telephone: Gini Cunningham, Dr. Jane Fisher, and Assemblyman James Oscarson

Members absent: Julie Kotchevar, Wendy Simons, and Albert Chavez

Alternates present: Jeffrey Duncan, LeeAnn Mandarino, and Jacob Harmon

Staff present: Jill Berntson

- 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.)

Gregory Martin, former legislative attaché for the 10<sup>th</sup> Assembly District of Nevada and current interim legislative attaché for the 6<sup>th</sup> Assembly District of Nevada, provided comments.

Mr. Martin shared personal experiences relating to losing his father and a friend to Alzheimer's disease. He urged TFAD to examine healthcare and insurance issues and emphasized the need to develop treatment for those living with Alzheimer's and other forms of dementia. He also described a community group that is working with the Nevada Department of Corrections (NDOC) to provide five years of free education to all of the NDOC locations. He suggested that this could free up money to go into healthcare.

Dr. John Yacenda, President of the Nevada Silver-Haired Legislative Forum, provided comments. He emphasized the importance of maintaining dignity for those living with Alzheimer's disease and other forms of dementia and urged TFAD to include this in the State Plan. This involves: dignity in care, dignity in services and language directed toward the care and treatment and support, social support, medical support and family support of persons with Alzheimer's disease and other forms of dementia.

Peggy Cunningham, Chief Operations Officer, Red Rock Hospital and Montevista Hospital, Las Vegas, Nevada, provided comments. Ms. Cunningham expressed appreciation for TFAD's work and shared information about services available at their facilities. She explained that two doctors currently serve their patients, and they are adding two more physicians to their staff to help assist in treating seniors.

Ms. Cunningham described the significance of her organization's commitment, as demonstrated by their plans to increase their capacity from 21 beds to 40 beds. They will also be moving from their current location on Twain to Montevista Hospital, the main campus, which will allow all patients and clients to be housed on one campus.

Ms. Cunningham affirmed their commitment to providing excellent service to both the people who suffer from Alzheimer's disease and their families.

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

Sen. Wiener explained that the goal for the meeting is to acquire and update as much language as possible for the State Plan to Address Alzheimer's Disease, which will be submitted to the Governor, the Legislature, and other vested parties in January 2017.

Sen. Wiener expressed appreciation for the work that has been done up to this point and for the commitment of TFAD members to be open to the possibility of new recommendations to address, as well as modifying or moving existing recommendations to the Appendix of the State Plan.

IV. Approval of the Minutes from April 1, 2016 Meeting (For Possible Action)  
Senator Valerie Wiener (Ret.), Chair

Peter Reed, Ph.D., moved to approve the minutes from April 1, 2016. Jane Fisher, Ph. D., seconded the motion. Minutes were approved unanimously.

V. Vote on Appointment of Officers for the July 1, 2016-July 1, 2017 Term  
(For Possible Action)

Julie Kotchevar  
Deputy Administrator  
Aging and Disability Services Division (ADSD)

Jill Berntson, Deputy Administrator, ADSD, conducted this item of business due to the absence of Julie Kotchevar, who was ill.

Ms. Berntson stated that the Nevada Revised Statutes (NRS) require that the appointment of the Chair and Vice Chair be renewed annually. Sen. Wiener and Dr. Reed have been serving as Chair and Vice Chair respectively, and their term of service will conclude on June 30, 2016, thus necessitating the voting process.

Ms. Berntson called for a motion for the continuance of existing officers or for nomination of new leadership for the July 1, 2016-June 30, 2017, term.

Sen. Joe Hardy moved to continue with current officers. Dr. Fisher seconded the motion. The motion carried unanimously.

VI. Review and Discussion on the State Plan, Including Possible New Recommendations (For Possible Action)  
Senator Valerie Wiener (Ret.), Chair

Sen. Wiener proposed that TFAD has enough history to consider creating an appendix for some of the recommendations for which action steps have already been taken and/or the issues are being addressed or resolved. The recommendations that are moved to the appendix would or should be monitored

at least annually. Also TFAD could determine to move any recommendations back into a future State Plan as needed.

Sen. Wiener asked for discussion on the new appendix, as well as a thorough examination of the State Plan. A summary of the discussion on the State Plan follows.

### **Recommendation 1: Statewide Information System—Albert Chavez**

Jacob Harmon, alternate for Mr. Chavez, provided input.

Mr. Harmon stated that Mr. Chavez indicated that he'd met with LeeAnn Mandarino, Cleveland Clinic Lou Ruvo Center for Brain Health, and Cheyenne Pasquale, ADRC Project Manager, ADSD, about the ADRC website and suggested TFAD continue to build upon this website.

Mr. Harmon suggested that the current recommendation is adequate. He observed that the work is ongoing both on the website and with the promotion of the statewide information referral systems, which exist through the Alzheimer's Association, and the Aging and Disability Resource Centers (ADRC).

