Legislative Committee on Health Care's Task Force to Develop A State Plan to Address Alzheimer's Disease (A.C.R. 10)

State Plan Draft
Draft for Discussion
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Executive Summary
(Will include an outline of all the goals/recommendations)

Chapter 1: Introduction

In May 2011, Assembly Concurrent Resolution No. 10 created the Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's Disease. The Task Force gathered information about existing services and gaps and made recommendations for the State Plan. The Legislative Committee on Health Care appointed members to the Task Force from diverse disciplines to reflect the many areas touched by Alzheimer's Disease. Experts in social work, medicine, psychology, nursing, public policy, and related disciplines were called to provide testimony.

Three working groups were created to dialogue and provide input in the following areas: Access to Services; Quality of Care and Regulation; and Impact on the State, Safety, and Independence.

The Task Force met five times between June and October 2012. All public hearings were conducted through simultaneous videoconferences between legislative meeting rooms at the Grant Sawyer State Office Building in Las Vegas, Nevada, and the Legislative Building in Carson City, Nevada. In addition, each meeting provided time for public comment. The working groups, health care professionals, educators, caregivers, and other members of the public provided input and recommendations to the Task Force for consideration. At the fourth meeting, members adopted several recommendations and goals for inclusion in the State Plan. At the fifth meeting, members conducted a work session in which they adopted the State Plan and a recommendation for legislation.

What is Alzheimer's Disease?

Dementia is an umbrella term for a number of distinct neurological diseases caused by plaques and neurofibrillary tangles, strokes, or other problems in the brain. Alzheimer's Disease is one form of dementia and is the most common, accounting for approximately 70 percent of cases. There are over 50 identified forms of dementia besides Alzheimer's Disease, including: vascular dementia, Lewy Bodies Disease, Parkinson's Disease, frontotemporal dementia,

and Pick's Disease. Some forms of dementia may be reversible, but for the majority, including Alzheimer's Disease, there remains no cure.

Symptoms include short and long term memory loss, difficulties problem solving and performing step-wise tasks, and impaired communicative abilities. The cognitive decline from dementia is significantly different than what is expected from normal aging and interferes with the completion of activities of daily living. Individuals with dementia may live from 2 to 20 years with the disease, becoming increasingly dependent on others for their care.

Prevalence of Alzheimer's Disease

The number of Americans with dementia is estimated at over six million.[1] In Nevada in 2010 the population with Alzheimer's Disease was estimated at 29,000, which marked a 38 percent increase from 10 years prior. The greatest known risk factor for dementia is age. As the population continues to age, nationally and locally, the number of persons with dementia will continue to increase. Nevada's median age rose from 35 in 2000 to 36.3 in 2010. By 2050, if there is still no cure, the number of Americans with dementia is expected to more than double.

Economic Impact

The cost of care for Alzheimer's Disease is estimated at $200 billion in the United States in 2012, and is projected to rise to $1.1 trillion by 2050. Over 15 million Americans provide unpaid care that is valued at $210 billion each year. In Nevada in 2011, over 130,000 unpaid caregivers provided over $1.8 billion in unpaid care.

The average Medicare payments for an elderly person with dementia are nearly 3 times higher than for an elderly person without dementia. Medicaid payments are 19 times higher for individuals with dementia. The cost to Medicaid and Medicare has been forecasted to increase by 500 percent by 2050.

Chapter 2: Access to Services

Long-Term Care Facilities in Nevada

In Nevada, options for residential long-term care include assisted living facilities, group homes, nursing homes, and specialized memory care units. Currently, no facilities specialize in working with residents with behavior problems, co-morbid dementias, or mental health issues. As a result, every month approximately 1 to 2 residents with behavior problems are forced to move to facilities in other states. This not only places a great deal of strain on the residents and their families, but also costs Nevada $2.4 million per year.

[1] Herbert et al, 2003; Plassman et al, 2007

Home-Based Services

Nevada's Aging and Disability Services' Community and Home Based Waiver (HCBW) and Community Service Options Program for the Elderly (COPE) provide home-based care to help maintain independence and delay placement to long-term care facilities. Private home-health agencies may also be hired to provide a variety of home-based services, and are regulated by the Bureau of Healthcare Quality and Compliance.

