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MINUTES

Name of Organization:	Task Force on Alzheimer's Disease (TFAD)
Date and Time of Meeting:	February 3, 2016 10:00 a.m.
Location:	Governor's Office of Economic Development 808 West Nye Lane Carson City, NV 89703 (775) 687-9900
	Governor's Office of Economic Development Grant Sawyer Building 555 E. Washington Avenue, Suite 5400 Las Vegas, NV 89101 (702) 486-2700
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: Sen. Valerie Wiener, Sen. Joe Hardy, Assemblyman James Oscarson, Albert Chavez, and Peter Reed., Ph. D

Members participating by telephone: Gini Cunningham, Jane Fisher, Ph. D., Julie Kotchevar, and Wendy Simons

Member absent: Charles Bernick, M. D.

Alternate present: LeeAnn Mandarino

Guests present: Cheyenne Pasquale, Daniel Mathis, and Robert Kidd

Guests participating by telephone: Susan Longchamp

Staff present: Jeff Doucet and 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.)

No public comment.

III. Welcoming Remarks

Senator Valerie Wiener (Ret.), Chair

Sen. Valerie Wiener expressed appreciation for the recent timely completion and submission of the Annual Report. She thanked TFAD members and staff for their efforts.

Sen. Wiener outlined important tasks for 2016, which will require work on both the revision of the State Plan and preparation of the Annual Report, as well as other ongoing tasks.

Staff will send reminders and coordinate requests for information and deadlines for work to be completed.

IV. Approval of the Minutes from December 11, 2015 Meeting (**For Possible Action)**

Senator Valerie Wiener (Ret.), Chair

Wendy Simons moved to approve the minutes from December 11, 2015. Gini Cunningham seconded the motion. Minutes were unanimously approved.

V. Review Purpose and Authority of TFAD and Make Possible Recommendations **(For Possible Action)**

Julie Kotchevar
Deputy Administrator
Aging and Disability Services Division

Sen. Wiener stated that Sen. Joe Hardy has agreed to sponsor a bill to extend the life of the task force in the 2017 Legislative Session.

Sen. Wiener asked Julie Kotchevar to review the scope and authority of TFAD.

Ms. Kotchevar provided an overview of the purpose of TFAD as follows:

- TFAD was established by NRS 439.5.

- The sunset date for TFAD is June 30, 2017.
- Duties are outlined in statute and include developing a State Plan and monitoring its progress; review and revise it, prioritize the actions necessary to carry out the State Plan; and research and review any other issues relevant and related to Alzheimer's disease.
- An Annual Report is required to be submitted to the Governor by February 1st of each year.

Ms. Kotchevar related that TFAD functions similarly to other advisory councils and task forces. She explained how an advisory committee works compared to one that has regulatory and statutory ability to take actions.

The role of TFAD, as an advisory board, is to focus on a designated issue and affected population group. TFAD is required to develop a plan to help guide the agencies on how services should be delivered. TFAD is not charged with funding related services.

Ms. Kotchevar described that typically the funding for a task force is put into a supporting agency. In this instance, Aging and Disability Services (ADSD) is the supporting division for TFAD. She explained that the funding for TFAD only pays for support of the task force and for travel to face-to-face meetings.

Responding to Sen. Wiener's query about a provision regarding gifts, grants, and donations, Ms. Kotchevar confirmed that there is such a provision and the money received can go into a special account that can be distributed for specific purposes to support the initiatives in the State Plan.

Discussion ensued about how money received as gifts from outside sources may be used. Ms. Kotchevar commented that TFAD and ADSD would have the ability to award grants for specific purposes, once agreed upon by vote of TFAD members. Should a large sum be received, ADSD could go to the Interim Finance Committee (IFC) to seek approval to accept the money and to distribute the money on behalf of TFAD.

Questions arose from LeeAnn Mandarino regarding how to raise funds for possible support of the Nevada Research Consortium on Dementia (NRCD). Ms. Kotchevar explained that, though the group did form in response to a TFAD State Plan recommendation, it is not officially a subcommittee of TFAD. Ms. Mandarino proposed looking at possible funding avenues and how funding can be secured for NRCD in the future.

Assemblyman Oscarson stated, for the record, he would co-sponsor a bill to extend the life of TFAD and continue this important work.

Sen. Wiener instructed staff to include the discussion to move forward plans for funding initiatives associated with TFAD State Plan recommendations.

VI. Discuss and Make Plans for Revision of TFAD State Plan **(For Possible Action)**
Senator Valerie Wiener (Ret.), Chair

Sen. Wiener reviewed the development of the State Plan to Address Alzheimer's Disease from the time of inception in the Assembly Concurrent Resolution 10 (ACR 10). She stated that TFAD members agreed to revise the State Plan every two years since then.

