TASK FORCE ON ALZHEIMER’S DISEASE ANNUAL REPORT

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Department of Health and Human Services
Task Force on Alzheimer’s Disease

(Assembly Bill No. 80, Committee on Health and Human Services, Statutes of Nevada 2013)

TASK FORCE ON ALZHEIMER'S DISEASE

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Introduction

The Task Force on Alzheimer's Disease (TFAD) was created within the Department of Health and Human Services with the passage of Assembly Bill 80 in the 2013 Legislative Session. TFAD is responsible for updating and revising the State Plan to Address Alzheimer's Disease. This plan serves as a blueprint for identifying specific actions that will allow for the development and growth of a quality and comprehensive support system for individuals affected by Alzheimer's disease.

TFAD, which is staffed by the Aging and Disability Services Division (ADSD), includes ten members with diverse interests in Alzheimer's disease, including medical professionals, caregivers, service providers, legislators, educators, and policy developers. TFAD, which is required to meet at least quarterly, is authorized to meet through June 2017.

The inaugural Nevada State Plan to Address Alzheimer's Disease, deemed as the official plan by the 2013 Legislature, was completed in January 2013. It included a list of 20 recommendations designed to improve: access to services; quality of care and quality of life; and public awareness regarding the disease. The State Plan was updated in 2015, allowing substantial review and refinements of the 20 recommendations included in the 2013 State Plan. (See State Plan to Address Alzheimer's Disease (2015)—Attachment A). The notable progress in Nevada reflects the level of commitment by the Governor, the Legislature, and a system of family and professional caregivers who are committed to assisting with or reducing the physical and financial impact on individuals with Alzheimer's disease and other forms of dementia, their families, and caregivers.

Legislative History

Passed during the 2011 Legislative Session, Assembly Concurrent Resolution No. 10, sponsored by Assemblywoman Debbie Smith, required the development of a State Plan to Address Alzheimer's Disease. A task force (ACR 10 Task Force) was established to accomplish this requirement. The ACR 10 Task Force met five times in 2012. Casey Catlin, who was working on her doctoral degree at the University of Nevada, Reno, drafted the State Plan quickly. During its final meeting in October 2012, the ACR 10 Task Force adopted 20 recommendations from more than 100 recommendations, submitted by independent work groups, experts, and the public. The ACR 10 Task Force also included potential funding sources—none of which were secured nor received by the ongoing ACR 10 Task Force—and indicators to help with monitoring the implementation of each recommendation. The ACR 10 Task Force viewed the plan as a living document. The importance of ongoing discussion and monitoring the implementation of each recommendation was noted as essential for the success of the State Plan.

During the 2013 Legislative session, Assemblywoman April Mastroluca offered to sponsor an ACR 10 Task Force bill through the Committee on Health and Human Services. The ACR 10 Task Force used this Bill Draft Request (BDR) for Assembly Bill 80 to create the Task Force on Alzheimer's Disease (TFAD) within the Department of Health and Human Services. The bill was signed by Governor Brian Sandoval on June 5, 2013, and became effective July 1, 2013. Mike Willden, then-Director of the DHHS, appointed eight members to TFAD during the first quarter, following the close of the 2013 Legislative session, and assigned Aging and Disability Services Division staff the responsibility to administratively support TFAD. On October 3, 2013, Nevada's Legislative Commission appointed two members, representing the Senate and the Assembly, to serve on TFAD.

The duties of TFAD are noted below.

NRS 439.5085

The Task Force shall:
(a) Develop a State Plan to address Alzheimer's Disease;
(b) Monitor the progress in carrying out the State Plan;
(c) Review and revise the State Plan as necessary;
(d) Develop and prioritize the actions necessary to carry out the State Plan;
(e) Research and review any other issues that are relevant to Alzheimer's disease; and
(f) On or before February 1 of each year, prepare and submit a report to the Governor and to the Director of the Legislative Counsel Bureau for transmittal to the Legislature concerning its findings and recommendations.

Working with Senator Valerie Wiener (Retired), Senator Allison Copening, chair of the Senate Health Committee (until Election Day 2012), offered two additional BDRs to the ACR 10 Task Force for introduction during the 2013 Legislative Session. Both BDRs addressed recommendations in the State Plan.

Senate Bill 86 required the Department of Health and Human Services (DHHS) to allocate money for certain programs relating to persons with Alzheimer's disease and other forms of dementia. This bill was signed by the Governor on May 21, 2013, and became effective immediately. Existing law required DHHS to allocate money to fund programs that assist senior citizens to live independently, including a program that provides respite care or relief of informal caretakers (NRS 439.630). SB 86 expanded that program to include respite care or relief for informal caretakers of any person with Alzheimer's disease or other forms of dementia regardless of the age of the person. In response to the bill passage, the Aging and Disability Services Division (ADSD) amended service delivery specifications utilized by agency-sponsored grantees to allow for the provision of respite care to individuals experiencing younger-onset Alzheimer's disease and other forms of dementia. The passage of SB 86 has allowed for progress under recommendation #4 of the 2013 State Plan, which indicates the necessity of removing "age barriers that typically keep people with younger-onset Alzheimer's disease and other forms of dementia from receiving services that are only available to seniors (disability services, legal services, meals, respite, and "continuum of life" programs such as assisted living services)."