Diagnostic Services

The importance of early detection of dementia cannot be understated. Patients and families need time to plan and educate themselves about the disease process. Additionally, persons with dementia may be at-risk for their behavior being misinterpreted if the disease has not yet been diagnosed. One example of a need for training about recognizing Alzheimer's Disease is with law enforcement. Many times law enforcement officers are called when a person with Alzheimer's Disease becomes violent or commits a criminal act. The person with Alzheimer's Disease may not recall what transpired, and there may be difficulty with taking the person into custody. Most jails do not have a place to house and care for them adequately, and often they can become victims within the jail system due to their disease.

Even within the medical system, dementia is often not diagnosed as early as it could be. This is likely due to stigma, fear, a deficiency in education for physicians, the general population's lack of education, and the lack of a disease-modifying treatment. Neuroimaging techniques and other methods of detecting Alzheimer's Disease and other dementia-related conditions are advancing; however, the cost of such procedures (such as amyloid imaging PET scans) remains high in the absence of Medicare coverage for such testing. In addition, physicians are reimbursed at inadequate levels for other routine diagnostic procedures.

Behavioral Services

According to an Alzheimer's Association survey, many families do not report learning about treatments or strategies other than medication. Though a cure for dementia is not available, there are many ways to improve quality of life for caregivers and care recipients. Socialization programs, support groups, counseling, care management, and other programs have been shown to reduce stress and improve quality of life.

Many people believe that those with Alzheimer's Disease, other dementias, and their caregivers prefer to be alone. Because communication can be difficult with those who have dementia, well-meaning friends often stay away. They may be afraid of interfering or simply fearful of the disease itself. Socialization programs can provide much-needed social interaction for the care recipient and a break for the caregiver. Caregivers often feel alone and isolated, believing that only they can provide care even as they enter new phases of the disease.

Support groups for caregivers are important for emotional support, stress management, and learning helpful techniques from others.

Nevada's Aging and Disability Resource Center (ADRC) website lists support groups and other non-medical services, and also publishes a Community Resource Guide. In addition, Alzheimers.gov is a national website that connects caregivers to available resources. Even with these referral sites, many of the individuals who testified before the Task Force noted difficultly for families and professionals in locating and connecting with existing resources. Many caregivers are unaware of available services in Nevada that are free or low-cost.

Rural Services

Nevada is a unique state on a geographical level. The three metropolitan areas, Reno/Sparks/Carson City, Elko, and Las Vegas, are located in corners of the State with vast stretches of open road and smaller towns between them. Patients in Nevada's rural areas are geographically isolated from many services. Consequently, isolated towns have difficulty recruiting specialists in neurology or geriatrics to provide services in their communities.

As hospitals throughout the State extend the use of tele-medicine, diagnosis and treatment will be delivered in a more timely and progressive manner. This will enable patients and families, physicians, and other medical personnel to act and interact to receive the best medical care. However, distance still makes face-to-face doctor-patient visits problematic without access to transportation services to metropolitan and other areas that offer special services. Providing transportation with well-trained drivers and support personnel is essential to the best care of individuals with Alzheimer's Disease.

Early-Stage

Those who have been diagnosed with dementia early in the disease process are likely to benefit from interaction with others who are in the same situation. Programs designed specifically for early-stage patients help to promote education, understanding, healthy coping strategies, and ways to maximize remaining abilities. These groups can prevent depression and anxiety, and allow those affected to still lead healthy, active lives.

Younger/Early-Onset

While Alzheimer's Disease and other dementia-related conditions are often grouped together, the etiologies and symptoms are quite varied. Additionally, Alzheimer's Disease is typically thought of as a disease of the elderly, when in fact it may affect those who are still young. The youngest documented case of Alzheimer's Disease was 26 years old, and an increasing number of cases are diagnosed in individuals who are under the age of 65. Such cases are considered "younger" or "early-onset."

Early/younger-onset patients face numerous challenges in the work place, in medical treatment, and in the availability of the best medical services. Many are denied the care and medications they need based on their age. Many services, even transportation and Medicare, are not obtainable until the age of 65. Thus when individuals with early/younger-onset Alzheimer's Disease become disabled in their 30s, 40s, and 50s, extra stress and expense are experienced by families who are already suffering. Young children and adolescents are often unable to cope with a parent or guardian who is incapable of living and maintaining a lifestyle as a breadwinner, head of household, or parent.