Jeff Duncan, Social Services Chief, ADSD, recommended considering adding wording to reference the virtual piece, including information on additional website resources to differentiate the physical sites from the virtual sites. He also shared information on the Nevada 2-1-1 website, which could serve as a partner in information sharing.

Mr. Harmon noted that, in addition to the ADRC website, both north and south Alzheimer's Associations keep and maintain a comprehensive dementia-specific resource list, which is available through their website and the 24/7 helpline. The Alzheimer's Association gets federal funding to maintain a 1-800 number or 24/7 helpline. The helpline also addresses cultural competency by providing assistance in 120 languages. Mr. Harmon affirmed that the Alzheimer's Association is willing to contribute these resources to the statewide information referral system.

Dr. Reed emphasized that these resources, particularly the ADRC website, should include language that promotes and doesn't hinder dignity for individuals living with Alzheimer's disease and other forms of dementia.

Sen. Wiener asked for support of Recommendation 1, incorporating the suggestions as discussed. All voted in the affirmative.

LeeAnn Mandarino, alternate for Dr. Bernick, recognized the importance of weaving the dignity of Alzheimer's patients throughout the State Plan's

recommendations. She suggested including a preamble or mission statement that could set the tone and the intent of the entire State Plan.

TFAD members concurred with this idea, and Sen. Wiener agreed to propose language for an introductory statement at the next TFAD meeting.

### **Recommendation 2: APRNs—Sen. Valerie Wiener (Ret.)**

Sen. Wiener recommended, with the actions that have been taken legislatively and work that has been done since then, that this recommendation be moved to the appendix, and continues to be monitored at least once a year.

Sen. Hardy remarked that part of the intent of this recommendation is to encourage more APRNs in the frontier areas, so it is crucial in the monitoring process to continue to identify the breakdown in APRNs in rural vs. frontier areas.

Sen. Wiener commented that she had included monitoring, at least annually, the number of licenses that are issued by the Nevada State Nursing Board, and these numbers should be provided to reflect urban, rural, frontier, and out-of-state licenses.

Sen. Wiener entertained a motion to move Recommendation 2 to the appendix with those conditions of areas to be monitored at least once a year.

Sen. Hardy moved to approve this action. Assemblyman Oscarson seconded the motion. The motion was approved unanimously.

### **Recommendation 3: Telehealth—Albert Chavez**

Jacob Harmon, alternate for Mr. Chavez, provided input.

Mr. Harmon explained that Assembly Bill 292 (AB 292), passed in the 2015 Legislative Session, provided a legislative framework for expansion of telehealth services throughout Nevada. Since then, a statewide telehealth consortium has been formed, facilitated by Nicole Anderson of the Alzheimer's Association. Two meetings have been held. At present, the group is gathering information about the number of telehealth services that are being delivered as a result of the passage of AB 292, while recognizing the operation of pre-existing programs.

Mr. Harmon described that progress has been made in identifying partners in both the nonprofit sector and the private for-profit business sector. However, information about services being provided is still limited. Outreach efforts to rural and remote areas, including Ely and Elko, have been undertaken. There are significant challenges, including questions about telehealth services and how

they're billed to insurance providers, including Medicare, as well as trepidation with physicians around those billing practices.

Assemblyman Oscarson observed that improvement in access to quality telehealth services has opened up a whole new world, especially for the rural frontier folks, and he questioned whether concerns about billing are systemic problems or provider problems. Mr. Harmon cited that the real issues are unclear.

Mr. Harmon added that questions about licensure are complicating this recommendation and progress with telehealth. Although great strides have been made in creating the infrastructure for telehealth, efforts need to be implemented to identify and facilitate the participation of providers in these programs and ensuring that people in rural remote areas know about and are accessing these services regularly.

Sen. Wiener suggested that perhaps TFAD needs to be more expansive with how this recommendation looks by addressing some of the challenges and opportunities that are available through the telehealth experience.

Dr. Reed discussed possible approaches, including building upon the legislative success of AB 292 to develop strategies for increasing and improving the integration of the system to promote access and availability.

Dr. Reed pointed out that one programmatic element involves provider and public education around the availability and the mechanisms by which you can access telemedicine services and get reimbursed for it. He explained that the other programmatic element relates to better integration across the providers that are currently doing it. The consortium has a great opportunity to address this by bringing together all of the groups that are currently providing either telemedicine or telehealth and finding ways to promote collaboration, which is critical for building that infrastructure.

Ms. Mandarino testified that the Cleveland Clinic provides telehealth services to rural areas in northern Nevada, but one of the biggest challenges is the service platforms or service support in remote areas. She shared a situation involving Battle Mountain, where service was discontinued because the volunteer who provided local support quit. She emphasized that there is a need for an organization that allows providers to reach patients in those areas.