Senate Bill 69 was introduced on January 9, 2013. The bill proposed revisions to the requirements governing Advanced Practitioners of Nursing. The bill would remove the requirement that an Advanced Practitioner of Nursing (APN) could only perform pursuant to a protocol approved by—and under the supervision of—a licensed physician and proposed that the State Board of Nursing be granted the ability to determine the authorized scope of practice for the nurse. SB 69 also proposed removing the provisions that refer to the supervision of an APN by a physician with respect to dispensing and prescribing controlled substances, poisons, dangerous drugs and devices. The ideas noted in this bill were eventually included in another bill, as noted below.

Assembly Bill 170 was introduced on February 25, 2013, with Assemblywoman Maggie Carlton as the primary sponsor. This bill also proposed revisions related to the Advanced Practice of Nursing. Existing law authorized the State Board of Nursing to grant certain registered nurses a certificate of recognition as an Advanced Practitioner of Nursing and set forth the requirements for obtaining the certification. AB 170 proposed modifying the authority of the Board to allow issuance of a license as an Advanced Practice Registered Nurse (APRN) and to require the maintenance of a policy of professional liability insurance in accordance with regulations adopted by the Nursing Board. AB 170 also allowed for an APRN to prescribe a controlled substance if the nurse has at least 2 years or 2,000 hours of clinical experience or if the nurse was prescribing pursuant to a protocol approved by a collaborating physician. The governor signed AB 170 into law on June 3, 2013. The legislation offers the opportunity to a Registered Nurse, who possesses a valid certificate of recognition as an Advance Practitioner of Nursing, to be deemed to possess a license if the nurse meets requirements set forth in Board-adopted regulations.

The passage of AB 170 has allowed for progress under recommendation #2 of the State Plan, which indicates the necessity of authorizing "nurse practitioners to have independent practices to provide better access to care, especially for rural elders."

Assembly Bill 9 was introduced on February 2, 2015. Sen. Wiener testified in the Assembly Judiciary Committee on this bill on Alzheimer's Advocacy Day. AB 9 initially required an accounting for assets under $10,000, particularly for those people with Alzheimer's disease or other forms of dementia. AB 9 was heard and many conversations took place with the courts. As a result, there was a shift from an 'accounting' of all people with assets under $10,000 to an "open court" review of the total well-being and status of the people who have those assets. Though this measure seemed to have consensus, it did not receive legislative support.

Senate Concurrent Resolution 2 was introduced on February 19, 2015. Sponsored by Sen. Joe Hardy, SCR 2 addressed Recommendations 11-14 of the 2015 State Plan. SCR 2 focused on Alzheimer's and dementia-related awareness, education, and training. SCR 2 passed and was enrolled on May 22, 2015 with the Secretary of State.

Senate Bill 196, also sponsored by Sen. Hardy, was introduced on February 26, 2015. SB 196 focused on the stroke registry. However, in Section 10, language from the bill states: "unless a specific statute or regulation requires or authorizes a greater number of hours, a provider of healthcare may use credit earned for continuing education related to Alzheimer's disease in place of not more than two hours each year of the continuing education that the provider of healthcare is required to complete, other than continuing education related to healthcare ethics."

This permissive provision gives flexibility to providers for Alzheimer's education up to two hours a year.

Senate Bill 177 was introduced on February 19, 2015. TFAD supported SB 177 in Recommendation 8 in the State Plan. This is AARP's CARE Act, which listed the Task Force on Alzheimer's Disease (TFAD) as a supporter of the measure. The bill addressed working with caregivers to assist people as they transition out of care facilities. It helped inform and educate them, ensuring the highest level of care and standards. SB 177 was signed by the Governor on May 6, 2015.

Two other bills which were not related to the TFAD State Plan, but were monitored by TFAD, included:

1. Senate Bill 262, which was introduced on March 13, 2015. SB 262 addressed the selection criteria of non-residents or residents becoming sole guardians of wards in Nevada, along with added restrictions, which could affect people living with Alzheimer's disease and other forms of dementia. SB 262 was signed by the Governor on June 9, 2015.

2. Assembly Bill 325, which was introduced on March 16, 2015. This bill provided for licensing and regulation of private professional guardians. AB 325 also allowed out-state-residents to become full guardians of people in Nevada. AB 325 was signed by the Governor on June 8, 2015.

In summary, five of TFAD's twenty recommendations in the State Plan, which required legislation, were successfully supported in the 2015 Legislative Session.

Current Status of the State Plan

In 2015, TFAD worked vigorously to address the growing needs of individuals living with Alzheimer's disease and other forms of dementia. TFAD regularly reviewed the status of the 20 recommendations included in the 2015 State Plan both to determine relevance and to monitor the most current updates and developments. TFAD members volunteered to continuously evaluate the current status of all the recommendations, with each choosing to review those that fell within his or her particular area of expertise or interest. Each member identified available resources, potential partners to prompt completion, action plan timelines, and other details necessary to advance or modify the recommendations.

