

# 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: April 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

Call to Order/Roll Call

Senator Valerie Wiener (Ret.), Chair

Members present: Sen. Valerie Wiener, Albert Chavez, Charles Bernick, M.D., Peter Reed, Ph.D., and Wendy Simons

Members participating by telephone: Gini Cunningham and Julie Kotchevar

Members absent: Jane Fisher, Ph. D., Sen. Joe Hardy, and Assemblyman

James Oscarson

Alternates present: Jacob Harmon and LeeAnn Mandarino

Alternates participating by telephone: Susan Longchamp and Dolores Ward

Guests present: Susan Hardwick, Robert Kidd, Daniel Mathis, and Sally Ramm

Staff present: Sunadda Woodbury

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.)

Barry Gold, Director of Government Relations, AARP Nevada, provided updates on the Caregiver, Advise, Record, Enable (CARE) Act.

Mr. Gold stated that the CARE Act is up and running, and hospitals have embraced the CARE Act. Hospitals and many agencies are developing materials on their own, including rack cards with information about the CARE Act, to distribute to patients and the community. The focus phrase has been "Making a Difference When You or Your Loved Ones Enter the Hospital."

Mr. Gold commented that AARP recently presented Sen. Hardy and Assemblyman Oscarson with the AARP's Capital Caregiver Recognition for 2015 for advancing legislation that helps family caregivers. Sen. Debbie Smith was also awarded the same recognition.

Mr. Gold emphasized that the CARE Act is continuing to be passed across the country, with the 22<sup>nd</sup> state having passed it last week. Nevada was state number nine to authorize this important legislation.

Dolores Ward, Education Coordinator, Nevada Geriatric Education Center, University of Nevada Reno (UNR) School of Medicine, provided comments.

Ms. Ward stated that she provides education and training on dementia in rural Nevada. She expressed her appreciation to serve as an alternate to Ms. Gini Cunningham on TFAD, and looks forward to learning about the goals and objectives of TFAD and how she can be of assistance.

III. Welcoming Remarks

Senator Valerie Wiener (Ret.), Chair

Sen. Valerie Wiener welcomed all to the meeting.

Per request from several TFAD members needing to leave the meeting early, Sen. Wiener noted that she will be taking agenda items out of order. She stated that agenda items X. and XI. will be discussed immediately following item V.

Sen. Wiener remarked that in preparation for the revision of the State Plan, a number of items will be discussed in the meeting that could potentially result in new recommendations.

IV. Approval of the Minutes from February 3, 2016 Meeting (<u>For Possible Action</u>)
Senator Valerie Wiener (Ret.), Chair

Wendy Simons motioned to approve the minutes from the February 3, 2016 meeting. Peter Reed, Ph. D., seconded the motion. Minutes were approved unanimously.

V. Review and Discuss the State Plan Including Updates and Recommendations from Task Force Members Regarding Their Assigned Areas and Possible New Recommendations (For Possible Action)

Senator Valerie Wiener (Ret.), Chair

Review and discussion of the State Plan comprised the following:

#### **Recommendation 1: Information Referral System**

Albert Chavez requested that updates be provided by Cheyenne Pasquale in agenda item VIII—Updates and Recommendations on Aging and Disability Resource Center (ADRC) Website.

#### Recommendation 2: Advanced Practice Registered Nurses (APRNs)

Sen. Wiener called attention to a letter that was submitted to the Nevada Legislative Health Committee, which includes a report and current statistics on APRNs in rural counties. (See Attachment A)

Sen. Wiener outlined highlights from the report including:

- AB 170, introduced in the 2013 Legislative Session and supported by the ACR 10 Task Force, was passed by the Legislature. This created the Advanced Practice Registered Nurse (APRN) category.
- In 2009-10, there were 664 Advanced Practice Nurses (APNs) statewide. Of those, 28 were in the rural areas, and 76 were licensed out of state.
- In 2015-16, there were 1343 APRNs statewide. Of those, 90 were in the rural areas. However, not considering Carson and Douglas counties, there would be only 42 in the other 'frontier' areas. 222 were licensed out of state.

Dr. Reed remarked that, according to the numbers presented, there seems to be a greater increase of APRNs in the urban areas vs. the rural areas. He encouraged TFAD to continue to emphasize growth in the rural areas.

Sen. Wiener noted that it's not certain where the APRNs who are domiciled outof-state are practicing.

Charles Bernick, M. D., questioned whether the rural hospitals are providing any incentives for APRNs or doing any recruitment.

Julie Kotchevar, ADSD Deputy Administrator, explained that there is a Primary Care office run by Laura Hale, Manager, Primary Care Office, Division of Public and Behavioral Health, who does extensive recruitment for Primary Care providers, nurses, social workers, and clinical social workers. Programs include loan repayment and different kinds of incentives to encourage the growth of the Primary Care practice in the rural areas. Ms. Kotchevar suggested it might be beneficial to have Ms. Hale speak to TFAD and address these issues.

Responding to Sen. Wiener's inquiry on whether there is information about APRNs who might be providing Telehealth/Telemedicine services from the urban areas to the rural areas, Ms. Kotchevar commented that she will see if the Department of Public and Behavioral Health (DPBH), who are working with Telehealth initiatives, can provide further information.