Chapter 3: Quality of Care

Measuring Quality of Care

The Bureau of Healthcare Quality and Compliance (BHCQC) is tasked with measuring and regulating the quality of care in Nevada's long-term care facilities and home health agencies. The BHCQC licenses certain facilities and agencies and conducts inspections on an annual basis. The BHCQC attempts to foster open communication and collaboration with the facilities and agencies.

While nursing facility administrators and administrators of residential facilities for groups are required to be licensed, the employees of such facilities are unlicensed personnel. Employees must pass a criminal background check, take a CPR course, and receive a set amount of training. However, the BHCQC does not evaluate or regulate the training materials. Currently, no requirement exists for employees who are working with individuals with dementia to receive any dementia-specific training.

Education and Training

Educators in public and private institutions from across the State testified about growing educational opportunities related to gerontology and aging in general. Overall, the programs seek to integrate curriculum, service, and research. The University of Nevada, Reno (UNR) offers undergraduate and graduate education in healthy and pathological aging, with both classroom and field experiences. Students have the opportunity to work and study with the Nevada Caregiver Support Center, a grant-funded organization providing empirically-supported treatment to families of persons with dementia. University of Nevada, Reno offers a gerontology minor and a gerontology certificate. Through the Sanford Center for Aging at UNR, students can volunteer for programs assisting the elderly. The UNR School of Medicine gives students early and frequent exposure to elderly patients and offers fellowship programs in geriatrics and hospice/palliative care.

The College of Southern Nevada offers certificate programs and Associates degrees with an emphasis in preparing students to provide direct services to the elderly or transferring to programs in psychology, social work, community health sciences, and related disciplines.

At the University of Nevada Las Vegas (UNLV), the school of dental work offers students training experience in working with the elderly, including those with dementia, and offers low cost screenings and dental services to the community. University of Nevada, Las Vegas has also opened a new community clinic that offers counseling and psychotherapy and clinical psychological assessment or testing. This clinic is called the PRACTICE (Partnership for Research, Assessment, Counseling, Therapy and Innovative Clinical Education), and it serves a variety of populations, including elderly individuals from the community.

Nevada's educational programs all show the potential for increased growth and collaboration, expanding education and training opportunities for families, healthcare workers, and students across the state.

Cultural Competency

Nevada's elderly population is growing increasingly more diverse, and minorities are less likely to utilize services. To address this population, Nevada will:

1. Meet the demand for culturally and linguistically sensitive information to increase awareness to persons living with and affected by Alzheimer's Disease and other dementia-related conditions.

2. Be inclusive in its approaches to serving all who are in any way affected by Alzheimer's Disease.

3. Develop relationships with diverse communities to educate, support, enhance care for, and inform them about Alzheimer's Disease and other dementia-related conditions.

Some of the areas of education and support are:

- Reactions to the diagnosis—These may be of infinite variety and nearly impossible to predict.

- The family—Spouses/partners and extended family may feel a sense of loss or loneliness as a result of the diagnosis and therefore need counseling and support.

- Children—Children, regardless of age, may experience a wide range of emotions and may feel that they did something to cause the disease, or may become resentful that they have to take on more responsibilities.

- Job—A person with Alzheimer's Disease, or a caregiver, may find work more difficult to perform and job requirements more problematic to complete. Eventually, an individual may need to reduce work hours, change job duties, or leave the job.

This will affect not only the person's health insurance and other benefits, but possibly those of the whole family. It is critical that health care coverage be available and reasonable for patients, caregivers, and families.

- Debt—Reducing one's work hours, changing job duties, and eventually not working at all may affect the ability to pay a mortgage, buy essentials, and continue to have a source of income.

- Legal issues—Individuals with Alzheimer's disease and their caregivers and/or family need to meet with an attorney to appoint a person to make financial and health care decisions for the future.

- Future care—Decisions about the day-to-day care of the person with dementia and the future care of the person with dementia must be made and recorded so that wishes can be met. Respite care for family caregivers is also a consideration with future care.

Communication Gaps Between Physicians and Patients

A survey by the Alzheimer's Association found that patients report that they are not receiving all the information they want from their physicians, though the physicians report providing the information.