In 2016, TFAD will be updating and revising the recommendations in the State Plan preparatory to the upcoming Legislative Session in 2017, as well as preparing the Annual Report, as required by statute. Therefore, work plans will have to move forward more expeditiously.

Sen. Wiener stated that a timeline for materials to be submitted will be distributed to members prior to the next meeting.

VII. Updates 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 stated that after receiving input from TFAD members at the meeting on October 23, 2015, she incorporated the various modifications/recommendations into the website. Some of the changes include: inserting the disclaimer about outside links, adding the 800 number for the Alzheimer's Association hotline, and updating the language defining Alzheimer's disease as one form of the many dementias that exist.

Ms. Pasquale presented an interactive update of the Aging and Disability Resource Center (ADRC) website by Power Point presentation, utilizing live content on ADRC website. Some of the content highlighted from the page included:

- Navigational and menu options to facilitate easier access to information.
- Alzheimer's Research page with information provided by the Alzheimer's Association and more to be added from the Cleveland Clinic Lou Ruvo Center for Brain Health and the Nevada Research Consortium on Dementia (NRCD).
- Dementia Library page with various definitions and helpful resources listed, as well as links to those resources.
- Print and email capabilities for informational pages and links on the website.
- Social media buttons available for information sharing.
- "I Need Help" page with contents still under development.

- Resource Directory compiled from applicants through the main ADRC page.

A copy of Ms. Pasquale's Power Point Presentation is attached on file (See Attachment A)

Discussion ensued about ensuring credibility of the Resource Directory. Sen. Wiener recommended putting the disclaimer on multiple pages, rather than just in one place, to clarify that TFAD is not endorsing the providers listed. Albert Chavez concurred, suggesting that a disclaimer bar could be added to every page.

Ms. Pasquale commented that a Frequently Asked Questions (FAQ) page could be added to include information specific to Nevada. She will work with Mr. Chavez and Jacob Harmon of the Alzheimer's Association to construct the page.

Sen. Wiener inquired about the inclusion of research information and templates about researchers and their pertinent information, citing caution again that material presented not be displayed as an endorsement by TFAD. Ms. Mandarino suggested that there could be a panel of physicians and researchers within the NRCD who could screen applicants who apply to be included on the ADRC research page. This could be an effective vetting process.

Jane Fisher, Ph. D. commented that the minimum bar for including research should be that it has been approved by a federally sanctioned Institutional Review Board (IRB), with strict federal guidelines, and explained the process of research approval.

Dr. Fisher suggested adding a question on the application to ask whether the research and studies have been approved by an IRB. Ms. Kotchevar shared that not all research is required to be approved by the IRB, so if that is the case, a provider should give an explanation of why the research was exempt.

Dr. Fisher encouraged an optimistic tone in how the ADRC website is presented, including using positive visuals, images, and language; promoting engagement by individuals and families; and enhancing/supporting relationships as people navigate living with Alzheimer's disease and other forms of dementia. She noted that, along with presenting the physiology of the disease, encouraging a positive outlook and preserving the quality of life is crucial.

Mr. Chavez expressed that there also needs to be a balance in the way the information is presented. Caregivers need help with understanding the diagnosis and that Alzheimer's disease and other forms of dementia are life-ending. They need to know that the stress of caring for loved ones with these conditions can be potentially life-threatening, so building awareness is extremely important.

Dr. Reed echoed Dr. Fisher's recommendation to help people recognize that, although Alzheimer's disease is fatal, it is possible to live well each day. This is a great opportunity to de-stigmatize the disease. Rather than emphasize the 'tragedy' of the disease, we should focus on improving the everyday living experience.

Sen. Wiener remarked that there are ways to present the gravity of the disease, and yet remain positive in providing solutions and assistance.

Assemblyman James Oscarson recommended looking at other states and organizations' websites to see how their information is presented and gather ideas for appropriate language to use.

Ms. Mandarino suggested presenting information/statistics on how to maintain a healthy brain to render a positive outlook on the opening page.

Ms. Mandarino and Mr. Chavez committed to assist Ms. Pasquale with the "I Need Help" page to present people living with Alzheimer's disease and their caregivers with connections to resources and how to find support.

Sen. Wiener proposed adding personal stories of those who are living meaningful lives with the diagnosis, along with caregiver stories, which could provide inspiration for others.

Sen. Wiener requested for Ms. Pasquale to give another update on the ADRC website at the next TFAD meeting.

