

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

Administrative Office 3416 Goni Road, D-132 Carson City, NV 89706

RICHARD WHITLEY Director

> **JANE GRUNER** Administrator

BRIAN SANDOVAL Governor

(775) 687-4210 • Fax (775) 687-0574 adsd@adsd.nv.gov

MINUTES

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

Date and Time of Meeting: October 23, 2015

10:00 a.m.

Governor's Office of Economic Development (GOED) Locations:

> Conference Room 808 W. Nye Lane

Carson City, NV 89703

(775) 687-9900

Division of Child and Family Services (DCFS)

6171 W. Charleston Blvd.

Building 8, Room A Las Vegas, NV 89146

(702) 486-0077

To Join the Telephone

Conference

Call-in Number: 877-336-1831

Access Number: 9186101

Agenda

Ι. Call to Order/Roll Call

Senator Valerie Wiener (Ret.), Chair

Members present: Sen. Valerie Wiener and Dr. Peter Reed

Members participating by telephone: Dr. Charles Bernick, Gini Cunningham, Dr.

Jane Fisher, Julie Kotchevar, Wendy Simons

Alternates present: LeeAnn Mandarino and Jacob Harmon

Presenters present: Kyle Devine, Kate McCloskey, Jeanne Hesterlee, Sandra Kitchener, and Cheyenne Pasquale

Presenters participating by telephone: Daniel Mathis and Sally Ramm

Guests: Susie Longchamp, Dr. Shawn McGivney, Kerry McGivney, Vangie Molino, Leo Molino, Jose Castillo, Joseline Castillo, and Theresa Brushfield

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.)

Shawn McGivney, M. D., provided comments on behalf of two residential care home associations: Residential Care Home Community Alliance of Nevada (RCHCAN) and Association of Home Care Owners of Northern Nevada (AHHONN). Dr. McGivney stated that these two associations represent most of the residential care homes in Nevada.

Dr. McGivney voiced concern about several factors contributing to the accelerated decline of long-term care beds for chronically ill Nevadans, especially those with mental illness, Alzheimer's disease, and other forms of dementia. (See Attachment A)

III. Welcoming Remarks

Senator Valerie Wiener (Ret.), Chair

Sen. Valerie Wiener, Chair, welcomed all to the meeting. She expressed appreciation for the high level of participation from both TFAD members and members of the public.

Sen. Wiener reminded members of the upcoming TFAD meeting on December 11, 2015, which will be a face-to-face meeting at the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas. She emphasized the importance of this meeting as TFAD will be working on the Annual Report.

IV. Approval of the Minutes from August 21, 2015 Meeting (<u>For Possible Action</u>)
Senator Valerie Wiener (Ret.), Chair

Wendy Simons moved to approve the August 21, 2015 minutes. Peter Reed, Ph. D., and Julie Kotchevar seconded the motion. Minutes were approved unanimously.

V. Updates and Make Possible Recommendations on Assembly Bill 9 and Other Guardianship Issues (For Possible Action)
 Sally Ramm

Elder Rights Attorney Aging and Disability Services Division

Sally Ramm provided an update on the work of the Supreme Court Commission to Study the Administration of Guardianships in Nevada's Courts. She stated that four meetings have been held, and three more are scheduled before the end of the year. She related that Justice Hardesty wanted all the work completed before the end of the year, but there is much work yet to be accomplished. Members of the Commission include public and private guardians, private attorneys, district attorneys, legal services attorneys, judges including juvenile court judges, a victims' advocate, legislators, and the media. Information is also being provided to the Commission by the public, including families of people who are or have been under guardianship.

Ms. Ramm reported the Commission is gathering information from many sources, including other states, and also information from members regarding their roles in guardianship.

Ms. Ramm explained the overall goals and objectives of the Supreme Court Guardianship Commission, including its intention to review the Nevada Revised Statutes that affect every aspect of guardianship. It plans to:

- Create rules that focus on accountability.
- Provide for investigations and compliance before, during, and after guardianship court proceedings.
- Examine legal processes, including:
 - Adequacy of petitions.
 - Physician statements.
 - Counsel or guardian ad-litem for wards from the beginning of the process.
 - Burden and standard of proof.
- Insure person-centered standards rather than being institution focused.
- Examine the length of time between required fiduciary reports. Is every 12 months adequate?
- Examine fees being charged to wards and who pays them when petitions are denied.
- Separate statutes for adult and minor guardianships.
- Improve information gathering of court statistics.
- Create training and education for wards, guardians, families, attorneys, judges, courts, and law enforcement.
- Address privacy concerns to clarify which information included in petitions for guardianship should be confidential and which must be made public.

Ms. Ramm added that more issues surface at every meeting. The Commission will decide which concerns can be addressed through changing court rules, which can be resolved through regulation, and which will require new legislation.

Ms. Ramm urged TFAD to pay particular attention to what is specifically addressed, including issues pertaining to TFAD concerns, such as AB 9 of the 2015 Legislative Session, which involve out-of-state placement.