Progress was made in all 20 recommendation areas. Significant developments include:

Recommendation 1: Sustain a statewide information and referral system for those with Alzheimer's disease and other forms of dementia, their caregivers, and their families to enable them to connect with local case management and support services, e.g., resource centers, such as Nevada Aging and Disability Resource Center (ADRC).

The new Aging and Disability Resource Center (ADRC) website, including the content and navigation for the Alzheimer's page is well into development, with content and navigation being formulated. The Alzheimer's home page will include: Nevada facts and figures on Alzheimer's disease; information on the three stages of Alzheimer's disease; Alzheimer's Help Links; and information about current research, as well as links to research study websites. The site will also include information about advocacy, including ways to get involved. Additional portal content will offer a resource directory, respite information, care options, educational materials, link to the Care ACT and American Association of Retired Persons (AARP), and other valuable resources.

Recommendation 2: Support and continue to monitor the progress of AB 170, passed in the 2013 Legislative Session, which authorizes Advance Practice Registered Nurses (APRNs) to have independent practices to provide better access to care, especially for rural elders. In addition, TFAD supports the connection between APRNs and health care teams to provide ancillary services.

According to the Nevada State Board of Nursing, the total number of APRNs, as of June 2013, was 880, with 12% in the frontier/rurals. As of June 2014, the total number of APRNs was 1053, with 22% in the frontier/rurals. By June 2015, the number increased to 1185 APRNs with 24% in the frontier/rurals. It is worth noting that, as of June 30, 2015, the number of APRNs working in the rural areas in Nevada has increased from 227 (June 30, 2014) to 276. There are no specific numbers of APRNs working with Alzheimer's patients, but the number of geriatric specialized APRNs has risen from 8 to 11 in the past year. Also the number of applicants from out-of-state, where they do not have this kind of licensure, continues to grow.

Recommendation 3: Evaluate and support legislation that improves access to quality telehealth services and work with other initiatives, such as Project ECHO Nevada, Renown Medical Center, and The Cleveland Clinic Lou Ruvo Center for Brain Health. The Aging and Disability Services Division (ADSD) will identify funding streams to develop and facilitate the full spectrum of telehealth services to rural communities, including training for providers in rural areas.

A telehealth bill (AB 292) passed in the 2015 Legislative Session. The bill "requires insurers to provide coverage to people who are insured for services provided through telehealth to the same extent as though provided in person..." The bill also focused on regulations and other developments related to telehealth, whether frontier, rural, or urban.

Because geographic isolation and limited access to specialty care can often delay early intervention for patients with memory loss and neurodegenerative disorders in rural locales, telehealth services are essential.

According to the Nevada State Office of Rural Health, the Telehealth program was initiated more than 20 years ago as an initiative of the Nevada AHEC system, starting with connections to rural sites through telephones, U.S. mail service, and fax machines. Developed as the Computerized Assistance Medical Information Link (CAMIL) to receive practitioner requests for medical literature, the University of Nevada School of Medicine (UNSOM) Library service provided the medical resources back to the community. Evolving with technology, the system eventually added the Nevada Telecommunications Network to serve the needs of education, administration, and telemedicine services. The network recognizes significant partnership resources, in particular, Nevada Rural Hospital Partners.

The three service aspects of the Nevada Telehealth Network provide compressed video technology to support administrative uses of health care practitioners, facilities, and organizations. Additionally, continuing education, continuing medical education, and educational courses are broadcast between fifty-six community sites. The system provides opportunities for telemedicine that allows rural and frontier patients to be seen by a practitioner in a comfortable environment, without having to travel long distances from their home communities. Local physicians bring treatment to local patients utilizing a network of interactive video sites that connect specialist physicians across the state.

Project ECHO Nevada is charged with meeting the needs of primary care providers by offering an alternative to costly travel and long waits for patients who need specialty care. By developing the knowledge base of primary care providers through the innovative telehealth consultations offered by Project ECHO, patients in rural and under-served areas benefit from specialty care becoming available locally, and without the cost and time of accessing specialists directly.

The UNSOM Community Partnership Network <u>annually</u> provides support for:

- 200-300 academic activities and 100-250 statewide meetings.
- Specialty consults for rural Nevadans, ranging from 94 to 126 hours of contact time with UNSOM physicians.
- 70 to 180 classes and training programs.
- Digital network supports for rural tele-radiology, which transmits 200,000 to 400,000 images a month for rural hospitals.

Renown Telehealth in Reno provides the use of telecommunications technologies to support healthcare at a distance through: support groups, distance learning, virtual visits, clinic telemedicine, hospital telemedicine, and remote monitoring.

The Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas also offers several programs through telemedicine. In 2015, the telemedicine program facilitated 32 new patient visits and 104 established patient visits. Video-conference technology connects rural locales to the Cleveland Clinic for medical care, including diagnoses and treatments, and the no-cost disease-related education program, "Lunch and Learn." Video-conference technology allows for a continuity of care for patients in their own communities. Otherwise, these patients would likely have no access to high-level specialty care from brain health experts.