VIII. Updates and Possible Recommendations on Behavioral Health Placements/Facilities **(For Possible Action)**

Daniel Mathis
President and CEO
Nevada Health Care Association

Daniel Mathis reported that, since the implementation of the new behavioral rate in May 2015, many facilities are bringing back the dementia/Alzheimer's behavioral unit model. The number of beds available in behavioral units has doubled from three skilled facilities to six skilled facilities, with seven more facilities expected to be added in 2016.

Mr. Mathis stated that the Subcommittee to Conduct a Study of Postacute Care will be meeting on February 17, 2016 at the Legislative Building in Carson City. Information on this meeting is available on the Nevada Legislature website.

Mr. Mathis explained that the Tier I and Tier II behavioral programming have been implemented without difficulty. However, the Tier III level has presented challenges for providers who are not certain whether they can provide that level of care.

Mr. Mathis invited Robert Kidd, President of the Perry Foundation, which is the 501(c)(3) educational arm of the Nevada Health Care Association (NVHCA), to share information on their work.

Mr. Kidd gave an overview of the foundation's work, which involves providing evidence-based education to caregivers and healthcare professionals in the skilled-nursing arena, as well as assisted-care and memory-care facilities in Nevada.

Mr. Kidd shared several initiatives that aligned with the interest of TFAD, including:

1. Music and Memory Grant (pending approval from CMS)
    - Will certify all the memory-care facilities in Nevada and Music and Memory facilities.
    - Will initially target 20 facilities, reaching up to 900 residents with Alzheimer's or other forms of dementia.
    - Over a two-year period, quality of life for these individuals will be improved through music therapy.
    - The program is called the Nevada Music Memory Initiative.

2. Behavior Health Education
    - Funded through the Civil Monetary Penalties (CMP) funds
    - 2-year grant targeting health care professionals, focusing on behavioral health education to improve quality of care.
    - Intended to meet increasing needs from facilities since the implementation of Behaviorally Complex Care Program (BCCP).

3. Academy of Healthcare Prep
    - Approved by the Commission of Post-Secondary Schools on February 3, 2016.
    - Curriculum to include Certified Nursing Assistant (CNA) training program.
    - Several skilled nursing facilities in Las Vegas and Reno, which offer clinical care, have agreed to be training sites.

Discussion ensued about the purpose and use of CMP funds. Sen. Wiener and Mr. Kidd offered explanations to clarify the process of securing and distributing the funds.

Responding from a query from Assemblyman Oscarson regarding why there would need to be federal approval for funds collected in the State of Nevada through CMP, Ms. Simons outlined the specific criteria for the use of these funds, particularly to improve quality of care for individuals. Assemblyman Oscarson would like to ensure that the funds can be accessed, without unnecessary challenges, for the benefit of Nevadans.

Sen. Hardy inquired about what amount of money is in the CMP funds at this time. Ms. Kotchevar commented that ADSD can pursue that information from Cody Phinney, the administrator for Department of Public and Behavioral Health (DPBH).

TFAD members discussed potential benefits from using CMP funds in the State of Nevada, which include enhancing education and awareness for behavioral programs.

Ms. Simons and Mr. Kidd also described a State-sanctioned account that may have available funds to promote behavioral health-related programs.

Sen. Wiener explained that, with the passage of Senate Concurrent Resolution 2 (SCR 2), a bill sponsored by Sen. Hardy and supported by TFAD, providers can use up to two credits for Alzheimer's-related education. She suggested that the Perry Foundation could promote this opportunity in their training and education efforts.

Ms. Cunningham reiterated that the Music and Memory program has been implemented in a long-term care facility in Winnemucca for more than a year with excellent results, not only for dementia but for pain management, agitation, and confusion. She emphasized that it is a very worthy program.

IX. Updates and Possible Recommendations on Guardianship **(For Possible Action)**
Senator Valerie Wiener (Ret.), Chair

Sen. Wiener read, for the record, a report on the Supreme Court Guardianship Commission submitted to TFAD by Sally Ramm, ADSD Elder Rights Attorney.

Ms. Ramm highlighted the following:

- The Commission has now been extended until May 2016.
- All Commission members submitted priority issues, which were combined into 29 recommendations for the Commission to vote on.
- Justice Hardesty expects all of the recommendations to be discussed by the end of the meeting in April.
- One of the approved recommendations is that the Supreme Court establishes a permanent commission to address issues of concern to those who would be subject to guardianships or alternative to guardianship processes in Nevada.
- Much attention is being paid to including people of all ages and all abilities in the conversation about guardianship.