Responding to a query from Sen. Wiener regarding the separation of adult and minor guardianship statutes and whether data is being provided on the statistics for each group, Ms. Ramm commented that Justice James Hardesty had ordered the review of all guardianship files—"scrub the guardianship files"—to gather all kinds of demographic statistics, including determining which are still active and which are not, as well as how many are pending. Ms. Ramm reported that Clark County started with approximately 8500 guardianship cases, and the number is now down to 3500. Washoe County started with approximately 1500 and is now down to under 1000.

Ms. Ramm stated that one of the primary goals is to create the IT infrastructure that allows for data sharing between Washoe and Clark Counties. This project is funded by grants from associations outside the state.

Responding to a query from Sen. Wiener in the discrepancies in the numbers of cases in Washoe County and Clark County, Ms. Ramm shared that it is likely that records have not been updated correctly. Often a temporary guardianship case has expired but remains on the record. Sen. Wiener expressed her appreciation that the guardianship files are finally being reviewed and cleared out appropriately.

Sen. Wiener thanked Ms. Ramm for the thorough report, and asked her to keep the TFAD updated on the outcomes from the Commission at the next TFAD meeting. Ms. Ramm provided notes to be included in the meeting file. (See Attachment B)

VI. Updates and Make Possible Recommendations on Behavioral Health Placements/Facilities (For Possible Action)

Daniel Mathis
President and CEO
Nevada Health Care Association

Representative American Health Care Association

Daniel Mathis commented that he extended an invitation to a representative from the American Health Care Association to attend the TFAD meeting, but there were several conflicts which prevented their coming at this time. He plans to solicit their involvement again in the future.

Mr. Mathis stated that the Nevada Health Care Association (NVHCA) met with Richard Whitley, Director of the Nevada Health and Human Services Department, to discuss a number of issues including:

- a) How to streamline the Medicaid programming requests in-house.
 - Residents who are already in skilled nursing facilities may qualify for behavioral programming but the process has a 12-page requirement which needs to be improved.
 - Often, requirement timelines for specific documentations are inconsistent, so this needs to be revised.
- b) Clarify and define the programming tiers.
 - What behaviors would be addressed at each level?
 - What professionals (i. e. psychiatrists, psychologists) would be involved and what approach would be used?
 - Work with regulators to ensure that appropriate care is given at the higher tiers, especially Tier II and Tier III where patients were often referred out of state.
- c) Work with the hospitals on pre-authorizing patients for behavioral rates before discharge.
 - Hospitals could let the nursing facilities know what tier the patients would qualify for before they leave the hospital.
 - This will help keep Nevadans in Nevada rather than being sent out of state.

Mr. Mathis reported that there will be another meeting with Director Whitley on December 16, 2015, to determine what progress has been made.

From the interest shown by the providers, Mr. Mathis related that in the next six to eighteen months, we will see resurgence in the number of behavioral units with appropriate programming in Nevada. Many facilities have contacted the NVHCA to receive training and learn more about the programming for the behavioral rates.

Discussion ensued on AB 242, a bill relating to the study of post-acute care. Mr. Mathis conveyed that the first hearing will be on November 17, 2015. This hearing will deal with quality of care. There will be presentations from the NVHCA, Health Care Quality and Compliance (HCQC), Division of Public and Behavioral Health (DPBH), Medicaid, and other associations that represent post-acute care providers.

Responding to a query from Sen. Wiener regarding whether an increase in interest from the providers can be quantified, Mr. Mathis testified that right now there are about 100 beds in skilled nursing facilities, specified as behavioral or Alzheimer's, which will initially increase to about 500 statewide.

Ms. Simons inquired whether there is any initiative to bring back those who have been placed out of state. Mr. Mathis stated that, according to the Department of Health Care Financing and Policy (DHCFP), each situation should be assessed on a case-by-case basis according to the needs of the individual receiving the care. Families will be informed of the services now available in Nevada. DHCFP would work with those families to help bring them back.

Mr. Mathis concluded that there will certainly be outcomes from the upcoming December 16, 2015 meeting.

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

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

Jane Fisher, Ph. D., reviewed the goals and objectives of the Driving and Dementia Subcommittee. She stated that the main goal is to develop recommendations that would support the independence of persons with dementia and their families, while also promoting their safety and the safety of the larger community. The potential loss of independence, due to losing one's driving privileges, can produce serious consequences for individuals. Therefore, the group wants to make sure their recommendations are well-informed.

The subcommittee is collecting information from three broad sources. First, the group is examining current research on the assessment of driving competence to understand what would be a valid, cost-effective way of assessing driving competence.

Dr. Fisher related that Susan Longchamp, a doctoral student in the clinical program at UNR, is assisting the subcommittee in collecting the data. Ms. Longchamp is doing this as part of a program requirement.

Second, the subcommittee is reviewing regulations that are being enforced in other states. There is a lot of variability nationally. For instance, in California, individuals automatically lose their driving privileges once a physician determines that they are experiencing moderate levels of cognitive impairment. This law has created an unintended consequence: Californians who are at risk for losing their driving privileges are avoiding their health care providers.

The third source of information is input from Nevada stakeholders. The subcommittee is collecting information from persons with memory disorders, as well as family members. These data are being collected in the context of town hall meetings, which are being conducted in both rural and urban communities.

According to Dr. Fisher, the cost of individuals losing their driving privileges and transportation support infrastructure vary significantly across the rural as well as more urban, developed communities in Washoe and Clark Counties. Therefore, the group must make sure to thoroughly assess what people are facing in the different locales.