Recommendation 4: Support NRS provisions, including those defined in SB 86 of the 2013 Legislative Session, that remove age barriers that typically keep people with younger-onset Alzheimer's disease and other forms of dementia from receiving services that are only available to seniors (disability services, legal services, meals, respite, and "continuum of life" programs, such as assisted living services.) Continue to monitor NRS provisions, related to these populations, as well as other provisions included in the Older Americans Act, which affect eligibility requirements for services that allow family caregivers of a person living with Alzheimer's disease and other forms of dementia to be served, regardless of the age of the person.

Senate Bill 86 amended NRS 439.630 to remove the age restriction on respite services that can be provided to seniors who have younger-onset Alzheimer's disease. ADSD currently provides grants to various community organizations that assist not only older populations but also younger-onset individuals. In 2015, ADSD also received a federal lifespan respite grant to help strengthen the current respite care system and provide vouchers for emergency respite services for the next few years. According to the Alzheimer's Association, 75 clients in northern and southern Nevada, who began their journey with Alzheimer's disease or other forms of dementia before they were 60 years of age, are currently receiving services. Some of these people are now older than 60, but are able to access services due to this legislation.

Recommendation 5: Support efforts to develop toolkits to assist public and private organizations in their outreach to different cultural communities.

Review of published toolkits is on-going. Data from surveys of Nevada families affected by dementia is being incorporated and toolkits are being reviewed by experts in cultural tailoring prior to disseminating toolkits to service providers in Nevada. Cultural tailoring is important to ensure cultural competency. Culture competency is having an awareness of one's own cultural identity and views about differences, and the ability to learn and build on the varying cultural and community norms an organization encounters.

The Nevada Department of Health and Human Services (DHHS) Grants Management Unit has made a commitment to include applicable cultural competency in its grant applications, which will be included in the 2016 grant cycle.

Recommendation 6: Address affordability of services for persons with Alzheimer's disease and other forms of dementia by using national data and explore other cost-sharing mechanisms.

Based on a 2014 University of Nevada Las Vegas (UNLV) report, which includes an analysis of provider rates and reimbursements, ADSD requested a provider rate increase for all agency providers during the 2015 Legislative Session. However, the legislatively approved budget addressed only an increase for developmental services providers who were paid 30% less than the Medicaid rates. ADSD is monitoring the national and state data, Medicare, and Medicaid to determine the rates for reimbursable services. ADSD, as part of its Strategic Plan, continues to make the reimbursement rates more equitable.

Recommendation 7: Support the Cleveland Clinic Lou Ruvo Center for Brain Health in its establishment of a Nevada Consortium to promote current and future research in our state. Expand the ADRC website to specifically include information on Alzheimer's research that contains information about current research and a registry that allows individuals to register to participate in clinical research.

The inaugural meeting of the Nevada Research Consortium on Dementia (NRCD) was held on November 20, 2015.

The goals of the NRCD are to investigate and encourage expanded research opportunities and collaborations throughout Nevada related to Alzheimer's disease and other forms of dementia. This group will also disseminate emerging information within the research community, as well as to those with Alzheimer's disease, their families, and caregivers.

During this organizational meeting, attendees created a *draft* mission statement, shared ideas about goals and objectives, and discussed various and timely logistical challenges. They also expressed their commitment to the role and importance of the NRCD, including fostering research and disseminating information throughout the state of Nevada. As an initial project, the idea of a website that could be a clearinghouse for researchers and research projects, along with a patient registry will be explored. This web page may be incorporated into the ADRC website and can provide information on current research studies and how the public can participate.

Methods to expand membership of the NRCD were also discussed, including invitations to various stakeholders to participate. For example, primary care providers may be able to help facilitate the referral of patients for clinical trials, and graduate students can also get involved with NRCD projects.

Additionally, the creation of a template with each researcher's title, contact information, picture, brief biography, and research projects was suggested. This valuable resource can be included on the ADRC website.

Recommendation 8: Support the adoption of specialized care pathways. Encourage the Nevada Hospital Association, in collaboration with subject matter experts from the Alzheimer's Association, as well as other research and educational organizations, to develop a best-practices care plan for the management of patients with cognitive impairment entering the hospital. In addition, TFAD supports the CARE Act, which will help caregivers when those for whom they care are hospitalized.

The CARE Act (SB 177) passed during the 2015 Legislative Session. The CARE Act requires hospitals to do three things: 1) Provide the patient with the opportunity to designate a family caregiver. 2) Inform the patient's caregiver when the patient will be discharged to another facility or back home. 3) Provide the caregiver with an explanation and demonstration of any medical tasks which will need to be performed at home, such as wound care or medication management.

Dr. Charles Bernick, Medical Director, Cleveland Clinic Lou Ruvo Center for Brian Health and a TFAD member, has assigned one of their center's interns to review and compile existent models of hospital care. The Cleveland Clinic Lou Ruvo Center for Brain Health will hold a meeting in the first quarter of 2016 to convene hospitalists, ER, EMTs, nurses, hospital security personnel, and anyone involved in the admitting, care, and security of individuals with dementia to discuss care path strategies for this population.