- Another approved recommendation is to include in the Nevada Revised Statutes a Bill of Rights for persons subject to guardianship jurisdiction.
- The Commission has approved the recommendation that adults facing guardianship must have their own attorneys. The Commission is also discussing the proposal that the adults must be at every hearing concerning them, unless the court finds that the reason they are not present is reasonable.
- Other issues are being discussed and voted upon, and participants must determine how to turn the Commission's recommendations into actions and outcomes.

The complete written statement by Ms. Ramm is attached on file. (See Attachment B)

Sen. Wiener remarked that the these progressive actions by the Commission are positive steps in improving the challenges that Nevadans have been facing, and TFAD will continue to work to address these guardianship issues.

Assemblyman Oscarson offered to lend support should any legislative action be needed regarding guardianship.

X. Updates and Possible Recommendations on the Nevada Research Consortium on Dementia and Care Pathways

(For Possible Action)

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

NRCD

LeeAnn Mandarino gave an overview of the Nevada Research Consortium (NRCD) and shared outcomes from the first meeting on November 20, 2015.

She stated a mission statement will be developed, which may include some variation of "encourage expanded research opportunities and collaborations throughout Nevada related to Alzheimer's disease and other dementias. Disseminate emerging information within the research community, as well as to those with Alzheimer's disease, their families, and caregivers."

Several recommendations were presented, including:

1. Creating a panel to help researchers throughout Nevada secure grants through the National Institutes of Health (NIH) and through University Research Services Administration (URSA), and act as a sounding board to make recommendations to how to bring more grants to Nevada.

2. Encouraging face-to-face meetings to enable researchers throughout Nevada to coordinate their efforts and expand possibilities for research.
3. Presenting research information on the ADRC website to link researchers to participants by displaying the researchers' biographies, contact information, research projects, and clinical trials.
4. Inviting graduate students to participate in research projects to increase opportunities for research development.

Ms. Mandarino noted that the next NRCD meeting will be presented via telephone conference on February 12, 2016. There will be presentations by Dr. Charles Bernick and discussions on the next steps.

NRCD inaugural meeting notes submitted by Ms. Mandarino are attached on file. (See Attachment C)

Care Path Consortium

Ms. Mandarino commented that plans are being discussed to convene hospitalists, various personnel within the hospitals, volunteers, and other stakeholders to solicit input on best-care practices for patients with Alzheimer's disease and other forms of dementia from the time of admission to discharge.

Ms. Mandarino proposed that each group of stakeholders could present recommendations for best-practice methods, and then meet to vote on suggestions/ideas they would like to present to TFAD.

Ms. Mandarino will contact Bill Welch from the Nevada Hospital Association for referrals to potential participants.

Discussion ensued regarding the possibility of combining the Care Path Consortium with the Telehealth/Telemedicine Consortium.

Mr. Chavez stated it would be beneficial to explore the arrangement, or possibly create a separate consortium, since a lot can be accomplished when a group of professionals come together. They can also share information about the telehealth/telemedicine programs.

Ms. Cunningham remarked that in Winnemucca the local hospital has a program for follow-up care for patients who have transitioned out, ensuring that they are not left alone and that post-care instructions are followed. This program has yielded very positive results.

Dr. Reed offered to participate further in the discussions around telehealth/telemedicine, citing that, in addition to the strong telehealth education program through UNR School of Medicine and Project Echo, the Sanford Center is also doing work specific to geriatrics. The Sanford Center just completed an eight-part telehealth education series on geriatric care, which included several modules relevant to Alzheimer's disease and other forms of dementia. These will be archived and have CEU credits attached.

Dr. Reed explained that these educational series served as an orientation for providers in rural communities to help them understand the telemedicine services. These services, which will be launched within the next couple of months, will provide rural primary care providers with specialty geriatrics consults for complicated patients.

Mr. Chavez concluded that it would be beneficial to include a link to telehealth programs and telemedicine services on the ADRC website.

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

Jane Fisher, Ph. D.
Department of Psychology
University of Nevada, Reno

Dr. Fisher presented an overview of the work accomplished by the subcommittee thus far. The overall goal is to address the issue of driving and dementia and the safety of persons with dementia and their families, as well as the entire community, while also supporting and promoting the independence of persons with cognitive disorders.

Dr. Fisher reported that the strategy has involved gathering input from stakeholders. These include: persons who are living with cognitive disorders, their families, and a variety of professionals. These professionals might either interact with persons with disorders or evaluate their competence to drive.

Nine town hall meetings have been held across Nevada, with the majority conducted in rural communities through the efforts of Gini Cunningham and the Alzheimer's Association of northern and southern Nevada.