Dr. Bernick stated that the APRNs at the Cleveland Clinic Center for Brain Health are providing telemedicine services to rural sites.

Ms. Simons suggested reaching out to Joan Hall, President of Nevada Rural Hospital Partners, for information on what the rural hospitals may be doing to utilize APRNs. Sen. Wiener encouraged Ms. Kotchevar to expand her outreach to Joan Hall.

#### Recommendation 3: Telehealth and Telemedicine

Mr. Chavez reported that several meetings have been held to discuss the formation of a Telehealth Consortium that will be meeting on a monthly basis. Jacob Harmon and Nicole Anderson of the Alzheimer's Association will be leading the agenda and building up the framework for this consortium. Those that provide Telehealth, Telemedicine, and Tele Education will be invited to join this consortium, including the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas. In the north, Mr. Harmon is also reaching out to Renown and Project Echo, as well as the Sanford Center on Aging.

Mr. Chavez explained that the inaugural meeting is anticipated for May 2016. With the vision of State Plan Recommendation 3, the consortium will discuss its membership, mission, and objectives.

Mr. Chavez commented that he will be working with Cheyenne Pasquale on an idea to develop a landing page on the Alzheimer's website that will include the providers of Telehealth, Telemedicine, and Tele Education.

#### Recommendation 4: Remove Age Barriers

Sen. Wiener asked Ms. Kotchevar to provide the update on respite numbers.

Ms. Kotchevar presented the number of recipients and other information related to respited services provided by ADSD, regardless of age, through both the waiver and non-waiver programs, including the Home and Community Based Waiver (HCBW) for the Frail Elderly, the HCBW for the Physically Disabled, and the COPE and PAS program.

Ms. Kotchevar highlighted the data as follows:

- The average age of recipients was 70, but there were people in the younger-onset age breakdown who received respite services.
- Data was broken down by counties.
- The average cost was \$1469 per individual.
- Total cost was \$473,000.
- 218 people were over the age of 65.

A statement reflecting the complete set of data provided by ADSD is attached. (See Attachment B).

Discussion ensued about how ADSD is working to incorporate different sources of funding for services to ensure that age does not affect the eligibility factors.

Sen. Wiener inquired about the federal limitations of the Older Americans Act, and whether ADSD is looking at other financial resources to address the concerns, besides respite, that may be challenges for those with younger-onset Alzheimer's disease and other forms of dementia and their families.

Ms. Kotchevar stated funding from the Tobacco Settlement funds, Medicaid funding, and other resources have allowed ADSD to offer services that are broadened to include the younger-onset individuals and people across the lifespan.

Responding to a query from Dr. Bernick about whether there is a list of services available to seniors versus the younger-onset individuals, Ms. Kotchevar explained that there is a list of services that are specifically funded by the Older Americans Act, which does have an age limitation. This list demonstrates what the funding source is, what the eligibility requirements are, and what services are provided to seniors. It does not include all public services, but Ms. Kotchevar can make the list available to TFAD.

Dr. Bernick reiterated that it would be helpful to understand what the gaps are between services that are covered by the Older Americans Act and other resources of funding that would cover the needs of younger-onset individuals. Sen. Wiener asked Ms. Kotchevar to provide a list of services and requirements for programs funded by the Tobacco Settlement funds.

Dr. Reed commented that beyond the aging-related services, there are challenges that people face when they're diagnosed at a younger age, particularly if they have to exit the workforce and income becomes a challenge if they're not yet eligible for social security or Medicare insurance. Dr. Reed remarked that there are some provisions for bringing people with Alzheimer's disease and other forms of dementia into appropriate eligibility, despite their age, but he is not certain about all of the details.

Sen. Wiener emphasized that testimonies have been heard from those with younger-onset challenges whose concerns were very compelling. Their burdens affect the whole family. Thus it would be a worthwhile effort to investigate some relief and assistance for these families.

#### Recommendation 5: Outreach to Cultural Communities

Ms. Simons commented that there are some veteran-specific worksheets, including Caregiver Self-Assessment and Shared Decision Making, which could be applicable to this topic. She observed that the "culture" of veterans is unique to the thread of military service. This dynamic affects how they deal with health considerations, including Alzheimer's disease and other forms of dementia, as well as other behavioral issues. There are 300,000 veterans in Nevada.

Sen. Wiener inquired whether there are statistics of how many of those veterans may be affected by Alzheimer's disease and other forms of dementia. Ms. Simons indicated that she will secure that data to inform the group.

Ms. Simons related that veterans affected by Alzheimer's and dementia often react differently. She shared an incident about a veteran who exhibited aggressive behaviors due to limited tolerance level. Ms. Simons remarked that TFAD can support further awareness and education opportunities and offer guidance to many entities.

Dr. Bernick commented that there may be unique risk factors for veterans and how they react and respond to dementia. He stated that a future issue may be chronic traumatic encephalopathy, which is a repetitive brain trauma due to exposure to blasts, that could affect many veterans developing dementia.