Assemblyman Oscarson remarked that the goal and objective of TFAD should be to encourage collaboration and education. He said, for example, that a place in Tonopah is going to become a complete telehealth clinic, and perhaps the Cleveland Clinic can engage with them so people won't have to travel so far, either to Las Vegas or Reno, for services.

Discussion ensued about retiring the existing Recommendation 3 to the appendix and continuing to monitor it to determine if the appendicized recommendation is progressing. In its place, TFAD could create a new Recommendation 3 that would address the concerns that have been shared regarding education and the telehealth experience. This would include what happens prior to getting people to the telehealth experience, as well as what happens following.

Sen. Hardy moved to approve this action. Dr. Reed seconded the motion. The motion was approved unanimously.

Discussion ensued about new language for the new Recommendation 3. Some components may include working with the telehealth consortium that's been established (collaboration piece), supporting the expansion of telehealth opportunities, and educating physicians or providers about telehealth.

Dr. Reed recapped that the new recommendation will focus on building upon the prior legislative success by supporting the telehealth consortium and its programmatic efforts to promote collaboration, access, and availability of services for an integrated network to support older persons in the state.

Sen. Wiener added that the indicators would include reporting from those who provide telehealth services, which may include utilizing a questionnaire/survey of the telehealth experience and its effectiveness.

Sen. Hardy moved to approve the formation of the new Recommendation 3, as discussed. Dr. Reed seconded the motion. The motion was approved unanimously.

#### **Recommendation 4: Remove Age Barriers—Sen. Valerie Wiener (Ret.)**

Sen. Wiener reviewed the intent of this recommendation and suggested moving it to the appendix and monitoring it at least annually: the cases and clients, those 50-plus receiving respite and other needed services, and new services that might be added for these populations. Also monitor to ensure that no age discrimination occurs, such as denial of services to people in the younger-onset age category. This would also include appropriate services to their families.

Mr. Harmon raised a concern regarding people under 60 not being able to receive assistance from Elder Protective Services (EPS), which is a service that is vital to the care of people living with Alzheimer's disease and other forms of dementia in Nevada. He questioned if EPS is covered under Senate Bill 86 (SB 86) from 2013, and, if not, if there is any way EPS could be included. He also asked if there would be budget implications.

Ms. Berntson confirmed that SB 86 does not include EPS. EPS is in NRS 200.5092, which identifies that people who are age 60 and older are served

through Aging and Disability Services Division. If TFAD wanted to make some recommendations to serve people under 60, it would come with a fiscal note.

Ms. Berntson explained that through Aging and Disability Services people under 60 could be served by their advocate for elders. Advocates are not authorized by law to conduct an Elder Protective Service investigation but they could certainly provide services, make referrals, and offer recommendations. However, it's not the same service as protective services. Under the current law, people under 60 are served by law enforcement. So if we wanted to provide the same protection for people under 60 that is provided to people over 60, we'd have to change the law and have the fiscal means to do that.

Ms. Berntson further added that many states do provide protective services to people of all ages. Nevada is one of only about eight or nine states that does not provide these services through a social service program. People under 60 in Nevada are served by law enforcement, which only engages to determine if a crime's been committed. This results in a gap.

Discussion ensued regarding the gap in services for the younger-onset individuals and the possibility of addressing these needs legislatively. Sen. Hardy addressed the budgeting process, as well as the legislative process, and the timeline necessary to meet the requirements.

Sen. Wiener proposed that the language of the recommendation be modified to reflect that TFAD would support legislation, including provisions to address the concerns that care should be extended to adults under 60 and over 18 who are living with Alzheimer's and other forms of dementia.

Extensive conversation took place regarding making changes to the language of the recommendation to include descriptors that would appropriately reflect specific scope of services that are needed for this "gap" population.

Much consideration was given to determine which particular services would best meet the needs of people with younger-onset Alzheimer's disease and other forms of dementia, which is estimated to be 4 to 5 percent of 41,000 individuals, or about 2,000 people in Nevada. Mr. Harmon described that the Sanford Center and the Alzheimer's Association partnered together to implement the Behavior Risk Factor Surveillance Survey, the Centers for Disease Control (CDC) survey, in Nevada, specifically around cognitive impairment and caregiving. The raw data will be more specific than the prevalence data and should be available for the 2017 Legislative Session.

Sen. Hardy urged starting with a focus on a few large items and then, in future legislative sessions, substantiating the need for other services with outcomes from what will have been accomplished.



Sen. Wiener entertained a motion for Recommendation 4 to extend EPS access for individuals under the age of 60 living with Alzheimer's disease and other forms of dementia, as well as adding language to support legislation, including provisions defined in SB 86, going forward.