Input from professionals, who are involved in the evaluation of an individual's driving competence and working with families directly when they're concerned about driving safety, is also crucial. A survey will be conducted among DMV staff across the state, along with social service professionals, including those from Elder Protective Services (EPS), Senior Centers, ADSD programs, and others who work with both older adults with cognitive disorders and their families.

Surveys will also be given to law enforcement officers. In addition, health care professionals, including physicians and nurses who work in specialty or primary care offices, will be surveyed. These professionals are directly involved in the diagnosis of individuals with neurocognitive disorder, reporting to the DMV, and counseling with individuals and their families.

Town hall meetings have been conducted in Winnemucca and Reno, and more events are being planned statewide.

At the end of this data-gathering process, the subcommittee will offer recommendations to TFAD for inclusion in the 2017 State Plan.

Gini Cunningham reported on outreach work that has been accomplished in the rural communities, beginning with the outcomes of the town hall meeting on September 16, 2015 in Winnemucca. Stakeholders from the community, including representatives from the police, the sheriff, the senior center, the city council, and caregivers participated. The meeting, which was well-attended, focused on driving and dementia, as well as discussing the bigger picture when people don't have their driving license. What services will be available to help them remain independently in their homes? Ms. Cunningham explained that a set of questions were used, which will be modified for other town hall meetings. The questions circulated around once the licenses are gone, what will be next?

Following the town hall meeting, a local group was formed to develop Winnemucca as an age-friendly community. The first meeting was held in early October 2015, and the group will be meeting monthly. An area of focus included improving transportation in Winnemucca, which will tie into the driving and dementia challenge.

Ms. Cunningham reported that a town hall was held in Lovelock, with a presentation on Alzheimer's disease and other forms of dementia. She is also planning to do another presentation for Carlin on October 29, 2015 at the Senior Center.

Ms. Cunningham reiterated that everywhere she visited, people are pleased that work to address Alzheimer's disease and other forms of dementia is being done. Additionally, law enforcement in all the communities expressed interest in receiving more training and education to better understand and serve those living with Alzheimer's disease and other forms of dementia.

Ms. Cunningham and Jacob Harmon of the Northern Nevada Alzheimer's Association are also planning a town hall meeting in Elko.

Dr. Fisher reinforced that the same set of questions will be utilized with panelists and stakeholders at each of the town hall meetings to achieve consistency with the information gathering. Ms. Cunningham conveyed that the stakeholders were hesitant to discuss their issues, perhaps due to fear of social stigma. Therefore, the questionnaire has been changed to communicate in the least threatening way to stakeholders.

Dr. Reed commented that the process that the subcommittee is engaging to identify a set of recommendations that is well-informed is very important and thorough. To have the research literature, the town hall meetings, and the surveys of the stakeholders and to be able to digest all that and synthesize, is a very thoughtful and meaningful approach.

Data from all Nevada sources and surveys are being collated and synthesized at the Psychology Department at UNR, and Susie Longchamp has been instrumental in managing the project. A team is entering the data into a spreadsheet, and ideally by mid to next Spring of 2016, the data could be ready to be shared with TFAD.

Dr. Fisher noted that the surveys for Nevada drivers and family members, as well as one geared for social workers, will be available on the ADSD website for anyone interested in learning more.

Of concern are possible ramifications if driver's license laws are changed and people refuse to comply and continue driving after they are prohibited. According to Dr. Fisher, two issues would need to be addressed in future recommendations:

- 1) The transportation infrastructure What will be available? What will the State be able to support in terms of support once the person losses the driving privilege?
- 2) Support for families What are some strategies for families to effectively handle the situation when someone is putting his/her life, as well as the safety of their community, at risk?

Discussion ensued about liability issues should an individual continue to drive when a license has been revoked. Another concern involves individuals who, when refused a license at/or fail, go to another DMV office and are issued a license. Additionally, Ms. Cunningham mentioned that a doctor could be held liable, once a certain diagnosis is made, and he does not prevent the patient from continuing to drive, even after reporting to the DMV.

Dr. Fisher expressed that we do not have enough data at this point to know whether the issue of variabilities at the DMVs is a significant issue or not. Physicians may also have difficulty assessing someone's behavior during an office visit compared to an out-of-office evaluation.

In addition, there is no specific data that links a person's poor driving performance with a specific diagnosis. Dr. Fisher pointed out that state agencies usually operate independently of one another. In most states, driving assessment is aged-based, rather than diagnosis-based. Therefore, at this point, there is no data specific to the history of poor driving performance as a result of a specific diagnosis.

Currently DMV provides a form on its website that can be used for anonymous reporting of drivers who might be neurocognitively impaired. The subcommittee is waiting for information from the DMV as to what they're experiencing and observing pertaining to these situations.

Sen. Wiener raised a concern about anonymous reporting. She stated that this method can be beneficial, but also risky. She urged the subcommittee to look into the DMV's procedures for determining the validity of the forms submitted by individuals regarding a person's ability or inability to operate a vehicle. How does the DMV make sure that the concern is authentic?