Sen. Wiener asked Ms. Simons and Dr. Bernick to have a conversation about these unique challenges regarding veterans and present information to TFAD, which will determine whether a recommendation addressing these concerns should be added to the State Plan.

Dr. Reed added that it will be beneficial to have the data from Ms. Simons to examine whether the veteran-specific concerns may be included in existing TFAD State Plan recommendations, rather than being developed as new recommendations.

#### Recommendation 6: Affordability of Services

Ms. Simons stated that TFAD has heard and will hear again updates on the advances of the behavioral units and the expansion of them, which now create a better opportunity to fund the specialized care that is needed for people with Alzheimer's disease and other forms of dementia.

Ms. Simons shared a case about a veteran whose benefits were elevated to a higher level, once a Veterans Service Officer discovered that he was not only afflicted with a physical challenge but also cognitive issues due to exposure to Agent Orange. She said that there are efforts to make sure that gaps are eliminated for veterans who need specialized services. Collaborations are ongoing with the ADSD Resource Centers to expand benefit captures for veterans and/or their spouses to improve affordability and access to quality specialized care.

In addition, Nevada Department of Veterans Services (NVDS) Director, Katherine Miller, has created an initiative, the Nevada Veterans Advocate Program, which provides an online course for people to obtain credentials on how to access benefits to maximize any kind of revenue available for care and services. The program is intended to create a statewide network of advocates, ensuring wherever a veteran lives, there's someone who can help that veteran on the path to accessing needed benefits.

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

Dr. Bernick reported on outcomes from the Nevada Research Consortium on Dementia (NRCD) meeting on February 12, 2016. Discussions encompassed the following:

- The organizational structure of the group and bylaws are being developed.
- LeeAnn Mandarino is working with Cheyenne Pasquale on information that will be included on the ADRC website for NRCD.
- Individuals, who are interested in participating in the NRCD, can now complete an online information form that will be placed on the website.
- A vetting process will be created to determine credibility/qualifications for membership and inclusion on the ADRC Research Landing Page.
- Next meeting is anticipated for April 2016.

Notes from the NRCD meeting on February 12, 2016, provided by LeeAnn Mandarino, are attached. (See Attachment C)

#### Recommendation 8: Specialized Care Pathways

Dr. Bernick explained that often hospital care for dementia patients is less than optimal, so the objective is to develop best-practice care methods that can be offered to hospitals to implement.

A group comprising representatives from a number of hospital systems in southern Nevada met to discuss preliminary plans, including:

- Identify potential participants in various areas of hospital care, such as:
  - 1. Emergency room
  - 2. Floor care
  - 3. Discharge planning
  - 4. Dietary
  - 5. Security
  - 6. Administration
- Examine each step in the hospital stay and draw from the practices that have already been advocated. For example, this might include guidelines established by the Alzheimer's Association that are modified or added to those with input from the experts involved.
- Explore recommendations from experts from different areas in the group.
- Draft a document outlining a care path that could be offered to the hospitals.
- Work with the Nevada Hospital Association to determine best-practice care methods.
- Solicit input from northern Nevada providers as well.

The next Care Pathways meeting is anticipated for the end of April 2016.

Sen. Wiener remarked that, together with the CARE Act, this specialized care pathway will make the entire hospital experience more responsive to the needs of people with specific challenges. The intent and work of TFAD is to elevate the experience of both providers and patients.

#### Recommendation 9: Quality Long-Term Care

Ms. Simons stated that this recommendation overlaps with Recommendation #6, discussed earlier. An update on the Behavioral Complex Care Program (BCCP) and facilities will be provided by Daniel Mathis later in this meeting.

Sen. Wiener asked about an update on those who are not in a facility, which may include a significant number of individuals and families living with Alzheimer's disease and other forms of dementia.

Ms. Simons described several methods presented in the State Plan to address quality long-term care, including:

- Recruiting an out-of-state provider with a specialty in working with this population to open a nursing home in Nevada;
- Developing a team to identify behavioral or supportive interventions necessary to address the needs of an individual and enhance patient safety. The team would be readily available to assist in a nursing home setting when a resident exhibits behavioral problems; and
- Using State-owned mental health facilities to serve individuals with severe behavioral problems.

Ms. Simons committed to gathering more information to inform TFAD at the next meeting.

#### Recommendation 10: Reducing Out-of-State Placement

Updates relating to the reduction of out-of-state placement will be provided by Mr. Mathis in agenda item VII.

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

Staff reported no update from Sen. Hardy on these recommendations.

Sen. Wiener inquired about obtaining statistics from various licensing boards to determine how many people have taken advantage of completing Alzheimer's-and dementia-related education for CEU credits since SCR 2 was passed in the 2015 Legislative Session. This data will be helpful to determine the effectiveness of the legislation that was passed.

Discussion ensued whether Alzheimer's-and dementia-related education satisfies the requirement for the ethics portion of CEUs. Language in SB 196, section 10, which clarifies that Alzheimer's-related training can be used to earn two CEU credits each year, stated "except related to ethics."

Dr. Reed emphasized that the allowance in SB 196 certainly presents an incentive for people to be more interested in Alzheimer's education, but the question is what is being done to promote awareness of this opportunity.