Mr. Duncan moved to approve the action as discussed. Sen. Hardy seconded the motion. The motion was approved unanimously.

### **Recommendation 5: Outreach to Cultural Communities—Dr. Jane Fisher**

Dr. Fisher stated that Recommendation 5 has to do with cultural competency. The language reads "Support efforts to develop tool kits to assist public and private organizations in their outreach to different cultural communities."

Dr. Fisher reported that a review of published tool kits on cultural competency has been conducted. The study looked at tool kits, which were designed for professionals and paraprofessionals. These tool kits help to orient them to considerations when working with diverse consumers, including people with dementia and other disorders. Many of the tool kits are not disease or disorder specific.

Dr. Fisher provided a summary of the findings, including:

- Most of the tool kits that are published actually have not been evaluated so they're not empirically supported, which is an issue.
- Often, the issue of acculturation isn't addressed in these tool kits. To assume the demographic or ethnic or racial label attached to one individual within that family applies to the others is probably a mistake. Often, when working with individuals with dementia, several generations of the family may be involved in providing care.
- Sometimes there is a stigma in marketing supportive services using language that pathologizes the person with dementia or assumes that the family is experiencing only negative outcomes.

Dr. Fisher stated that, at this point, the goal is to have a tool kit prepared by November 1, 2016. Information is being gathered on what a tool kit should include and what features would be important to incorporate, specific to the support of persons with dementia and their families. She also emphasized that the focus will be on the marketing and language that's used to educate and support families, as well as providers, and avoid stigma-promoting language.

Sen. Wiener proposed retaining Recommendation 5 and adding language about supporting efforts not only to develop but also to "distribute" the tool kits.

Dr. Fisher moved to approve the motion. Sen. Hardy seconded the motion. The motion was approved unanimously.

## **Recommendation 6: Affordability of Services—Wendy Simons**

Wendy Simons was absent.

Dr. Reed noted that Ms. Simons had provided updates to staff at the April 1, 2016, meeting. It appears that this recommendation is ongoing. Dr. Reed suggested that in Ms. Simon's absence, the discussion be tabled and the recommendation be tentatively retained at this time.

Sen. Wiener entertained a motion to retain Recommendation 6, pending possible language modifications.

Dr. Reed moved to approve this motion. Sen. Hardy seconded the motion. Motion passed unanimously.

Sen. Wiener remarked that as a follow-up from June 1, 2016, meeting, Ms. Simons will be presenting a possible new recommendation specific to veterans.

## **Recommendation 7: Establishing a Nevada Consortium to Promote Current and Future Research—Dr. Charles Bernick**

Ms. Mandarino reported on the status of what is now called the Nevada Consortium on Dementia Research. Three meetings have been held to date, with the next one scheduled for June 17, 2016. They are also working with Cheyenne Pasquale to create a web page for the consortium.

Discussion ensued on the possibility of how the consortium might be able to apply for grants and other funding, which is one of its primary concerns. Sen. Wiener commented that information on this had been presented by Julie Kotchevar previously. TFAD cannot be a funding entity.

Ms. Mandarino suggested moving this recommendation to the appendix because it is underway, active, and progressing forward. Sen. Hardy concurred and advised that perhaps the consortium could partner with some other nonprofit organization that has legal status to accept gifts, grants, and donations, as well as look for other venues for funding.

Dr. Reed added that the consortium is still in the process of getting established organizationally. In the meantime, if there is opportunity for funding, Dr. Reed proposed that ADSD could provide support by housing the funds in an account designated for specific purposes of the consortium.

Sen. Wiener concluded that TFAD can support the work of the consortium, through letters or other means, but it is not the role of TFAD to actively pursue funding.

Sen. Wiener entertained a motion to move Recommendation 7 to the appendix, with the idea to monitor it at least once a year.

Sen. Hardy moved to approve this action. Dr. Reed seconded the motion. The motion was approved unanimously.

### **Recommendation 8: Specialized Care Pathways—Dr. Charles Bernick**

Ms. Mandarino reported on the progress of this recommendation, the adoption of specialized care pathways, which is another responsibility of the Cleveland Clinic Center for Brain Health. She stated that the first teleconference was held on March 25, 2016. With the help of the Nevada Hospital Association, 10 hospitals were recruited for involvement. Since then, questionnaires soliciting opinions on best practices have been distributed to various stake holders, including hospital personnel, administrators, ER doctors and nurses, and chief nursing officers. Once the responses are received, a face-to-face meeting will be convened.

Ms. Mandarino explained that the recommendations from various parties will be compiled and presented to TFAD for action or for publication on creating best practices for the State of Nevada. She remarked that from the current research, there are few best practices in the United States, although there are many in other countries, like Australia and Great Britain. Therefore, Nevada could become a leader in this regard.