Ms. Cunningham stated that in Winnemucca, the police department has the anonymous reporting form one can submit, as well as request further investigation by the police department. Currently, DMV can automatically deny driving privileges to those who fail the written or the driving test. However, they don't have training or ability to assess whether someone is too impaired to continue driving simply based on the complaint from someone else, so they rely heavily on physician reporting, which may take up to two years to process.

At the Reno town hall meeting, a DMV representative stated that, regarding liability, it is uncertain who would be held accountable.

Mr. Harmon confirmed that the DMV has a process for removing a driver's license with a signed physician's report that a person is no longer able to operate a vehicle safely. DMV technicians do receive some training to identify signs and symptoms related to dementia, and anonymous reporting can put people on the

radar, but ultimately the DMV cannot take any action without authorization from a physician.

Mr. Harmon commented that the DMV currently has a task force of their own dealing with a project dealing with elder driving. He suggested it might be worthwhile to invite the project lead from the DMV to address TFAD.

Mr. Harmon noted that the Alzheimer's Association recently partnered with the Sanford Center for Aging to collect a behavioral risk factor surveillance survey data, which is a program run by the Center for Disease Control and Prevention (CDC), on both cognitive impairment and caregiving in Nevada. Those questions are set at this time, but when the survey is run again in two years in Nevada, particularly if there is funding from TFAD or ADSD, we could get questions added to that survey specifically around driving with cognitive impairment. Mr. Harmon suggested this would be a respectable way of gathering data within the scientific community.

Dr. Charles Bernick stated that, from a physician's standpoint, there is no statute requiring physician reporting of cognitively impaired people. The statute that is present pertains to Epilepsy or conditions categorized by lapse of consciousness. The Department of Public Safety, at one point many years ago, actually did include dementia as being under that category. Dr. Bernick conveyed that to his knowledge, not many physicians are aware of that statute. He emphasized that to get physicians involved, there would have to be statutory changes in the law.

Dr. Reed suggested that one of the standards for an appropriate approach is the competence testing, but the question is what is the trigger for that? Dr. Reed observed that it seems, in California, if that trigger is the diagnosis then there is a tendency for people to avoid seeking diagnosis, or engaging with the provider, which seems like a major complication. We also know that about half of the people who are estimated to have Alzheimer's disease don't even have a diagnosis. So a large number of people won't be detected with a diagnosis trigger.

Discussion ensued about whether there could be a 'blanket' approach to the testing, one that's not age-based, so there could be a determination, aside from Alzheimer's disease, of whether or not a person is capable of driving. Dr. Reed pointed out this may affect a lot of folks who don't have that diagnosis needed to trigger the testing, and we want to encourage early detection. In sum, is the diagnosis the preferred trigger? Or should we pursue a broader approach?

In California, once an individual is judged by a physician to be mildly cognitively impaired, he/she automatically losses the driver's license. The diagnosis of moderate cognitive impairment directly triggers the loss of license.

Responding to a query of whether the California statute is being appealed, Dr. Fisher affirmed that in larger metropolitan areas, like Los Angeles, attorneys specialize in helping older persons recover their driving privileges, such as individuals who may have lost their driving privileges because of multiple moving violations. Some cases are very dramatic, involving personal use histories of multiple moving violations and these persons may not be required to have a reassessment until they are more than 100 years old.

Dr. Fisher concurred with the idea to invite the elder driving project lead for the DMV and explained the plans for surveying physicians.

LeeAnn Mandarino recommended involving insurance companies in the process of information gathering.

Discussion ensued about possible dates and future town hall meeting locations. Ms. Longchamp informed the group that the dates for southern Nevada have not been set yet. Ms. Cunningham commented there will likely be six held in rural northeastern Nevada. Dr. Fisher stated that there will be a few held in the Clark County and Henderson areas, which will add to about four to six in southern Nevada. Sen. Wiener advised that Pahrump, Mesquite, and Moapa Valley would be communities that are unique in their relationship with the urban communities, and could be affected by concerns around senior driving issues as well.

VIII. Presentations and Make Possible Recommendations on Skilled Nursing Facilities, Residential Group Home Facilities, and Supportive Living Arrangements (For Possible Action)

First presenter: Kyle Devine Bureau Chief, Health Care Quality and Compliance (HCQC) Division of Public and Behavioral Health

Kyle Devine stated he was asked to give a presentation to clarify the difference between Residential Facilities for Groups (RFFGs) and Supportive Living Arrangements (SLAs). He presented an outline of his presentation as follows:

- Overview of the responsibility of the Bureau of Health Care Quality and Compliance (HCQC)
- 2. Overview of Residential Facilities for Groups
- 3. Differentiation between RFFGs and SLAs

Mr. Devine conveyed that the purpose of the Bureau of HCQC is to assure that health care facilities comply with all federal and state regulatory requirements, which assure the minimum standards and safety of all the residents in these facilities. Mr. Devine reported that there about 35 different health care facility types that HCQC oversees throughout Nevada, which includes approximately 1200+ licensed facilities statewide. Mr. Divine then presented statistics for

different health facility types and their locations. He also pointed out that Homes for Individual Residential Care is often confused with Supportive Living Arrangements.