Sally Hardwick, President of Nevada Physicians' Order for Life-Sustaining Treatment, stated that she was the former Director of Nevada Center for Ethics and Health Policy, and has been responsible for many ethics CEUs. She

commented that there are lots of ethical issues associated with Alzheimer's disease; therefore, to gain ethics CEUs along with Alzheimer's-related education would not be a problem. Encouraging ethical dimensions of Alzheimer's care would be an easy combination to make and satisfy those ethics credits as well.

Sen. Wiener summarized that part of the recommendation TFAD may consider going forward would be stronger clarifying language to encourage the development of CEUs that satisfy the ethics requirements.

Mr. Chavez reported that, as a result of Sen. Hardy's work on Recommendation 14, the Alzheimer's Association has been able to provide a number of different first responder trainings in the last fiscal year in Henderson for the fire department and paramedics, along with the Las Vegas Metropolitan Police Department. This fiscal year, they're looking to provide training for the Indian Springs Fire Department in April. In Pahrump, training will be held for paramedics, fire department, and police. A first responder training will be held in Mesquite in June. Other training opportunities are being explored for Laughlin and Primm Valley.

Mr. Chavez commented that he and LeeAnn Mandarino from the Cleveland Clinic Lou Ruvo Center for Brain Health were able to meet with LVMPD's Undersheriff to discuss the possibility of doing some online Alzheimer's-and dementia-related training for the police, as well as getting involved with the Police Academy.

Jacob Harmon of the Northern Nevada Alzheimer's Association asserted that they have been working with the Washoe County Sheriff's Department, offering training to them and other first responders in Washoe County, along with involving them in the Dementia-Friendly Summit. They are also working closely with White Pine County and offer rural trainings for law enforcement, the Bureau of Land Management staff, the fire department, and paramedics. The trainings will take place in May 2016. Other rural counties have also expressed interest and requested similar trainings.

#### **Recommendation 15: Respite Services**

This recommendation relates to caregiver support, which will be discussed later in agenda item XII.

Robert Kidd, President of the Perry Foundation, will be giving an update regarding evidence-based education in agenda item VII.

#### **Recommendation 16: Volunteers**

Gini Cunningham reported volunteer capacity has increased in Winnemucca, where they are working on being an Age-Friendly Community. This includes

addressing concerns of people with Alzheimer's disease and other forms of dementia, as well as veteran-specific issues.

The hospital in Winnemucca has been promoting medical residency for graduate students, and Ms. Cunningham will learn how APRNs can become involved as well. Telehealth programs are also being utilized in Winnemucca.

Ms. Cunningham stated that her plan is to recruit and train additional volunteers. She said that first responders in Winnemucca are actively learning how to care for those with Alzheimer's disease and other forms of dementia. She said that other communities, such as Ely, Elko, and Lovelock, would also like to be involved and receive more dementia-related training and education.

#### **Recommendation 17: Guardianship**

Sen. Wiener reviewed the history of Assembly Bill 9 (AB 9) pertaining to guardianship. It was heard but not passed during the 2015 Legislative Session. Since then, the Commission to Study the Administration of Guardians in Nevada's Courts was established, and Sally Ramm, ADSD Elder Rights Attorney, has been participating with the Commission and providing regular updates to TFAD.

Sen. Wiener shared information provided by Ms. Ramm, including:

- The Commission continues to listen to public comment regarding personal experiences with guardianship issues.
- The Commission is considering 30 recommendations for reform.
- To date, about half of the recommendations have been adopted by the Commission.
- New information on numerous facts of guardianship continues to be presented and discussed.
- No legislative action has been identified yet because more time is needed to analyze and discuss the issues.
- More meetings are scheduled on April 1, April 26, and May 20, during which time legislative action may be proposed.

A written statement submitted by Ms. Ramm is attached. (See Attachment D)

Sen. Wiener commented that it would be beneficial for TFAD to allow these three meetings to unfold to determine the recommendation of the task force.

#### **Recommendation 18: Hospital Transitional Care Programs**

Sen. Wiener noted that this recommendation has some overlap with other recommendations. It encompasses the CARE Act, the Care Pathway, pre-hospitalization, and post-hospitalization or "transitional care" beyond the hospital, so the scope of the recommendation is large.

Ms. Cunningham shared that in Humboldt County, the Ambulance Corps has added another dimension to the CARE Act, which is unique to Winnemucca. She explained that when someone transfers from Winnemucca to a hospital elsewhere, upon return there is a direct follow-up by the Ambulance Corps to ensure the individual has an immediate contact should any need arise.

Sen. Wiener asked Ms. Cunningham to provide staff with additional information and an overview of this transitional care program being implemented in Winnemucca.

## Recommendation 19: Collaborations and Partnerships on Education and Training for Caregivers and Recommendation 20: Public Awareness Campaigns

Dr. Bernick commented that LeeAnn Mandarino has put together awareness materials, including the compass, which outlines ways to navigate Alzheimer's disease and other forms of dementia.

The Cleveland Clinic Lou Ruvo Center for Brain Health also has a website called healthybrains.org. The website allows people to be proactive, offering various tips on brain health, as well as opportunities to participate in research.