Discussion ensued about language modifications, in particular relating to the Care Act which has already been passed, as well as incorporating appropriate language to support the present work of the Nevada Legislative Subcommittee to Conduct a Study of Postacute Care, chaired by Assemblywoman Robin Titus.

Further conversations followed regarding the differentiation between Recommendation 8 and Recommendation 18. Dr. Reed summarized that 18 is complementary to 8 in certain ways because it falls across the continuity of care, but it's a legislative recommendation that is actively being pursued by the Postacute Care Subcommittee. Recommendation 8, on the other hand, is not legislative. Rather, it is a programmatic effort of a group of collaborators to develop a best practice for these care pathways and then encourage their adoption and use. So, Recommendation 18 is legislative; recommendation 8 is programmatic. They can mutually support each other but they are distinct.

Dialogue was exchanged between Sen. Wiener and Sen. Hardy regarding what to do with the numbering of recommendations once some are moved to the appendix. Sen. Hardy suggested retaining the numbers as they are and keeping their place even after they are moved.

Gini Cunningham reminded the group of developments in Humboldt County where rural communities follow a patient to a suburban hospital, and, upon return

to Winnemucca, the patient receives follow-up care through the local hospital. This demonstrates other possibilities of steps that can be taken, especially in the rural areas, beyond just the Care Act. In particular, the involvement of Emergency Medical Services (EMS) for follow-up care can be a valuable service.

Discussion ensued regarding changes to the language of Recommendation 8 to include collaboration with first responders.

Sen. Wiener entertained a motion to retain Recommendation 8 with changes as discussed. Ms. Mandarino moved to approve the motion. Mr. Duncan seconded the motion. The motion was approved unanimously.

### **Recommendation 9: Quality Long-Term Care—Wendy Simons**

Dr. Reed reported that in the prior year, Ms. Simons chaired a subcommittee that included Dr. Jane Fisher and him. They did significant work on revising Recommendation 9 at that time, and it's an issue that's going to continue for the foreseeable future in terms of developing systems to enhance the quality of care being delivered in long-term care supports and services.

Dr. Reed moved to retain this recommendation, with the opportunity for Ms. Simons to provide some additional revisions moving forward. Sen. Hardy seconded the motion. The motion was approved unanimously.

### **Recommendation 10: Reducing Out-of-State Placement—Dr. Jane Fisher**

Dr. Fisher provided an update on the progress of this recommendation and proposed that it be moved to the appendix.

Dr. Fisher indicated that she received data from Sandra Kitchener, Long-Term Services and Supports (LTSS), providing a detailed overview of the findings of the Behaviorally Complex Care Program (BCCP). Highlights from the findings included:

- In 2015, seven individuals were averted from being approved for out-of-state placement. As of May 2016, 12 individuals in Nevada have been diverted from out-of-state placement.
- 21 out of 25 nursing facilities participating in the BCCP have received training.
- Center for Medicare and Medicaid (CMS) data on anti-psychotic use is showing that Nevada has demonstrated a 13 percent decline in the use of psychotic drug from 2011-2015.

Dr. Fisher stated that the data generally indicates significant progress towards reducing out-of-state placements.

Dr. Fisher moved to transfer Recommendation 10 to the appendix, with the provision for annual monitoring. Sen. Hardy seconded the motion. The motion was approved unanimously.

Post-vote discussion ensued with a statement by Dr. Reed. He remarked that simply giving people funds to encourage them to retain people living with Alzheimer's disease is not sufficient. They really need the training and the education. There's been some progress on education, but much, much more needs to happen.

Dr. Reed reported that another initiative has recently been launched. It's the Nevada Alliance for Transforming the Culture of Aging, or NATCOA, and it will be a multi-year state-wide multi-organization collaborative process, between the Perry Foundation and the Sanford Center for Aging, to define aspirations for what the culture of care should look like and then to mobilize all of the organizations in pursuing that collectively. This can have a tremendous impact on the quality of care and delivery of more innovative and effective education.

Dr. Reed indicated that he will discuss with Ms. Simons, who is participating in this process, to talk about whether or not to reinforce the educational elements of Recommendation 9, since that's the one that will be retained, or whether to develop a separate, newer recommendation to focus on the education and collaborative transformation efforts of the new NATCOA.

**Recommendation 11: Awareness and Education for Health Care Providers; Recommendation 12: Continuing Education Opportunities for Nurses and Other Health Care Professionals; Recommendation 13: Training for Hospital Personnel; Recommendation 14: Training Hours for First Responders—Sen. Hardy**

Sen. Hardy stated that he would like to discuss these recommendations as a group and proposed that they be moved to the appendix as actions have already been taken and they're actively in process.

Sen. Wiener remarked that Recommendations 11, 12, 13, and 14 were all included in Senate Concurrent Resolution 2 (SCR2) which passed in the 2015 Legislative Session. She entertained a motion to move this set of recommendations to the appendix with the minimum annual monitoring to determine if they should move back into the State Plan or stay in the appendix.