Mr. Devine presented an overview of Residential Facilities for Groups (RFFGs) and homes for individual residential care. He related that, simply put, RFFGs are facilities that provide for the daily needs of an individual who resides in that facility. The same definition applies to homes for individual care, although because of the lower ratio of residents to caregivers, the care is more individualized. Mr. Devine explained that both of these facility types provide care to person with Alzheimer's disease and other forms of dementia, or memory care issues.

Mr. Devine commented that RFFGs are allowed to carry a number of endorsements. Those endorsements can include Alzheimer's disease, memory care, dementia, mental health, and other areas. Those who are endorsed for Alzheimer's disease must meet additional care and safety regulations, including safety standards, personnel standards, and training standards. He further detailed the requirements for the various standards.

Mr. Devine described the differences between RFFGs and SLAs, citing definitions found in the Nevada Revised Statutes and the Nevada Administrative Code. In distinguishing an RFFG from an SLA, an RFFG is a facility while an SLA is a service that can be provided in the home or other location and is individualized with the goal of maximizing independence. He provided a chart, which highlights the overview of the differences between RFFGs and SLAs.

A copy of Mr. Devine's Power Point summary for this presentation is on file. (See Attachment C)

Responding to a query from LeeAnn Mandarino regarding personnel training and certification for RFFGs, Mr. Devine provided details of the training requirements, including timelines for completion after initiation of employment.

Mr. Harmon inquired whether there are basic standards of training. Mr. Devine responded that regulations do not prescribe specific standards of training, so that is left up to the administrator, with the assumption that they're providing the training that is going to give the best care to the clients whom they serve.

Dr. Reed raised concern that beyond the specific dimensions that have to be included, which were mentioned earlier, there is no real assessment of the quality of training and the parameters in which it's being provided so people can understand how to really deliver high quality dementia care.

Mr. Harmon also asked about standards for activities in the facilities, and Mr. Devine informed him that, again, it is up to the administrator of the facility to direct the activities as appropriate to the needs of the residents.

Discussion ensued whether there have been workshops held to address the quality of training rather than the hours spent, which may not include the training that's effective or essential. Mr. Devine reported that, to his knowledge, these issues have not been addressed. However, HCQC may be opening up the regulations in certain areas for review and clarification. He stated that he can keep TFAD informed of these developments. Sen. Wiener reiterated Dr. Reed's concern that there is no measurement in the training standards or qualifications, aside from hours spent.

Responding to a query about who has the authority to set new regulations, Mr. Devine stated that the Board of Health is authorized. If TFAD should make recommendations in certain areas, HCQC would have to make sure that there are no prohibitions for moving forward with those regulations. If regulatory change is needed, the regulation would be drafted by the Legislative Counsel Bureau (LCB), public workshops would be held; the Board of Health would need to give approval; and the Legislative Commission would need to approve the regulations.

Ms. Mandarino requested that TFAD be notified of hearings concerning these matters. Mr. Devine confirmed that notices will be available to TFAD as well as the public.

Second presenter: Kate McCloskey Quality Assurance Manager Developmental Services, ADSD Sierra Regional Center

Kate McCloskey explained that a Supportive Living Arrangement (SLA) is a service, rather than a facility, and that service follows the person wherever he/she goes. The individual can move to various different community-based settings and receive that service.

Ms. McCloskey testified that the services are offered through the NV 1915(c) Home and community Based Waiver Program, which is funded through the Center for Medicaid and Medicare Services (CMS). This waiver serves people with intellectual disability or related conditions, such as autism or cerebral palsy. Ms. McCloskey described that SLAs are provided on a continuum, based on individual need. The focus of home and community-based services is to provide an alternative to an institutional setting for people with intellectual disability. SLAs provide individually designed habilitative services according to the recipient's preferences.

Ms. McCloskey highlighted a list of various supports and services that can be obtained through SLAs.

Ms. McCloskey pointed out that the reasons for the changes in federal requirements to provide an alternative to institutional services resulted from the Olmstead v. L. C. case in 1999. She explained that the Court established several requirements as a result.

Ms. McCloskey clarified the CMS and Community-Based Setting Requirements. She provided descriptions of the setting options.

Ms. McCloskey specified that Person Centered Planning requirements are also enforced in the SLA program and described the various prescribed approaches. She emphasized that the plan must identify the strengths, preferences, needs, and desired outcomes of the individual.

Ms. McCloskey also discussed regulations, policies, and other requirements for SLA Services. She described that NRS & NAC 435 give Developmental Services under ADSD the authority to take certain actions, including certification of providers and investigation of complaint or allegation of abuse, neglect, or exploitation of those receiving SLA services.

Ms. McCloskey gave details on the oversight of SLAs, which involve a very comprehensive process that can take up to six to nine months to complete. She pointed out the differences between certification and licensing, in particular underscoring that for SLAs, certification is done for an organization rather than the actual setting. The organizational capacity to serve people with intellectual disability is evaluated. An in-depth review of personnel and staff outcomes is also undertaken, including an assessment of required trainings and observations of staffs to ensure appropriate care is given.

Ms. McCloskey further expounded on the process of certification review, using a grading system and consequences when standards are not met.

Annual reviews are conducted of each 24-hour supported living arrangement, in addition to the comprehensive certification review. Service coordinators have monthly home visits to all 24 hour supported living arrangements. Service coordinators also have quarterly face-to-face contacts with all HCBW participants. Developmental Services also conducts investigations into all allegations of abuse, neglect, and exploitation.