Recommendation 9: Continue to review current funding and funding streams to support the development of quality long-term care options for people living with dementia in Nevada. Provide funding or incentives to encourage existing long-term care providers to increase capacity for placement of individuals with Alzheimer's disease and other forms of dementia with an emphasis on person-centered planning and initiatives.

Expanded funding from Medicaid for behavioral rate and tiered funding was initiated in May 2015. Local providers in Nevada, both old and new entities, have expressed interest in learning more about how the funding works, what the programming looks like, and what the requirements are. The Nevada Health Care Association (NVHCA) reported that there are an unprecedented number of new beds, about 600, coming on-line in an 18-month period starting about six months ago into 2016. Two new buildings have been opened in southern Nevada, and there are plans for two new buildings in northern Nevada.

The Department of Health Care Financing and Policy (DHCFP) has enriched the funding stream by implementing the Behaviorally Complex Care Program (BCCP), and will be encouraged to continue to build upon it.

Recommendation 10: Reduce the need for out-of-state placements in Nevada by:

a. **Preventing the conditions that lead to the development of responsive behaviors and increase the risk of out-of-state placement. Accomplish this by creating a clearinghouse for information on evidence-based, person-centered approaches to**

promoting the behavioral health and quality of life of individuals with Alzheimer's disease and other forms of dementia and their family caregivers.

Nevada ADRC has made significant progress in constructing a website (http://www.nevadaadrc.com/services-and-programs/alzheimer-s-information) that can serve as a statewide clearinghouse for information on evidence-based, person-centered approaches to living with dementia. The website will address positive lifestyle choices, guidelines for healthy living, and meaningful and relevant care options improve quality of life for persons with dementia and their families and caregivers.

b. Initiating a public health information program to increase easy access to information on: 1) "optimal' care and quality of life and 2) expected vs. unexpected behavior changes in persons with dementia.

TFAD members will continue to provide this information to ADRC website designers.

c. Increasing the ability of family and professional caregivers (in primary, acute, emergency, and long-term care settings) to appropriately and effectively respond to care needs and behavior changes in persons with Alzheimer's disease and other forms of dementia through education and guided practice by experts in evidence-based methods of behavioral healthcare for persons living with dementia.

Several private and public agencies, as well as other organizations, are actively engaged in work that is relevant to this goal (e.g., the Alzheimer's Association, the Nevada Geriatric Education Center, the UNR Nevada Caregiver Support Center, the DHHS Aging and Disability Services Division, the Nevada Lifespan Respite Coalition), to disseminate information about the care of persons with dementia to their families and other caregivers. It is vital that we continue to seek expansion of these services and those that provide guided practice in evidence-based behavioral healthcare for persons with dementia and their caregivers. New programs funded by ADSD (e.g., a positive behavioral support program of the UNR Nevada Center for Excellence in Disabilities) are currently in development.

d. Using a higher reimbursement rate as an incentive for providers to successfully deliver appropriate care.

A higher Medicaid reimbursement rate was established on May 25, 2015. The BCCP covers those Nevada Medicaid recipients with severe, medically-based behavior disorders resulting in the recipient posing a danger to self and/or others. Medically-based disorders include, but are not limited to, traumatic/acquired brain injury, dementia, Alzheimer's disease, Huntington's Chorea, or a condition that causes diminished capacity for judgment. Also, reimbursement is allowed for a resident, who meets the Medicaid criteria for nursing facility level of care and who has a medically-based mental health disorder or diagnosis and exhibits significant behaviors.

e. **Developing mobile individuals or teams that respond to--and evaluate--persons in need of specialized interventions. These multidisciplinary teams or individuals evaluate the persons with dementia, provide assessment, and give training to staff and family members or other caregivers before the person with dementia moves into a catastrophic situation.**

Discussions between programs prepared to provide this service (e.g., UNR Nevada Caregiver Support Center and the UNR Nevada Center for Excellence in Disabilities) are in progress. Costs and outcomes of related programs in other states are being examined.

f. **Bridging gaps between innovative care approaches and regulatory restrictions.**

g. **Reviewing regulatory measures and pursuing regulatory reconciliation in order to assure consistency across agencies, which are involved in regulatory oversight, to reduce barriers to providers who are willing to deliver care to persons with dementia.**

h. **Investigating the feasibility of developing units in facilities in Nevada that specialize in dementia care for individuals with a history of being described as "unmanageable" and rejected by other facilities**

Feasibility assessment is on-going. The goal of the Behaviorally Complex Care Program (BCCP) is to increase the infrastructure in Nevada, as well as reduce the number of out-of-state placements. Medicaid has stated that it is already seeing positive shifts. Since the May 2015 implementation of the BCCP, 21 facilities have initiated the BCCP. As of December 2015, 117 individuals have been approved for BCCP. Training is being offered to nursing facilities and hospitals, targeting their collaboration to reduce out-of-state placements. Hospitals are informed initially that BCCP rates are available and can be approved before patients are placed in nursing facilities. Those providers would then be able to bill that rate automatically upon admission, which is a very appealing incentive. Nevada Medicaid Long Term Support Services (LTSS) reported that BCCP Tier pre-approval has averted eight out-of-state placements. LTSS is providing a step-by-step training process for providers. BCCP training is available on site and via conference call.

