Nevada Task Force on Alzheimer's Disease

State Plan Recommendations Planning

New Recommendation

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Proposed title for recommendation area: Dementia Crisis Services and Supports

Justification:

In Nevada, Mobile Outreach Safety Team, community social workers and APS workers report frequent interactions with individuals in crisis who may have dementia. Often, the person is handcuffed and transported to a hospital emergency room causing confusion, fear and a worsening of their condition. According to studies of dementia crises, delusions, hallucinations, and reports of "wandering" (i.e., getting lost) and "stealing" (i.e., confusion about property, possessions, and purchases) were key behaviors contributing to crises especially when the behaviors present a to risk the individual or others.

According to the *2021 Nevada Elders Count Report*, the growth of the older adult population in Nevada continues to outpace the United States growth. From 2011 to 2018, Nevada experienced a 40% increase in people age 65 and older as compared to a 25% increase nationally.[i]

Additionally, the growth rate for the age 85 and older population is double the national rate and Nevada's population is expected to continue at higher rates through 2030.

According to the Alzheimer's Association's *2022 Facts and Figures*, Nevada is estimated to have 64,000 people age 65 and older living with Alzheimer's by 2025. That is a 30% increase from the 2020 estimate. That is the third fastest rate of growth in the nation. In addition, the hospital readmission rate for people living with dementia is 25.8%, while 80.2% of caregivers of people living with dementia are experiencing chronic health conditions themselves.[ii]

In both the *2022 Facts and Figures* report and the *2021 Elders Count Report*, workforce and infrastructure are noted barriers for older adults in Nevada, these workforce shortages have been exasperated by the COVID-19 pandemic and will continue to have a disproportionate impact on people living with dementia and their family caregivers, thus causing further strain on Nevada's resources to support this vulnerable population.

In Nevada, Mobile Outreach Safety Teams (MOST), consisting of county social workers, Adult Protective Services (APS) workers and members of law enforcement were created to help triage crisis support services in Nevada's most rural communities. Through these efforts, Nevada has recognized there are frequent interactions with individuals in crisis who may have dementia. These crises, often the result of unmet needs, caregiver burnout, and/or interpersonal conflict stemming from confusion and communication difficulties, are mostly avoidable given proper education, supports and a person- and relationship-centered approach.

However, currently lacking such a system of support, vulnerable Nevadans are often handcuffed and transported to an emergency room or inpatient psychiatric hospital, causing increased confusion, anxiety and exacerbating their behavioral crisis. This is commonly followed by chemical, physical, and/or environmental restraints which accelerate decline and lead to increased mortality.

Further, delusions, getting lost ('wandering'), misplacing and losing things, mistakenly taking things that belong to other people ('stealing'), and hallucinations are the primary contributors to crises, especially when the person displays behavior which presents a risk to themselves, their caregivers, or others. Behavioral crises predominantly happened in the moderate to late stages of dementia and were the catalyst for admissions to psychiatric inpatient settings, specialist-care units, long-term care settings, or for referrals to psychiatric community services.

Few long-term care facilities are willing to take people with dementia who are in crisis. Additionally, few stabilization options exist, with emergency rooms and inpatient psychiatric hospitals serving as the default receiving facilities.

These gaps currently affect tens of thousands of Nevadans, causing unnecessary suffering, overburdening the acute care sector, and violating the right to receive care and support in the least restrictive environment. Providing more targeted support through a "no wrong door" approach can help people living with dementia and their family caregivers through informed choice, empowerment, and planning.

Recommendation:

Establish a Dementia Care Specialist (DCS) Program

Wisconsin has been in leader with their DCS program. With legislative support, they have a professional (and most often, a graduate-level) DCS in every county. Maryland and Georgia are also looking to emulate Wisconsin's DCS program. Over a period of ten years, the Wisconsin DCS program has grown from 5 DCS positions to 70 today, including staff in tribal communities. This program has also been highlighted by the Administration on Committee Living.

Significant cost savings to state Medicaid programs can also be achieved by timely and appropriate caregiver supports. A 2014 study published by Mary Mittelman of the NYU School of Medicine showed that people with dementia resided in the community an average of 557 days longer, compared to those in the control group. For the caregiver, the intervention was associated with a decrease in depressive symptoms and related symptoms of distress.[iii]

The Wisconsin DCS program has three goals, which are referred to as the three pillars of the program. The three pillars are:

1. Train staff at the ADRC and other county and municipal offices to assist local systems to become dementia-capable.
2. Help communities become dementia-friendly where people with dementia can remain active and safe, and caregivers can feel supported by their community.
3. Provide education and support to people with memory concerns or dementia, and their families, to allow them to live at home safely.