Ms. McCloskey provided an overview of the five categories of Developmental Services Standards and gave brief descriptions of each category.

Ms. McCloskey reported that the Nevada Disability and Law Center conducts external investigations into complaints or allegations of abuse, neglect, or

exploitation referred to them. Annual Program Audit is also conducted by Nevada Medicaid. Furthermore, the Commission on Behavioral Health provides oversight of all restraint and denial reports.

Ms. McCloskey concluded by sharing statistics of the number of people who are participating in the SLA Program throughout different regions in Nevada.

A copy of Ms. McCloskey's Power Point Summary for this presentation is on file. (See Attachment D)

Sen. Wiener inquired how much of the direction of the Medicaid Waiver Program is mandated by the Federal Government and how much discretion does the State of Nevada have, in terms of that waiver, in running that program? Ms. McCloskey stated that there are federal requirements for all HCBW programs that CMS has established. CMS has a technical guide that's about 500 or 600 pages. The waiver has to be renewed every five years, and that is done in collaboration with Nevada Medicaid. In the application, it must be demonstrated how the program requirements will be met.

Discussion ensued about the newly issued certification program, which requires a quality assurance component.

Responding to a query from Sen. Wiener regarding the imbalance in the number of people being served in northern, southern, and rural Nevada, Julie Kotchevar provided clarification. Ms. Kotchevar explained that each of the rural regional centers is given a specific budget account and how many people they can place in supportive living according to how much money they're given. All regional centers have a waitlist, and how many waivers they can issue is dependent on how much money is available and how intensive the level of service that is needed by an individual. Ms. Kotchevar related that some of the numbers may appear to be off balance because the service is dictated by each center's budget. She said ADSD has worked to increase the funding but has not been able to secure the money, and that is why there is a long waitlist for SLA services.

Dr. Fisher asked if there is data on the age range for those receiving SLA services. Ms. McCloskey replied that there is data available but she cannot provide it at this time. However, she stated the majority of service recipients are adults.

Dr. Fisher also inquired whether a program recipient will usually remain in the same setting as they age. Ms. McCloskey confirmed that the goal is that the person will remain in the same home and community and age in place. There are cases where the individual cannot be served due to medical fragility or other needs that may go beyond what SLA can provide. Ms. Kotchevar added that as recipients as well as caregivers, who are often family members, are aging, ADSD is striving for the aging programs and developmental services to work together to

help make transitions between programs as seamless as possible. Ms. Kotchevar pointed out that people in the development services program can access other Medicaid programs, such as for health care needs.

Dr. Reed asked whether the intellectual and developmental services program includes individuals with Alzheimer's disease and dementia as well. Ms. McCloskey commented that the program involves other diagnoses but as the recipients age some may develop dementia or Alzheimer's disease. Dr. Reed stressed the value of the person-centered approaches, permitting people to choose a setting they want to live in. With Alzheimer's disease and other forms of dementia, however, how does one get to participate in making decisions for the type of care desired? According to Ms. McCloskey, those who are familiar with these individuals will know their preferences and can assist in making decisions and providing information for consideration to ensure that the most preferred situation can be arranged. Dr. Reed urged the expansion of the HCSW program to include not only people with intellectual and developmental disabilities, but also people living with Alzheimer's disease and other forms of dementia. Ms. McCloskey affirmed that all waiver programs are required to develop person-centered planning, including the aging programs.

Ms. Kotchevar shared that ADSD has rolled out person-centered training throughout their programs, including train the trainer. Last year, about 400 people at ADSD, rehab, developmental, and staff from other sister agencies received the training, which is ongoing.

Ms. Simons asked about tracking and expanding the affordability of services as indicated in the 2015 TFAD State Plan, Recommendation 9 indicator. Ms. Simons asked if any of the waiver programs would benefit those living with Alzheimer's disease and other forms of dementia. Ms. Kotchevar explained that the HCSW for the Frail and Elderly and the Physical Disabilities waiver could apply. Other non-waiver programs may also be available. Each of the waivers and programs has different services that can be available to individuals with Alzheimer's disease and other forms of dementia. Ms. Kotchevar said the ADSD is committed to meeting individual needs and guiding them to the programs that best target those needs. In the budget planning process, which is already starting for next biennium, ADSD did receive additional waiver spots but not enough to eliminate the waitlists. However, ADSD is assessing the most critical areas and how to ensure that the services offered under the waivers are reflective of the needs of Nevadans.

Responding to Sen. Wiener's query regarding what can be expected with the waitlists, Ms. Kotchevar responded that each of the waivers have different criteria for qualifications, and the average wait time varies but is usually between one and three years depending on the particular needs of the individual.