Mr. Chavez remarked that he, Ms. Pasquale, and Ms. Mandarino have also discussed adding awareness materials to the ADRC website.

Staff reported that ADSD has contacted the State of Nevada Employee Assistance Program (EAP) to offer information on the ADRC website as a possible resource for their referral system. The information has been forwarded to the vendor for EAP and a reply is pending.

VI. Presentation on Physicians Order for Life Sustaining Treatment for Nevada Residents (NV POLST)

Sally Hardwick, M.S. President Nevada POLST

Sally Hardwick, President of Nevada POLST, provided the history and overview of the program.

Some of the highlights from the presentation included:

- NV POLST, established under NRS 449.691-697, specifically educates and trains the public and health care providers throughout Nevada.
- It is the only entity to provide state-approved Nevada POLST forms that travel with the individual.
- It has distributed about 48,000 POLST forms statewide.

- The program is geared toward the frail elderly who are near the end of a life-limiting illness and not expected to survive a year.
- Treatment preferences are elicited, documented, communicated, and honored in all settings.
- POLST forms are completed with and signed by patient, Durable Power of Attorney (DPOA), or legal guardian, and signed and validated by a physician.
- For people with Alzheimer's disease and other forms of dementia, there is a 2 minute video, Volante video, that can be shown to assist with their decision making regarding POLST.
- "Choosing Wisely", an initiative of the American Board of Internal Medicine, provides guidelines specific to people with Alzheimer's disease and other forms of dementia in planning their end-of-life care.
- More information can be found on www.nevadapolst.org

Ms. Hardwick discussed concerns regarding how many patients with Alzheimer's disease and other forms of dementia have lost mental capacity and do not have a DPOA or a guardian, which raises the need for someone to be able to speak on behalf of these individuals. Ms. Hardwick appealed to TFAD for help with establishing the ability for the next of kin to speak for and complete the POLST form for the patient when a legal guardian and DPOA have not been appointed.

Ms. Hardwick also solicited support to modify the existing law that allows only physicians to validate the POLST form. She proposed that Advanced Practice Registered Nurse (APRNs) and Physicians Assistants (PAs) should be able to sign the form as well, because access to physicians in the rural areas is limited. Also patients who are on hospice at home often have difficulty getting physicians to their residence to sign the form.

Ms. Hardwick summarized the recommendations that she's asking TFAD to support.

- 1. Revise NRS to allow APRNs and PAs to sign POLST medical orders.
- 2. Encourage the use of the Volante video for Advanced Care Planning (ACP) sessions.
- 3. Revise the next-of-kin statute to allow decisional authority for incompetent patients if there is no designated DPOA-HC or legal guardian appointed.

The complete presentation on NV POLST and a sample POLST form are available on file. (See Attachment E)

Discussion ensued about the availability and access to the POLST forms. Dr. Bernick questioned whether the forms can be made available electronically to provide easier access by both providers and patients. Ms. Hardwick explained that the POLST form is sent home with patients, and they are told to put it by their bed or on the refrigerator. People are also encouraged to submit the form

to their living will lockbox at the Secretary of State's office. In return, individuals are given a wallet card with an access number and information on who their DPOA or alternate is. Quality assurance, including methods to verify electronic signatures and authenticity of information, still needs to be improved. Having an electronic registry could also potentially be very helpful, but funding for these processes is limited.

Regarding the next-of-kin authorization, Dr. Bernick queried which next of kin gets to decide when there are multiple family members involved. Ms. Hardwick explained that the authority would first go to the spouse, then the adult children, then the parents, then siblings, etc. Dr. Bernick raised concern surrounding possible discord among family members and how there needs to be an adjudication process in place should these circumstances arise. Ms. Hardwick emphasized that advanced planning and having a DPOA is crucial.

Dr. Reed commented that advanced care planning should be addressed in the State Plan, because it would allow people diagnosed with Alzheimer's disease and other forms of dementia, including early-onset Alzheimer's disease individuals, to have a genuine opportunity to participate in determining what their care experiences may be moving forward. NV POLST is a tool for people who are more severely progressed in any number of conditions and much closer to the end of life.

Dr. Reed remarked that the recommendations for NV POLST align with many of the recommendations in the existing State Plan but some issues still need to be addressed. He added that he would like to collaborate further with Ms. Hardwick to present ideas to submit to TFAD at the June 2016 meeting.

VII. Update and Possible Recommendations on Behavioral Health Placements/Facilities and Evidence-Based Education Programs (For Possible Action)

Daniel Mathis
President and CEO
Nevada Health Care Association

Robert Kidd President Perry Foundation

Mr. Mathis stated that May 2016 will be the first anniversary of the Behaviorally Complex Care Program (BCCP). Data should be forthcoming, and a review of the program should be ready by February 2017.

Some of the data will include:

- Breakdown of diagnoses of patients served.
- Programming breakdown of which tiers of service were provided within the three-tier system.

- Total number of Nevadans that have been served.
- Total number of out-of-state placements data (to determine if there has been an impact since the BCCP program started.)