Sen. Hardy moved to approve this motion. Mr. Duncan seconded the motion. The motion was approved unanimously.

### **Recommendation 15: Respite Services—Dr. Jane Fisher**

Dr. Fisher reported that, working with Julie Kotchevar, she received data from ADSD on the number of grant dollars that have been allocated to services focused on persons with dementia. They are working on establishing a practical indicator for monitoring progress on meeting the needs of families relating to services, such as respite care.

Discussion ensued on modifying language of the indicator to include components that will better measure progress and if needs are truly being met. Another factor to consider would be monitoring people on the waitlist who are not being served, along with the annual number of consumers and caregiver support services within the indicator.

TFAD members discussed various sources of data that can be used, not limited to direct services from ADSD. Dr. Reed commented that he has information on data received through a survey of all non-ADSD-funded organizations that deliver caregiver support services. This would be valuable, in combination with data from ADSD-funded programs, to present a more comprehensive view of what is happening in the state.

Dr. Fisher moved to approve the motion to retain Recommendation 15, with the suggestion of the revised indicator. Sen. Hardy seconded the motion. The motion was approved unanimously.

### **Recommendation 16: Volunteers—Gini Cunningham**

Ms. Cunningham stated that this recommendation is active and should be retained. There is uncapped potential in volunteers throughout the state. She suggested including other organizations in the active capacity-building of volunteers. A questionnaire regarding an age-friendly community could be used as an outreach tool to solicit more volunteers.

Discussion ensued regarding various avenues and programs that can be utilized to expand the volunteer base. Mr. Duncan proposed that, with this recommendation, there is a possibility of expanding or applying for the expansion grant to implement two programs that are being piloted in the Lifetime Respite Grant—the REST program (volunteer respite) and the Care Consultation Program (a telephone based caregiver empowerment program.) The CCP could provide an opportunity to identify local champions, or volunteers, who can train other volunteers to provide respite services, or they could provide volunteers with training and education to help them better serve people living with Alzheimer's disease and other forms of dementia.

Mr. Harmon presented information on the Alzheimer Association's trained volunteers and the services they are offering to the rural and remote areas,

including programs, such as curricula on the basics of Alzheimer's disease, understanding and relating to dementia-related behaviors, and effective communication strategies. He indicated that the Alzheimer's Associations of both northern and southern Nevada can provide the training and logistical support for identifying locations and marketing these programs to the rural areas, but they need other organization to share information for contacts in those areas.

Sen. Wiener proposed that an expansion could be included in the indicator of Recommendation 16 to monitor which organizations recruit volunteers, such as RSVP, Sanford Center for Aging, the Alzheimer's Associations, and the Lou Ruvo Center for Brain Health. This is not an all-inclusive list but it expands TFAD's opportunity to identify organizations that could collaborate and work with others to recruit people to attend these trainings.

Sen. Wiener entertained a motion to retain number 16 with the proposed changes. Sen. Hardy moved to approve. Dr. Reed seconded the motion. The motion was approved unanimously.

### **Recommendation 17: Guardianship and Small Estates—Sen. Valerie Wiener (Ret.)**

Sen. Wiener reviewed the language and legislative history of this recommendation pertaining to guardianship of persons living with dementia, including but not limited to Alzheimer's disease.

Sen. Wiener explained that legislative efforts in 2015 to shift to an open review in court in order to address the total well-being of the individual seemed agreeable to all parties. However, the bill that was presented in the 2015 Legislative Session did not move forward. Subsequently, the Commission to Study the Administration of Guardianships in Nevada's Courts was formed to review guardianships for all ages. As a result, many participants have provided input and numerous recommendations to the Commission, including the establishment of the Bill of Rights for people involved in guardianships.

Discussion ensued on the ways in which TFAD may be able to lend support for this Bill of Rights, which is still being developed at this time. Several possibilities were discussed regarding the appropriate language to use to express general support and intent to pursue effective implementation of whatever does get developed, upon review and approval of TFAD.

Sen. Wiener proposed a revision to Recommendation 17 with language about supporting a Bill of Rights as discussed. Sen. Hardy moved to approve this action. Dr. Reed seconded the motion. The motion was approved unanimously.

### **Recommendation 18: Hospital Transitional Care Programs—Sen. Joe Hardy**

Sen. Hardy stated that Recommendation 18 had to do with the Care Act, which had been discussed earlier. At this time, we're seeing how the implementation by the hospitals is working. So TFAD can continue to monitor the progress for now, leave the language as is, and determine if any changes need to be made in the future.

Dr. Reed moved to retain Recommendation 18 in the State Plan. Sen. Hardy seconded the motion. The motion was approved unanimously.