Third Presenter: Sandra Kitchener Nevada Medicaid Long Term Support Services Nevada Division of Healthcare Financing and Policy

Sandra Kitchener from Nevada Medicaid Long Term Support Services reported on the Behaviorally Complex Care Program (BCCP). The goal is to increase the infrastructure in Nevada, as well as reduce the number of out-of-state placements. To date approximately 18 to 20 facilities have initiated the BCCP. Ms. Kitchener explained the process of getting approved by the State of Nevada for the program. Training is being offered to nursing facilities as well as hospitals, targeting their collaboration to reduce out-of-state placements. Hospitals are informed in the training that BCCP rates are available and can be approved before patients are placed in nursing facilities. Those providers could bill that rate upon admission, which is a very good incentive for these facilities. A step-by-step training process for providers is available on a new website at http://dhcfp.nv.gov/. Medicaid is also contacting both hospitals and nursing facilities to offer the training so that they can understand the whole process and clarify any questions. Details of the BCCP Program are provided in the training, and the responses from the providers are very positive. BCCP is turning around the culture of out-of-state placements and allowing Nevada providers to better care for those living with behaviorally complex challenges. The BCCP rate, which provides a definite incentive for providers, should increase in the number of Alzheimer's, Dementia, and Behavioral Units coming online.

Handouts from Ms. Kitchener's presentation are one file. (See Attachment E)

Ms. Simons extended her appreciation and compliments to Ms. Kitchener and the BCCP team for all the many hours of hard work they have dedicated to this valuable project.

IX. Presentation and Make Possible Recommendations on ADRC Website (For Possible Action)

Cheyenne Pasquale ADRC Project Manager Aging and Disability Services Division

Cheyenne Pasquale presented an overview of the newly created Alzheimer's disease subsite within the Nevada Aging and Disability Resource Center (ADRC) website. Ms. Pasquale indicated that the information can be accessed from the main page on http://nevadaadrc.com/ Three ways to access the Alzheimer's disease page include:

- 1. A link under the main menu "Programs".
- 2. Under "Common Searches" tab, a category on "Alzheimer's Information" is listed.
- 3. A rotating banner on the home page will show information on Alzheimer's in Nevada.

Ms. Pasquale explained that the main page of the subsite falls under the "Alzheimer's Information" link. This is where a definition of Alzheimer's disease is given, along with Nevada facts and figures relating to Alzheimer's disease. A link to the 10 signs of Alzheimer's disease on the Alzheimer's Association website is also displayed. At the bottom of the page, the three stages of Alzheimer's disease are highlighted to demonstrate the signs and progression of the disease. Ms. Pasquale described that brief descriptions are included, but people can investigate further through the link to the Alzheimer's Association website.

Ms. Pasquale shared that the most helpful information may be found on the Alzheimer's Helpful Links page. She outlined the three categories that people may choose to explore, depending on their circumstances relating to Alzheimer's disease. The categories include:

- 1. I'm Not Diagnosed Yet.
- 2. I have an Alzheimer's Diagnosis.
- 3. I'm Caring for a Loved One.

The categories are established to assist people in guiding them to the resources that they need for their particular situations.

Ms. Pasquale said that these are preliminary steps, and additional information is being gathered to build the content and present research information, advocacy materials, frequently asked questions (FAQs), and educational materials.

Additional measures that can help those living with Alzheimer's disease and other forms of dementia are accessible on the ADRC website. These materials include:

- A Resource Directory page, which is a compilation of service providers. Currently, organizations can sign up to add their information.
- Educational materials, including personal assistance training modules, Elder Abuse Prevention Training, and Care Connection Partner Training.
- A Respite Information page for caregivers.

Ms. Pasquale stated that work on the Alzheimer's subsite will be ongoing, and she would appreciate feedback from TFAD on how to improve the content as well as other suggestions and ideas. She asked TFAD members to email her with their input.

A Power Point summary of Ms. Pasquale's presentation is on file. (See Attachment F)

Sen. Wiener noted that it is important to use appropriate language in the content of the website to provide clarification, and in particular specifying that Alzheimer's disease is only a type of dementia and there are various forms of dementia that are affecting the population. There should be a distinction noted that Alzheimer's disease encompasses only about 70% of dementia cases, and TFAD addresses all forms of dementia.

Addressing concerns about how the integrity of the information on the subsite will be managed, Ms. Pasquale clarified that organizations will only be able to add their name, location, and a brief description of their resources to the Resource Directory. External links are added only upon review and pre-approval and there is also a disclaimer that will be included on the page. Sen. Wiener emphasized that those coming to the website will be seeking assistance for the difficult situations they're facing, and they can be very vulnerable. It is crucial that visitors to the site understand that we are not endorsing any external links.

Sen. Wiener also urged Ms. Pasquale to work with Ms. Mandarino on including information about the Nevada Research Consortium on Dementia, which is being formed and will involve key partners from the community. Consortium activities may provide valuable resource for the website.

Ms. Simons suggested that information about veterans' services can also be included. Mr. Harmon praised the Respite page because it is important for caregivers to have those resources.

Mr. Harmon echoed the concerns about maintaining the integrity of the Resource Directory page and accurately categorizing the resources. He stressed the importance of objective review of listings. Mr. Harmon stated that, in addition to the website, it is important for people to be able to access a live person as well. He stated that the Alzheimer's Association nationally receives federal funding to have a 24/7 information referral system available. They also have a comprehensive list of available resources throughout Nevada. Mr. Harmon suggested including the 800 number on the ADRC website for those who may prefer to speak to a live person. Mr. Harmon added that the Alzheimer's Association serves people with all forms of dementia. He pointed out that while the specifics of the various forms of dementia may differ, the caregiving and the support are similar. There are support groups for specific types of dementia, as well as resource libraries available for various forms of dementia. Mr. Harmon explained that while Alzheimer's disease is the most common, other related dementias are included under the same umbrella.