Most of the services have been provided at the Tier I level, but Tier II and Tier III are also getting approved across the state. There have been 150 approvals for the BCCP since 2015, and the number is expected to reach 200 by the end of May 2016.

Mr. Mathis explained that 20 Skilled Nursing Facilities (SNFs), most of them in urban areas, have BCCP Programming. More SNFs are planning to become involved, which might include rural areas. Providers are concerned about the ability to provide appropriate staffing of behaviorists required to participate in the program.

Mr. Mathis reported that transitions from acute care to SNFs are improving. Admission coordinators at the hospitals are communicating with discharge planners at the hospital to ensure appropriate transitions to the SNFs. Now that hospitals are recognizing BCCP, they are training discharge planners on which tier of services might best meet the patients' needs.

Transition from SNFs to home and community-based services is a concern. The question is: Once someone completes the SNF-based tiered program, is there a place in the home and community-based services to which these individuals can be discharged?

Ms. Simons inquired about whether a facility needed to belong to a particular provider 'group' or company in southern Nevada that prescreens and sets them up with a vendor number in order for hospitals to work with them to find availability for placement. Mr. Mathis is not aware of this type of operation and will make further inquiries.

Robert Kidd provided an update on grants and approvals of work programs that would provide education for caregivers and long-term care, including assisted living and skilled nursing facilities. The Bureau of Health Care Quality and Compliance (BHCQC) has approved a proposed work program for a one year, six-workshop program, to educate caregivers and assisted living facilities on the education of caring for individuals who are behaviorally challenged or living with Alzheimer's and dementia-related diseases. This program will begin in May 2016, with the first to be held in Las Vegas and then in Reno, and will continue into the beginning of 2017.

Mr. Kidd shared that a similar two-year program for nursing facilities to address the higher number of individuals (mostly discharged from acute facilities) coming into these facilities, was denied by Centers for Medicare and Medicaid Services (CMS). Unfortunately, these facilities are now tasked with providing that education on their own. With the high acuity that the facilities are dealing with and the increase in care needed, Mr. Kidd asked TFAD for help and suggestions.

Mr. Kidd discussed the Music and Memory program, developed by Dan Cohen, which has been submitted and approved by the State. It was then approved by the CMS regional office in San Francisco and is now awaiting final approval by the national office. BHCQC held a meeting with CMS and expects it to be approved. The program will affect every nursing facility in Nevada, improving the care for Alzheimer's and dementia-related individuals. Initially, it will be used with more than 900 people and be expanded in the second year.

Mr. Kidd commented that the Perry Foundation has begun discussions with LeeAnn Mandarino, Program Manager at the Cleveland Clinic Lou Ruvo Center for Brain Health, Las Vegas, to partner with the Clinic's Lunch and Learn Program. Currently, there are tentative plans for sessions with Dan Cohen and a viewing of "Alive Inside" in Las Vegas in June. Once the Music and Memory Program receives final approval, the kick- off will be in Las Vegas in conjunction with the Lunch and Learn Program.

Ms. Mandarino stated that they received a grant from NV Energy for their therapy programs, particularly centered on art and music. They will work with Mr. Kidd to kick off the Memory and Music program.

Responding to a query from Sen. Wiener on how many people the program might reach, Ms. Mandarino said that the last Lunch and Learn session attracted about 126 individuals, which might be representative of future numbers. Also, different groups of people may attend, depending on the subject and the speaker and how well the event is marketed. Ms. Mandarino assured TFAD that marketing will be emphasized for the Music and Memory program, which will be ongoing after the initial implementation.

Regarding the program that was denied by CMS, Dr. Reed questioned what the nature of the program was that was denied and whether alternative funding sources can be found. Mr. Kidd commented that they had complied with all the program requirements that have been similarly approved by CMS, and he is not certain why this particular program was denied. Dr. Reed encouraged the investigation of other possible funding sources.

VIII. Update and Possible Recommendations on Aging and Disability Resource Center (ADRC) Website (For Possible Action)

Cheyenne Pasquale ADRC Project Manager Aging and Disability Division

Cheyenne Pasquale provided an update on the progress of the ADRC website.

Ms. Pasquale stated that she has been focused on information gathering since she provided the last update to TFAD. Some of the work accomplished included:

- Addition of a descriptor and mission statement for the Nevada Consortium for Research on Dementia (NRCD).
- Exploration of options to determine how to best incorporate biography of researchers on the site after they are vetted by NRCD.
- Information provided by Ms. Mandarino and Mr. Chavez for the "I Need Help With" page and Learn About Library.
- Insights gained from attendance at Dr. Bill Thomas' workshops on ways to frame more positive thoughts around dementia.
- Research on other states and their Alzheimer's disease information.
- Possible ways to include a community toolkit to help inform communities about Alzheimer's disease and other forms of dementia, as well as ideas to increase community involvement by learning what is being done in other states.

Further plans of action include:

- Meeting with Dr. Jane Fisher to review some of the language on the site to change the tone.
- Modifying the home page to have a brief introductory story that is more positive versus the clinical "What is Alzheimer's Disease" that is there now.
- Compiling 2-3 positive, uplifting stories from people living with dementia to be included on the site.
- Looking at a way for allowing people to be able to submit their stories.