### **Recommendation 19: Collaborations and Partnerships on Education and Training for Caregivers—Dr. Charles Bernick**

Ms. Mandarin reviewed the language of the recommendation and outlined progress as follows:

- Work is ongoing in collaboration with Cheyenne Pasquale, ADSD, to create an Alzheimer's page where information on early, mid, and late stages of Alzheimer's disease and symptoms are presented.
- The Cleveland Clinic Lou Ruvo Center for Brain Health will start publishing research and prevention trials through the Nevada Consortium on Dementia Research. The same page will include access to an e-library and a navigation compass that enlightens patients and caregivers about resources and next steps, once a dementia diagnosis is established.
- A community campaign in collaboration with the Alzheimer's Association and the Dementia-Friendly America Organization is being initiated, with the first meeting held in May 2016 and a follow-up meeting scheduled for June 15, 2016.
- Efforts are underway to reach out to financial organizations, nonprofits, healthcare, first responders, and others to hold discussions about the creation of a dementia-friendly city, county, and state.

Mr. Duncan reiterated that the dementia-friendly data project mentioned above won't have a lot of fiscal impact on the communities if grassroots campaigning and awareness are encouraged. However, other public awareness campaigns, especially involving media, would have a fiscal note attached and are very expensive, which is something to keep in mind as we work on this recommendation.

Mr. Duncan shared the possibility of exploring funding sources from grants, such as funding through the Administration for Community Living (ACL), Alzheimer's Disease Initiative Specialized Supportive Services (ADISS), and other resources.

Discussion ensued about adding language to include "gifts, grants, and donations" to the potential funding portion of every recommendation.



Sen. Wiener entertained a motion to retain Recommendation 19 and remove language that limited to the three awareness campaigns. She suggested revising the language to allow for additional and/or more expansive opportunities. Revised language also includes the “gifts, grants, and donations” addition to potential funding.

Mr. Duncan moved to approve the action as discussed. Ms. Mandarino seconded the motion. The motion was approved unanimously.

### **Recommendation 20: Public Awareness Campaigns—Dr. Charles Bernick**

Ms. Mandarino reviewed the language of the recommendation and remarked that the goals outlined can be managed through the dementia-friendly campaigns, as discussed in Recommendation 19. She expressed the desire to include State of Nevada employees to join forces with the campaign. Also the Alzheimer’s Association has a program that helps reach out to employers regarding how to educate both employers and employees about Alzheimer’s disease and other forms of dementia.

Dr. Reed encapsulated that the idea of dementia-friendly communities could be a higher level goal or umbrella for both Recommendation 19 and 20. In other words, both of these recommendations could be reframed to be about promoting dementia-friendly communities throughout Nevada. Then use the awareness campaigns and the other elements as the strategies by which the ultimate goals—the successful development of dementia-friendly communities in a dementia friendly state—could be accomplished.

Mr. Harmon commented that the power of the dementia-friendly movement in Nevada is the grass roots level involvement of businesses. It’s very important to engage nontraditional partners in talking about Alzheimer’s disease in a way that it reduces stigma and encourages people to seek help and services that are available. The ADRC Alzheimer’s landing page is a great resource, but the problem is not a lack of information about available services. The challenge is people’s willingness to access that information. It’s not that they don’t know where to go to get that information. It’s that they’re uncomfortable accessing services because of the stigma.

Mr. Harmon expressed that Recommendations 19 and 20 support our talking to different people in different ways about Alzheimer’s disease, in ways that promote person-centered ideas for living with Alzheimer’s disease and other forms of dementia. This will motivate people to support their continued engagement with that community. He affirmed that the goals of the dementia-friendly communities truly provide an effective overall focus for everything TFAD is doing.

Dr. Reed commented that one of the goals in the preamble of the State Plan can be to promote and develop dementia-friendly communities.

Ms. Cunningham observed that increased public awareness in rural towns, such as Winnemucca, Henderson, as well as interest shown from others, prove that communities are not only willing but also eager to make changes that encourage their communities to be more dementia-friendly.

Mr. Harmon shared that the Alzheimer's Association's partnership with Sanford Center and the Retired and Senior Volunteers Programs were featured on the news for a program on which they collaborated. This program provides a safe and supportive environment for people with Alzheimer's disease and their caregivers to go for walks and learn about the plants and animals that live in northern Nevada. This is not a social service program, but it's an opportunity for people to get together to walk and to socialize, which is good for everyone. This program has also generated significant amount of interest in terms of media and awareness.

Mr. Harmon suggested that TFAD could seek assistance from the Governor's Office to start talking about programs that already exist, such as one mentioned above, to promote opportunities for people with dementia to live optimally in their communities.

Ms. Mandarino added that an incentive program for businesses, supported by the mayor and the Governor, could help grow community involvement in and support of the dementia-friendly movement in Nevada.