Medicaid is also contacting both hospitals and nursing facilities to clarify the process, answer questions, and offer the training. This includes information about specific program requirements and timelines for approval. BCCP is providing a vital opportunity to reverse the culture of out-of-state placements and allow Nevada providers to better care for those living with behaviorally complex challenges. The BCCP rate, which can incentivize providers, should increase the number of Alzheimer's, dementia, and behavioral units coming online in the future.

Recommendation 11: Encourage the Board of Medical Examiners, the State Board of Osteopathic Medicine, professional associations, and educational institutions to promote awareness and education to health care providers by:

a. **Approving continuing medical education (CME) training programs that provide primary care physicians and other allied health care professionals with ongoing education about recent developments, research, and treatments of Alzheimer's disease and other forms of dementia.**

b. **Encouraging primary care physicians to refer persons with cognitive deficits for specialized cognitive testing when appropriate.**

c. **Encouraging primary care physicians to refer persons with dementia and their families to dementia-related community resources and supportive programs.**

Recommendation 12: Encourage schools in Nevada with programs in nursing and other health care professions to ensure that the programs include specific training regarding Alzheimer's disease and other forms of dementia in their curriculum and expand related continuing education opportunities for nurses and other health care professionals in the acute care setting.

Recommendation 13: Encourage and promote training and education opportunities to increase awareness and understanding of Alzheimer's disease and other forms of dementia for all levels of medical personnel in a hospital, including emergency room personnel and others responsible for admission and discharge.

Recommendation 14: Encourage first responders, law enforcement, and fire department personnel to have a specified number of hours of training to help them assess and learn how to respond to people with Alzheimer's disease and other forms of dementia.

To address Recommendations 11, 12, 13, and 14, Sen. Joseph Hardy, a member of TFAD, introduced Senate Concurrent Resolution 2 during the 2015 Legislative Session. SCR 2 encouraged education of medical providers and first responders regarding care for persons with Alzheimer's disease. Sen. Wiener testified and showed her support for SCR 2 before the Senate Health and Human Services Committee. In addition, in Senate Bill 196, which Sen. Hardy also sponsored, Section 10 included a provision to allow a provider of healthcare to use up to two hours of continuing education units (CEUs) each year for Alzheimer's-related education. SB 196 became law in 2015.

Recommendation 15: Provide caregivers with access to evidence-based education and support services that promote knowledge and understanding of Alzheimer's disease and other forms of dementia and how to best support people living with dementia. Provide and expand respite services for family and informal caregivers of persons with Alzheimer's disease and other forms of dementia. Broaden the eligibility requirements for use of respite programs and grant funding so that more families may benefit from them regardless of financial status or age.

Senate Bill 86 of the 2013 Legislative Session amended NRS 439.630 to remove the age restriction on respite services that can be provided to seniors who have younger-onset Alzheimer's disease. The restriction was lifted and respite services are available through a number of sources. Persons, who are served through either the Home-and-Community-Based Waiver for the Frail Elderly or the Waiver for Independent Nevadans (for persons with physical disabilities), can receive respite services funded by Medicaid. In 2014, 379 consumers received respite services under one of these two waivers.

ADSD provides grant funding through Older American Act and Independent Living Grants to community organizations that provide respite services. In 2014, ADSD applied for and received approximately $360,000 of federal funding through the Administration For Community Living for the Lifespan Respite Integration Program. This grant will help to strengthen the current system providing respite care in Nevada across the age spectrum while also providing vouchers for emergency respite services over the next several years.

The 2014 Lifespan Respite Grant and the 2014 Creating and Sustaining a Dementia-Capable Service System Grant support the Benjamin Rose Institute Care Consultation Program. Care Consultation is a telephone-based empowerment intervention that helps family caregivers and care receivers by providing information about health problems and available resources that mobilize and facilitate the use of informal supports and formal services. It also provides emotional support. In addition, through the Older American Act, Title III-D and III-E, ADSD allocated approximately $400,000 to provide caregivers with access to evidence-based education and support services that promote knowledge and understanding of Alzheimer's disease and other forms of dementia.

The Alzheimer's Association, the Nevada Geriatric Education Center, the UNR Nevada Caregiver Support Center, the Cleveland Clinic Lou Ruvo Center for Brain Health, the Nevada Lifespan Respite Coalition, Nevada Senior Services, (NSS), Seniors in Service, Helping Hands, East Valley, St. Rose, and Family Resource Center of Northeastern Nevada are actively involved in work that is relevant to this goal. They work collaboratively to disseminate information that addresses the needs of both persons with dementia and family caregivers.

Private agencies are donating blocks of respite services that are not tied to an age requirement. Seniors in Service (http://www.seniorsinservicenevada.org) is currently managing a list of the agencies that are donating these services.

Recommendation 16: Encourage the active capacity building of community organizations to recruit and manage volunteers. Provide volunteers with training and education so that they can better serve those living with Alzheimer's disease and other forms of dementia and their families.