The written summary of the ADRC website updates provided by Ms. Pasquale is attached. (See Attachment F)

Mr. Chavez and Ms. Mandarino expressed appreciation for all the progress made. Ms. Mandarino stated she can supply personal stories for the website.

### IX. Update and Possible Recommendations on Guardianship (For Possible Action)

Sally Ramm
Elder Rights Attorney
Aging and Disability Services Division

An update on guardianship was provided during the discussion on State Plan Recommendation 17 earlier.

Staff reported on a news release, dated March 31, 2016, pertaining to the announcement from Nevada Attorney General Adam Paul Laxalt, Las Vegas Metropolitan Police Sheriff Joseph Lombardo, and Clark County District Attorney Steve Wolfson regarding an ongoing joint investigative and prosecution team to help combat guardianship and elder exploitation in Nevada. Assembled last

summer, the team coordinates local and state efforts to investigate alleged instances of financial exploitation by court-appointed guardians.

A copy of the press release is attached. (See Attachment G)

X. Update and Discussion on the Nevada Research Consortium on Dementia (NRCD) and Care Pathways. Make Possible Recommendations on Funding for NRCD (For Possible Action)

> Dr. Charles Bernick Medical Director The Cleveland Clinic Lou Ruvo Center for Brain Health Las Vegas

> LeeAnn Mandarino Program Manager The Cleveland Clinic Lou Ruvo Center for Brain Health Las Vegas

Dr. Bernick presented an update on NRCD and Care Pathways earlier in agenda item V.

Sen. Wiener asked Ms. Kotchevar to clarify the requirements of an official subcommittee versus a work group within TFAD, as well as possible funding support for the NRCD.

Ms. Kotchevar provided an explanation as follows:

- A task force can vote to offer support for anyone whether they are an officially delegated subcommittee or not.
- If NRCD were an official subcommittee, open meeting law requirements would have to be fulfilled.
- When any task force creates a subcommittee, resources allocated to support the task force can be extended to support the subcommittee.
- A work group tends to comprise two or fewer people who are assigned a specific task to accomplish and report back. The work group is less formal and does not have the same authority as the task force.
- A task force can vote to support a particular initiative or write a grant letter on behalf of an organization.

Sen. Wiener stated that NRCD is not designated as a TFAD subcommittee, but was formed as a result of a recommendation in the State Plan. Therefore, TFAD can lend support by providing a letter of recommendation to seek financial resources as deemed appropriate.

Discussion ensued regarding the proper process of securing and expending funds, should NRCD receive grants from various donors. Dr. Bernick inquired whether there is a way for funds to be received through the State to avoid the

complications of having to establish themselves as a nonprofit corporation. Ms. Kotchevar explained that ADSD has the ability to receive funding through a gift account, as long as the money is specified to be used for a specific purpose. For example, in support of TFAD's State Plan, NRCD could promote the role of research and collaboration in the community. Then TFAD could vote to allocate the money for that particular purpose.

Dr. Bernick questioned whether the NRCD could function as a group under TFAD in some capacity without having to be designated as an official subcommittee. Sen. Wiener asked Ms. Kotchevar to consult with legal counsel to seek guidance on whether NRCD can be considered a work group with no more than two TFAD members participating, but with a number of other participants from various entities. She tasked Ms. Kotchevar with getting the information on the distinctions and possibilities of organizing under the umbrella of TFAD.

Dr. Reed queried whether ADSD could be a "fiscal home" to the NRCD, which could function independently as a group of researchers working together for a common cause.

Sen. Wiener reemphasized again the need for clarification of appropriate avenues for receiving and expending funds.

XI. Report from the Driving and Dementia Subcommittee and Possible Recommendations (For Possible Action)

Peter Reed, Ph. D. Director Sanford Center for Aging

Susan Longchamp, M. A. University of Nevada Reno Nevada Caregiver Support Center

Susan Longchamp provided updates as follows:

- 1. The Driving and Dementia town hall in Carson City, hosted by the Alzheimer's Association, will be from 9:30 a.m.-11:30 a.m. on April 22, 2016 at the Legislative Building and Plaza, Room #2134 in Carson City. (See Attachment H for flyer.)
- Jacob Harmon, Northern Nevada Alzheimer's Association, has offered to distribute the survey for persons with dementia and their family members at support groups, which will increase participant input from Washoe County.
- 3. The subcommittee is in contact with LeeAnn Mandarino at the Lou Ruvo Clinic in Las Vegas, and is shortening the survey so that it can be distributed to clients at the Center to increase input from Clark County.

Dr. Reed commented that surveys are being conducted with people living with Alzheimer's disease and other forms of dementia and their care partners, both in northern and southern Nevada and rural communities. Town hall meetings are also being hosted. Surveys will also be administered to physicians and healthcare providers about their perspectives on driving and dementia. This information will help the subcommittee formulate recommendations. The draft of these recommendations will be presented to TFAD in June 2016.