Mr. Duncan recapped that TFAD definitely has a role in the dementia-friendly initiative, and forming an overarching statement of support to be included on the State Plan would be ideal.

Discussion ensued about changes to the language of Recommendation 19 and 20, noting that there is enough of a distinction between the two to keep them separate. Talks included blending of some wording in each and removal of specific categories of public awareness campaigns. Modifications proposed include:

- In Recommendation 20, remove the term "create" employee assistance programs to "implement" since these already exist.
- In Recommendation 19, use "Foster the development of Dementia-Friendly awareness campaigns..."

Additional dialogue took place about the new proposed preamble statement. Ms. Mandarino requested that the term "dementia" be addressed in the preamble, making it more inclusive of all dementias, because there's been so much focus on just Alzheimer's disease. She suggested there might be a need for some differentiation.

Sen. Wiener expressed the need to be accurate on the presentation of definitions and statistics for Alzheimer's disease and other forms of dementia in making the decision of what terms to use in the State Plan.

Mr. Harmon suggested that TFAD may need to make a decision on which terminology to ensure clarity.

Sen. Wiener proposed that she would offer language for the new preamble, clarifying the work that is representative of TFAD, for consideration and further discussions by TFAD at the next meeting.

Dr. Reed recapped that it is important to be clear about what TFAD's purview is, irrespective of what the name of the task force may be.

Sen. Wiener entertained a motion to approve retaining and making changes as discussed, and adding some dementia-friendly language to Recommendation 20.

Dr. Reed moved to approve the motion. Sen. Hardy seconded the motion. The motion was approved unanimously.

- VII. Report and Make Possible Recommendation on Physicians Order for Life Sustaining Treatment for Nevada Residents (NV POLST) **(For Possible Action)**  
Peter Reed, Ph. D.  
Director  
Sanford Center for Aging  
University of Nevada Reno

Dr. Reed provided a report on the work that Nevada POLST is doing to refine some of the legislation for supporting POLST, which is the Physicians Order for Life Sustaining Treatment. For full disclosure, Dr. Reed stated that he serves on the NV POLST Board as well.

Dr. Reed stated that the board for the NV POLST has been discussing several agenda items, but he wished to highlight one that is most relevant to TFAD's work—legislative changes needed for NRS 449.626, regarding enabling family members to serve as surrogates for people who lack capacity. This relates directly to people living with Alzheimer's disease in terms of the progression of the disease ultimately resulting in a point when they're unable to make decisions about their own life sustaining treatments and work with their physician to enact the physician's order for their preferences. Currently, family members are enabled to make decisions around withdrawal of life support or refusal of life support, but language within the legislation is needed to specifically give family members the authority to work with the physician to complete a POLST, based on their knowledge of the preferences of those individuals who lack decisional capacity.

Dr. Reed explained that NV POLST already has a path for moving this legislation forward through the BDR process, and there's nothing TFAD needs to do specifically at this time. However, TFAD may review the State Plan recommendations and identify if the State Plan needs language that specifically address the importance of end-of-life care and decision-making for people living with Alzheimer's disease and other forms of dementia. As the legislative process moves forward, TFAD will be able to voice support for this issue, which is relevant to the people affected.

Sen. Wiener noted that the end-of-life matter was presented at a previous TFAD meeting with the intention of considering it as a possible new recommendation for the State Plan, which is why Dr. Reed has provided a follow-up today.

Sen. Hardy commented that this subject can fit into some of the Alzheimer's-related education in Recommendations 11, 12, 13, and 14. So it is relevant and could be included in a BDR.

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

Discussion ensued on the possible new recommendations to be discussed in the next meeting, including:

- End-of-life care and POLST
- Driving and Dementia
- Caregiver Support
- Veterans

Mr. Harmon remarked that he would like to see a recommendation regarding care coordination with physicians, particularly primary care physicians, on the importance of accurate and timely diagnosis.

Ms. Cunningham suggested that the presentation by EMS from Humboldt County about their transitional care program be postponed until the following meeting. Sen. Wiener concurred, citing the need for time to discuss the new recommendations first.

Dr. Reed added that he would like to see an agenda item on reviewing the current roster, terms of appointment, and contact information to determine if any vacancies on TFAD need to be filled.

Sen. Wiener encouraged TFAD members to bring forward very solid language for the possible new recommendations, along with language for the indicators and potential funding, to present at the next meeting.

Sen. Hardy moved to approve the items to be included on the agenda, as discussed above. Dr. Fisher seconded the motion. Motion passed unanimously.

IX. Discuss Next Meeting Date of August 5, 2016 (**For Possible Action**)  
Senator Valerie Wiener (Ret.), Chair

The next meeting date is scheduled for August 5, 2016.

X. **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.

XI. Adjournment

The meeting was adjourned at 2:02 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