The Wisconsin Department of Health Services has also integrated a dementia crisis response effort into their no wrong door/aging and disability resource center (NWD) model using the DCS Program. This involves a three-pronged approach: the initial crisis response, crisis stabilization, and providing long-term care and supportive services for people with extremely challenging behaviors, which are usually expressions of unmet needs.[iv]

In Wisconsin, the DCS does not go on crisis calls and operated during regular business hours, However, they are available to:

- Provide training on dementia, and how to work effectively with a person who has dementia in a crisis situation, to any professional first responder or public safety agency, including law enforcement, emergency medical service providers, fire and rescue teams, adult protective services workers, and crisis response workers within their service area.
- Accompany adult protective services workers on home visits during regular work hours when dementia is suspected to be involved in the case.
- Consult with crisis workers and other emergency responders on individual cases during regular business hours.
- Consult with or serve on local coalitions or task forces that are working to improve local systemic responses for people with dementia in crisis.

Importantly, the DCS is proactive by working with all individuals living with dementia and their families to create individual care plans and crisis prevention and preparation plans to prevent an initial crisis from occurring for that individual or family related to the symptoms of dementia.

In addition to crisis response, the DCS Program also works to support people living with dementia and their caregivers, and to build dementia capability within the community to ensure the highest quality of life possible while living at home. To accomplish this, the dementia care specialists (DCSs), embedded within each county:

1. Provide free information and assistance to adults with memory or cognitive concerns, or who have been given a dementia diagnosis as well as;
2. Provide information, education and support to family members and friends who are caregivers of people living with memory loss and/or dementia.
3. Help develop dementia-friendly communities where people living with dementia can remain active and safe, and caregivers can feel supported.
4. Train Resource Navigators at Nevada Care Connection AKA the Aging and Disability Resource Centers (ADRCs) and other county and municipal offices to be dementia capable.

Nevada is well positioned to replicate this model as part of its Nevada Care Connection network.

We recommend that the Aging and Disability Services Division (ADSD) replicate the Dementia Care Specialists (DCS) program in Nevada by developing funding necessary to establish one or more DCS positions as a pilot. These positions could be housed in county health and human service agencies, senior community centers or non-profit organizations serving the elderly.

The DCSs will serve as the primary, local contact for people living with dementia, family caregivers, law enforcement, hospitals, healthcare professionals, community social workers, and other community members who encounter individuals who may have dementia. They will also conduct memory screenings; facilitate obtaining an accurate diagnosis; provide information and assistance to connect families and individuals with community support services; provide evidence-based and/or evidence - informed, person- and relationship-centered education, training and support; connect people with options for counseling as well as access to public and private programs and benefits; provide consumer advocacy; lead and facilitate local dementia-friendly efforts in coordination and partnership with Dementia Friendly Nevada; and conduct other outreach activities with an aim to bring additional dementia-related services to the region.

Program outcomes include:

1. Replicate the Wisconsin DCS model in Nevada.
2. Increase caregiver support through implementation of the bi-lingual REACH Community intervention.
3. Strengthen ADSD efforts to raise awareness and community support of people living with dementia.

Training and oversight can be provided by the UNR Dementia Engagement, Education, and Research (DEER) Program, which also provides an administrative home for the Dementia Friendly Nevada initiative. Program evaluation will be could be conducted by the UNR Sanford Center for Aging, or another appropriate academic department experienced in this area.

Indicators:

1. Reduction in avoidable emergency department and hospital admissions;
2. Reduction in avoidable incarceration of individuals with suspected dementia;
3. Increase in pro-active training of first responders, staff in community-based organizations and county agencies serving the elderly; and
4. Increase in safety and well-being of individuals living with dementia, their families and caregivers.

Potential Funding:

Grants, donations, state appropriations and Medicaid administrative claims funding.

[i] 2021 Elders Count Report, published by NV Aging and Disability Services Division, accessed 5/1/22.

[ii] 2022 Alzheimer's Facts and Figures Nevada, Alzheimer's Association

[iii] Mittelman MS, B. S. (April 2014). Translating research into practice: case study of a community-based dementia caregiver intervention. *Health Affairs*, 33(4):587-95.

[iv] Wisconsin Department of Health Services, 2021