XII. Discussion and Possible Recommendations on Caregiver Support for the State Plan (For Possible Action)

Albert Chavez and Jacob Harmon Alzheimer's Association

Jeff Duncan
Chief
Supportive Services
Aging and Disability Services

Mr. Chavez stated that new facts and figures were received in March 2016. To date, there are about 41,000 individuals in Nevada battling Alzheimer's disease. The number keeps increasing and there is no cure.

Mr. Chavez commented that there are three major areas of deficiency in Nevada and across the nation. These areas include:

- 1. Awareness
- 2. Assessment and Diagnosis
- 3. Navigation and Placement

Navigation relates to caregiver support. Mr. Chavez observed that a number of programs and services support this effort, but they need to be better promoted. Both evidence-based programs and State-funded programs and services can be publicized on the website, as well as through other venues.

The Alzheimer's Association offers programs, such as the Family Care Consultation, Respite Vouchers for caregivers, Trinity Care Program to relieve caregiver stress, Early State Partners in Care (EPIC), and other education programs. Nevada Senior Services also offers various programs to assist caregivers. Collectively, a number of existing programs and services are available, but the information about them needs to be better disseminated.

Jacob Harmon explained that there is also a robust portfolio of services available to families living with Alzheimer's disease and other forms of dementia in northern Nevada, including programs offered through the Alzheimer's Association and other community partners. Additionally, caregiver respite programs allow for needed breaks. The Caregiver Support Grant through the

Aging and Disability Services Division (ADSD) provides funding for outreach education and training, as well as individualized case management throughout northern Nevada in both urban and rural areas.

The Alzheimer's Disease Supportive Services Program (ADSSP) grant funds the EPIC program which involves early stage engagement, but lack of awareness and lack of proper knowledge/diagnosis limit participation the program. Outreach to physicians and medical providers would be critical in improving caregiver support, especially for early stage engagement.

Mr. Harmon commented that tremendous work is being done in Winnemucca to promote an age-friendly community, and progress has been achieved through similar efforts in Henderson. He stated that the Alzheimer's Association and their community partners are convening a Dementia Friendly Summit on May 11, 2016 in both northern and southern Nevada. The northern Nevada meeting will be held at the Governor's Office on Economic Development. TFAD members are invited to participate. The goal is to begin a statewide conversation about the changes that we can make and partnerships that we can create with private businesses, state agencies, and non-profit organizations. Working together, for cost-effective changes, we can improve access and engagement in our communities for people living with Alzheimer's disease and other forms of dementia.

Sen. Wiener remarked that, should the TFAD legislative members be interested, they could introduce a concurrent resolution to include an awareness component for licensing entities as part of the training they already require. It could address how to facilitate connections with support services.

Sen. Wiener charged Mr. Chavez and Mr. Harmon with putting together specific language to address the recommendations regarding caregiver support.

Ms. Simons noted that there are State Plan recommendations, relevant to caregiver support, cited on the Alzheimer's Association State Policy Platform, so there already appears to be interest in the expansion of these objectives.

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

Sen. Wiener reviewed the work timeline for the revision of the State Plan. Action items for next meeting will include:

- 1. Discuss and vote on what to retain, remove, or add.
- 2. Discuss language revisions.
- 3. Move former recommendations, as determined by TFAD, to appendix.
- 4. Review Driving and Dementia first draft.
- 5. Review first draft of other new recommendations.

- 6. Decide further legislative action on any recommendations.
- XIV. Discuss Next Meeting Date (For Possible Action)
  Senator Valerie Wiener (Ret.), Chair

The next meeting is scheduled for June 1, 2016.

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

Kris Kingery, a long term caregiver for her mother, provided comments. Ms. Kingery offered suggestions on ways to increase education and awareness, emphasizing the benefits of using social media, which she believes would promote easier access and allow simpler exchange of information. Input from caregivers to better meet their needs can also be solicited through social media.

Ms. Kingery related personal experiences surrounding driving and her mother's dementia. She suggested that if a program were tied into the AARP's driving safety course, some incentives could be offered for safe senior drivers to promote more compliance.

Regarding POLST, Ms. Kingery remarked that the amount of paperwork caregivers have to handle on behalf of their wards is already overwhelming. A centralized access point for the POLST form, Power of Attorney (POA), guardianship forms, etc., would be helpful. She also suggested that individuals should be able to complete the POLST form and have it in place well before the end-of-life care is needed.

Dr. John Yacenda, President of the Nevada Silver-Haired Legislative Forum, provided comments. He expressed particular interest in agenda items XI and XII.

On agenda item XI, Dr. Yacenda emphasized that many older adults who don't have dementia are able to handle driving just fine without family intervention by making gradual changes to the ways they drive as they age. However, it's different for persons with Alzheimer's disease and other forms of dementia. For individuals with declining cognitive functions, several issues surface in different stages. Therefore, a focus on dignity and sensitivity should be underscored when addressing the concerns on driving and dementia.

On agenda item XII, Dr. Yacenda offered several suggestions to assist caregivers. He remarked that it is very important to express gratitude often to caregivers. Recognizing the signs of caregiver stress and offering respite care to them is also paramount.

Dr. Yacenda submitted a written statement on his comments which are attached. (See Attachment I)

#### XVI. Adjournment

The meeting was adjourned at 1:15 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.