Chapter 4: Quality of Life

For the Care Recipients

The profound changes brought on by cognitive disorders such as Alzheimer's Disease often lead to frustration, sadness, anger, and worry. Individuals with dementia gradually lose the ability to complete activities of daily living and also have a limited ability to seek or access pleasant events. The prevalence of depression and anxiety in dementia is very high. Clinically significant depression has been found in 20 to 30 percent of those in samples of individuals with dementia living in the community, which is significantly higher than the estimated 2 percent prevalence of depression in individuals over the age of 65. [2] Anxiety has been found in 20 percent of community-dwelling individuals with dementia. [3]

For the Caregivers

Caregivers of those with dementia also report high rates of depression, anxiety, stress, and burnout. These may manifest in physical symptoms as well, with caregivers at an increased

[2] Ballard, Bannister, & Oyebode, 1996; Ross, Arnsberger, & Fox, 1998
[3] Lyketsos et al., 2000; Lyketsos & Lee, 2004

risk of cardiovascular disease, high blood pressure, and impaired immune systems. Elderly caregivers have a 63 percent higher mortality rate than non-caregivers of the same age.[4]

The high stress on caregivers, particularly combined with a lack of education about dementia and poor coping skills, can put the care recipient at an increased risk of elder abuse. The research literature on elder abuse is lacking, but rates of elder abuse are highest from family members–documented at 90 percent.

Chapter 5: Public Safety and Public Awareness

Public Safety and Awareness Programs

Senate Bill 245 (Chapter 184, *Statutes of Nevada 2011*) created the Statewide Alert System for the Safe Return of Missing Endangered Older Persons, a type of "Silver Alert" program that has been successfully implemented in 28 other states.

Although Nevada has yet to implement a State-specific dementia awareness program, the Alzheimer's Association and the U.S. Department of Health and Human Services have begun television, radio and print advertisements describing Alzheimer's Disease, research efforts, and encouraging visits to websites such as Alzheimers.gov.

The Alzheimer's Association's MedicAlert Safe Return bracelets program has been available for those with dementia to help identify them should they become lost or need assistance. In Nevada, the Alzheimer's Association has reported that this program has been underutilized.

Driving

Driving is a public safety issue for persons with Alzheimer's Disease and other dementia-related conditions. Driving is an important part of independence and identity for many people, and individuals often choose to continue driving even after receiving a diagnosis of dementia. Individuals may also feel that they need to continue driving out of necessity, as public transit or other transportation options are often very limited in Nevada. Because of the visual, spatial, motor coordination, planning, and memory deficits inherent in dementia, driving is very dangerous. The Department of Motor Vehicles (DMV) may revoke an individual's license if they fail a paper or driving test. Physicians or friends may make referrals to the DMV if they are worried about someone's driving abilities. However, public safety could be greatly improved if efforts were taken to ensure that individuals with dementia do not slip between the cracks of the current system.

[4] Schulz & Beach, 1999

Chapter 6: Policy Recommendations

A. Identified gaps in services

1. Dementia is under-diagnosed, especially in younger-onset dementia cases;
2. Physicians are not reimbursed to spend a longer amount of time with patients, explaining the diagnosis and services available;
3. Patients report not receiving the information they want from their physicians, even though physicians report that they have provided the information;
4. The Bureau of Healthcare Quality and Compliance has no measure by which to evaluate or regulate the merit of the training that facilities and agencies receive;
5. No requirements exist for facilities or agencies to provide dementia-specific training to employees who will be working with persons with dementia;
6. Long-term care facility residents may be forced to move out-of-State when facilities are unable or unwilling to admit them, costing Nevada $2.4 million per year and causing unnecessary suffering for families;
7. No long-term care facilities in Nevada specifically cater to elderly patients with co-morbid dementia and mental health issues. Patients with dementia commonly live in settings alongside psychiatric patients, which is a poor match for both groups;
8. Minorities are less likely to utilize services and many services may not be available in languages other than English;
9. Those under the age of 65 with dementia do not qualify for Medicare until they qualify for disability, and wait 24 months;
10. The children of those with younger-onset dementia do not receive any benefits;
11. Retirees aged 55 to 64 fall into a gap of insurance coverage and may wait until qualifying for Medicare at age 65 to receive needed treatments, at which point the treatment may be more costly;
12. Patients with dementia who have a power of attorney for health care may not be admitted for psychiatric treatment via the Legal 2000 process; and
13. The process of a patient acquiring a guardian is time-consuming and costly.

B. Goals
(Arranged by chapter)

Conclusion
(Future Task Force meetings?)