Dr. Reed confirmed that the Alzheimer's Association does serve people across the continuum of all forms of dementia. Particularly when a person-centered approach is taken, the specific diagnosis, in terms of the needed supports and services in the community, is not as relevant as the impact of the condition on their everyday life and functioning. Dr. Reed added that, in fact, he has served

the board for the Alzheimer's Association, and originally the actual incorporation was the Alzheimer's disease and related dementias association. So that has been fundamental to their mission from the beginning.

Dr. Fisher commented on the importance of differential diagnoses. She stated that families are often referred without a clear diagnosis to the UNR Caregiver Support Center. The Center advises with families to ensure that a neurological exam is conducted to determine what is causing the cognitive impairment. Dr. Fisher explained that there are hundreds of causes of cognitive impairments, some of which are reversible if identified early. She emphasized that they work with the families to ensure that they receive a clear diagnosis so they can pursue the appropriate course of care. It is particularly important to identify the treatable conditions that may respond to treatments that may reverse the cognitive decline.

X. Discuss and Approve Work Plan for Annual Report (<u>For Possible Action</u>) Senator Valerie Wiener (Ret.), Chair

Sen. Wiener stated that the focus of the next TFAD meeting, which will be a face-to-face meeting in Las Vegas, on December 11, 2015, will be the revision of the Annual Report. The meeting will be held at the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas, beginning at 10:00 a.m.

Sen. Wiener explained earlier in the meeting that at her request, staff had sent out reminders to all members regarding providing an update on their assigned recommendations. Though presenters may have been invited to address TFAD about areas relating to certain State Plan recommendations, it is still the duty of the member to report the status update of their assigned areas.

Sen. Wiener emphasized that all members should review the status of their assigned recommendations on the latest version of the Recommendations Grid and send a response to staff, even if to indicate there is nothing to report. It is crucial for everyone to provide feedback so the preparation of the draft of the Annual Report can move forward as soon as possible.

Sen. Wiener suggested that the draft of the Annual Report be prepared and distributed for review by TFAD members at least seven days prior to the December 11, 2015 meeting.

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

Sen. Wiener stated she doesn't anticipate there will be any first-time presentations at the meeting. However, TFAD would like hear brief updates on guardianship by Ms. Ramm, as well as from Mr. Mathis, and other work TFAD is continually monitoring. The bulk of the meeting will be concentrated on working on the Annual Report.

Mr. Harmon made a suggestion for the Nevada Research Consortium on Dementia to include regional partners, citing that many clients and families in northern Nevada are going to UC Davis and USF to participate in research projects, along with people in southern Nevada maybe going to Arizona and Southern California to do the same. Sen. Wiener commented that an agenda item could be added to discuss the outcomes of the inaugural meeting, which is scheduled to be held at the end of November. She suggested that the focus be highlight the research being done in Nevada first.

XII. Discuss and Approve Next Meeting Date (For Possible Action)
Senator Valerie Wiener (Ret.), Chair

The next meeting is set for December 11, 2015 at 10:00 a.m. at the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas.

XIII. 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.)

Dr. Shawn McGivney commented on concerns about driving and dementia. He stated that it would not be fair to single out just people with dementia as the target group, but people with other forms of mental illnesses should be considered. Dr. McGivney described that often senior drivers are able to adapt their driving distances and other needs to the limitations in their driving. He urged the group to examine statistics of fatalities that are actually caused by cognitively-impaired drivers and to be careful in their considerations before making further recommendations that may impact taking away people's driving rights and privileges. He related experiences with his own mother.

Dr. McGivney stated that today's SLA presentation focused mainly on the developmental SLAs but there are many people with needs that pertain to other kinds of SLAs in southern Nevada, and he would like to hear more about those programs.

Dr. McGivney described the qualifications of his care facility and would like to be placed on the resource list.

Theresa Brushfield commented on concerns about SLA certifications and reviews targeting only the individuals and not the facilities. She stated that there is not enough oversight when private pay individuals choose to be in locations that are not under HCQC regulations. She conveyed that, to her knowledge, those facilities cannot receive proper inspection. She is concerned that there are people over whom the State has no oversight, and these people are advertising that they can provide care for people with extreme medical needs.

Vangie Molino from Vista Adult Care provided comments regarding the delay in Medicaid reimbursements, which may take several months. She indicated that

this is contradictory to the statement that the patients can be approved for BCCP rate before they leave the hospital. She questioned the validity of the reimbursement process.

Jose Castillo from AHONN commented that he would like to see more transparency provided by HCQC. In contrast to personnel training for SLAs, which had been stated to be dependent on the facility administrators, Mr. Castillo said that group homes follow the requirements, including medical management, activities, etc., mandated by the State. He also expressed concerns about lack of safety inspections with SLAs. Mr. Castillo explained that the group home administrators are constantly receiving ongoing training and adhere to the requirements put forth by the State.

XIV. Adjournment

The meeting was adjourned at 1:08 p.m.