Gini Cunningham, a member of TFAD, traveled throughout eastern Nevada, with some funding assistance from ADSD, to distribute outreach materials. These included posters on "The Seven Stages of Alzheimer's Disease" and brochures on "Alzheimer's Disease: Facts, Symptoms, and

Support," that promote Alzheimer's-related education and awareness. She reported very positive reception and high interest from these communities, which are seeking ways to become more involved and receive additional training and education regarding Alzheimer's disease and other forms of dementia. In-person presence proved valuable in making connections and generating interest.

Recommendation 17: Propose legislation to change NRS 159.076, providing an exception to the law allowing summary administration of a small estate if the ward is living with dementia, including but not limited to Alzheimer's disease. Ask the Legislature to send a letter to all district courts requesting close supervision of all guardians whose wards live with dementia, including, but not limited to, Alzheimer's disease, to insure that all reports on the person and estate of the wards are filed and reviewed according to the existing law.

Chair Wiener testified in the Assembly Judiciary Committee on AB 9 on March 16, 2015--Alzheimer's Advocacy Day. This bill initially addressed persons with assets under $10,000 with required accounting of these assets. If such assets were monitored and managed appropriately, many of these persons could stay at home with care. The bill was heard and many conversations took place with the courts. As a result, language shifted from an "accounting" of all people with assets under $10,000 to an "open court review" of the total well-being and status of the affected people. Though this measure seemed to have consensus, it did not receive legislative support. However, subsequently, the Supreme Court Commission to Study the Administration of Guardianships in Nevada's Courts was formed. The Commission is studying every aspect of the statutes, including the possibility of separating the adult guardianship statutes from the minor guardianships, temporary guardianships, fees, and other practices. Though formal recommendations are still being finalized, there is a determination to make the whole system more transparent, efficient, and user-friendly.

Recommendation 18: Ensure best-practice hospital transitional care programs that include information on community resources for caregivers and persons with dementia. Investigate federal funding opportunities through Medicare Innovations or Centers for Medicare and Medicaid Services to develop a transitions planning program or to avoid the hospital setting altogether, i.e., a mobile dementia team approach.

The Cleveland Lou Ruvo Center for Brain Health has an intern currently reviewing and compiling existent models of hospital care. An advisory group, including ER and floor nurses, hospitalists, hospital pharmacists, administrators, security, nutritionists, physical therapists, occupational therapists, and speech therapists will be invited to discuss best practices from admitting to discharge and follow-up care. The goal is to create a care path that will expedite diagnoses, improve treatments, enhance well-being, and avoid prolonged hospitalization and readmissions.

Recommendation 19: Foster the development of three awareness campaigns to provide information about the earliest signs of dementia and to rebuke the stigma of Alzheimer's disease and other forms of dementia. The campaigns will include updates about current

research and prevention trials that can delay progression, as well as information about how earlier diagnosis and intervention can lead to a more productive and valuable life. The campaigns will be designed to help citizens feel more supported and hopeful, as well as encourage access to available services. The campaigns will be promoted through public service announcements; broadcast and print interviews; newspaper, magazine, and website articles; and other Internet venues. The respective target audiences for each public awareness campaign are:

- **a. Allied health professionals, bankers, emergency first responders, financial planners, lawyers, and other professionals who may have contact with persons with dementia.**
- **b. Caregivers and family members of persons with dementia. This campaign will focus on ways to help alleviate the fear, stress, and stigma surrounding dementia and the sense of isolation and aloneness that often accompanies the disease. This includes educating and informing caregivers about support group opportunities and other available supportive services that will help them care for themselves and their family member.**
- **c. The general public.**

LeeAnn Mandarino, Program Manager at the Cleveland Clinic Lou Ruvo Center for Brain Health, Las Vegas, an alternate TFAD member, has reached out to first responders, including paramedics and Las Vegas Metropolitan Police, and discussed doing an education program with them on signs and symptoms of dementia. TFAD is also considering the incorporation of information into the ADRC website for greater exposure, as well as creating and distributing awareness materials. In 2015, ADSD provided funding to produce a compass that Ms. Mandarino created, which shows how to navigate Alzheimer's disease and other forms of dementia once a diagnosis is received and how to access needed resources. The compasses are being distributed statewide. In addition, informational posters are being developed for distribution to primary care physicians statewide.

Recommendation 20: Collaborate with the business community to create employee assistance programs that include education and training for employees, including those who are caregivers. Develop partnerships with other organizations that are also affected by Alzheimer's disease and other forms of dementia, such as diabetes, stroke, and heart organizations, to help promote information about services and care for those who have symptoms of dementia.

According to Jacob Harmon, Regional Director, Northern Nevada Alzheimer's Association, the Alzheimer's Association's program, the Alzheimer's Workplace Alliance (AWA), provides trainings for Human Resource (HR) departments and employees of major corporations in and around the northern Nevada and northern California area. The program helps educate companies on both how they can support their employees who are caring for their loved ones and how they can educate employees about the resources that are available. ADSD is also looking into the possibility of presenting information on Alzheimer's disease and other forms of dementia through the State of Nevada Employee Assistance Program (EAP).