Dr. Fisher explained that surveys will be conducted with healthcare providers through Dr. Reed. Input will be solicited from social services professionals and law enforcement professionals as well.

At the last subcommittee meeting on February 1, 2016, Department of Motor Vehicles (DMV) professionals were invited to present information related to seniors and driving. Jude Hurin and April Sanborn, Program Managers at Nevada DMV, shared details about a program in the state of Iowa that involves a screening tool for assessment. The Driver Orientation Screen for Cognitive Impairment (DOSCI) card is used to test the orientation of a person and screens for possible cognitive impairment. Nevada's DMV expressed interest in working with the subcommittee to explore this and other driving and dementia-related programs to provide solutions for Nevada.

Dr. Fisher remarked that Ms. Ramm, Elder Rights Attorney, also presented an overview of Nevada law regarding driving and dementia based on research from both the Nevada Revised Statutes and the Nevada Administrative Codes.

Dr. Fisher asked Susan Longchamp, a doctoral student in Clinical Psychology, who has been involved in constructing survey instruments, organizing and leading town hall meetings, and synthesizing data, to present preliminary data from the town halls meetings and stakeholders, derived from 128 persons, including persons with cognitive disorders, from eight Nevada Counties. See Attachment D for further details.)

Sen. Wiener encouraged soliciting more input from urban areas, because samples do not appear to be representative of the general population of Nevada.

Dr. Fisher indicated that there are additional town hall meetings planned for Clark County and Washoe County.

Discussion ensued about the distinctions between the needs for alternative transportation in rural vs. urban areas. Ms. Cunningham shared concerns regarding lack of alternative transportation in the rural communities, whereas Sen. Wiener noted the availability of those resources in urban areas; however, there is often a lack of support from friends and families.

Ms. Mandarino offered to secure approval from the administrator to distribute the surveys at the Cleveland Clinic Lou Ruvo Center for Brain Health and to deliver them through their outreach programs as well.

Mr. Chavez also proposed that surveys can be dispersed through educational events, Latino conferences, and other programs in southern Nevada.

Members shared personal experiences regarding cases involving concerns with driving and dementia. Some of the issues surrounded negative interactions with physicians, which resulted in adverse outcomes. Individuals felt that a diagnosis should not be the only basis of judgement that someone is no longer capable of driving. A more thorough assessment process should be used.

Dr. Fisher concluded that additional work needs to be done to ensure a comprehensive study of the issues surrounding driving and dementia, and the subcommittee will continue to keep TFAD abreast on its progress.

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

Possible agenda items for the next meeting include:

1. Discussion on State Plan Revision (Timeline will be distributed ahead of time)
2. Further discussion on ways to garner resource funding for NRCD and other programs TFAD support.
3. Update from Cheyenne Pasquale on the ADRC website.
4. Update on facilities from Daniel Mathis, along with status of grants and new programs from Robert Kidd.
5. Update on Guardianship
6. Status of NRCD and Care Path Consortium
7. Update from Driving and Dementia Subcommittee

XIII. Discuss Next Meeting Date **(For Possible Action)**
Senator Valerie Wiener (Ret.), Chair

The next meeting is scheduled for Friday, April 1, 2016.

XIV. 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, Executive Secretary for Ward 1 and Ward 5, Las Vegas, provided comments and shared personal experiences regarding caring for friends and family living with Alzheimer's disease. Mr. Martin described his engagement in various Alzheimer's and dementia-related projects. Mr. Martin related personal challenges and urged TFAD to continue to carefully investigate the driving issue and other concerns of those living with cognitive impairments.

Leo Molino, accompanied by Jose Castillo, Jr. both representing the Association of Homecare Owners of Northern Nevada (AHONN), provided comments. Mr. Molino stated that 60-80% of the residents in the group home setting have dementia. In order to educate the owners, administrators, and caregivers, they need the training to learn how to care for those with dementia in their setting. Mr. Molino asked for recommendations of people who may be able to provide the training and education needed. He requested further contact to be made to www.ahonn.org.

John Yacenda, Ph. D., MPH, President of the Nevada State Silver Haired Legislative Forum, provided comments. Dr. Yacenda emphasized the need for maintaining and restoring dignity to those living with Alzheimer's disease and other forms of dementia by instilling positivity and optimism in all the work that we're doing on their behalf. Dr. Yacenda commented that the forum would be interested in assisting with input for the ADRC website. He suggested adding an area where those living with Alzheimer's disease and other forms of dementia can share their first-hand daily-living experiences and their views.

XV. Adjournment

The meeting was adjourned at 12:40 p.m.

<u>NOTE:</u> 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