TFAD Activities--2015

As prescribed by law, TFAD is required to meet at least quarterly each year. However, to address the vital issues related to Alzheimer's disease and other forms of dementia, TFAD met seven times in 2015: January 7, February 25, April 1, June 24, August 21, October 23, and December 11. The primary focus of each meeting involved review, assessment, and refinement of the 20 recommendations, which are categorically included in one of three focus areas of the State Plan to Address Alzheimer's Disease: 1) Access to Care, 2) Quality of Care and Quality of Life, and 3) Public Awareness.

Throughout the year, TFAD members facilitated the recommendations in the State Plan that involved their areas of expertise. Each member was charged with determining if his or her assigned recommendations were still timely and relevant. If TFAD agreed that a recommendation should be retained, the assigned member was responsible for refreshing substantive information, including: medical updates; data and statistical revisions; funding resources; and indicators.

In addition, TFAD members, Dr. Jane Fisher, Dr. Peter Reed, and Gini Cunningham, working with ADSD staff, organized five town hall meetings to address the challenges related to the topic of driving and dementia in Reno, Las Vegas, and rural communities. Additional town hall meetings are also being planned for southern and rural Nevada in 2016.

DHHS, which has statutory responsibility for providing staff support to TFAD, has recognized the value of TFAD's work and the far-reaching impact of its contributions to the State Plan and its effect on the people of Nevada. To further support this work, Aging and Disability Services Division (ADSD) applied for, and received, funding for a part-time contract staff position to provide clerical support to TFAD. Sunadda Woodbury was hired to fill this role and has substantially assisted TFAD with the revision and updates for both the State Plan and the Annual Report.

In September 2014, TFAD was notified that ADSD was awarded a 2014 Alzheimer's Dementia Capability Grant of $450,000 (federal grant), with required $256,000 state match (Tobacco Settlement and Incline Match). Three goals for the program are:

1. Develop screening for early identification of persons with Alzheimer's disease or dementia and their family care providers.
2. Connect individuals living with Alzheimer's disease and other forms of dementia and their caregivers to appropriate program and service modalities based on consumer needs and person-centered approaches. (i.e., implementation of BRI Care Consultation and other planned program expansion).

3. Establish and improve datasets to quantify measurable outcomes and expand program evaluation to facilitate program improvements.

ADSD continues to work with TFAD to ensure that the State maximizes the outcomes of the grant by funding Supportive Services Programs for individuals with Alzheimer’s disease and other forms of dementia, including: Alzheimer’s Diagnostics; evidence-based programs; caregiver supportive programs; respite; and adult daycare. Through Older American Act and Tobacco Settlement Funding, ADSD funded four programs specific to Alzheimer’s disease and other forms of dementia: Care Partners Reaching Out (CarePRO), Early Stage Partners in Care (EPIC), Alzheimer’s Associations Care Consultations, and Living with Alzheimer’s.

The second year of the Dementia Capability Grant began on September 1, 2015. Accomplishments during the first year of the project include:

- Added: A caregiver and cognition element to the Level 1 Screen, as part of the Balancing Incentive Payment Program initiatives.
- Initiated: Two evidence-based programs to expand Nevada’s toolbox of supportive services programs for individuals with Alzheimer’s disease and other forms of dementia and their care partners.
    - Early Stage Partners in Care (EPIC): an eight-week intervention program intended to assist people with early-stage memory loss and their care partners. Currently, eight dyads or 16 clients have been served or are being served.
    - Care Consultation Program: a phone/ technology-based support program. Approximate enrollment in Care Consultations is 15 clients.
- Continued: Funding for existing evidence-based programs through Older American Act and Tobacco Settlement Funding to support and expand existing caregiver support programs for individuals with Alzheimer’s disease and other forms of dementia.
- Continued: Environmental scan of existing data collection elements currently collected.
- Continued: An evaluation plan to help measure the outcomes of the project.
- Initiated: A Statistical Package for the Social Sciences (SPSS) Database to gather data elements consistently provided across programs, while identifying elements that still need to be collected.

In addition, TFAD is working with ADSD on several of the State Plan's recommendations to monitor the indicators and secure funding, such as working with the State of Nevada Grants Office to locate and secure available funding.

TFAD appreciates the value of collaboration, which allows us to maximize resources that otherwise might not come together. Therefore, throughout 2015, TFAD focused on ways to create and re-enforce collaborations to address Alzheimer's disease and other forms of dementia, including the partnering of nonprofits, educational institutions, foundations, and State agencies, e.g., The Cleveland Clinic Lou Ruvo Center for Brain Health and the Alzheimer's Association partnering to increase trial matches for research.

In November 2014 and January 2015, TFAD met to finalize the details of the 2015 State Plan to Address Alzheimer's Disease.

Conclusion

The members of the Task Force on Alzheimer's Disease appreciate the opportunity to serve the State in this very worthwhile endeavor. The development and biannual updates of the Nevada State Plan to Address Alzheimer's Disease allow TFAD to pursue solutions and resources for people living with Alzheimer's disease and other forms of dementia, their families, and caregivers. Nevada should take pride in its proactive response to plan for the care and comfort of these individuals. Throughout 2016, TFAD members will continue to work to more fully develop service delivery policy goals; identify and pursue funding for recommendations; and recommend necessary statutory changes that are essential to the success of the ever-evolving State Plan.