

March 20th, 2018 Listening Session to Inform the SB121 Interim Committee on the Cognitive and Behavioral Care Needs of Older Persons

EXECUTIVE SUMMARY

Introduction

With more than 45,000 Nevadans currently living with Alzheimer's disease, and that number predicted to rise to 64,000 by 2025, there is an urgent need to understand more about the challenges that people with dementia face, and to develop effective solutions to help overcome those challenges. As the disease progresses and individuals become more reliant on care providers, it becomes ever more important to ensure that those in a caring role (either as family caregivers or professionals in the field) have the information, tools and resources they need to ensure the provision of quality care. This kind of care preserves autonomy for individuals with dementia, helps avoid institutional placement and improves quality of life.

To enhance our understanding, the Alzheimer's Association hosted a statewide Listening Session on March 20, in partnership with Aging and Disability Services and the Department of Public and Behavioral Health. The purpose of the event was to convene a representative group of family and professional caregivers from six Nevada communities to share their experiences of caregiving, including what barriers they faced and what suggestions they might offer for managing the care needs of those living with dementia.

Overview of the Listening Session

More than 60 people were present at the event hub in Carson City, and dozens more joined by videoconference from Las Vegas, Sparks, and Elko. Several more participated by phone from Winnemucca and other locations. A total of 100 Nevadans took part in the event, including individuals living with dementia, family and professional caregivers, and staff and partners of ADSD and DPBH. Representatives from the offices of Senator Heller and Senator Cortez Masto, as well as staff of the SB121 Committee to Study the Behavioral and Cognitive Care Needs of Older Persons, were also present to hear the testimonies first hand.

Caregivers and professionals spoke to the following questions and posed solutions depending on their role:

- *As a family member, what was one of the difficult behavioral symptoms you encountered in caring for your loved one with Alzheimer's or Dementia?*
- *If one thing could have helped you during that time, what might that have been? This might include access to dementia-capable care, support services, respite, or other ideas you have that could have influenced your situation.*
- *As a professional, what are some of the barriers to care you see for people with behavioral symptoms in your community?*
- *What possible influencers or solutions might help alleviate these in your community?*

A total of 14 testimonies were verbally presented by both groups while 48 other stories were captured in written form. Copies of all 62 testimonies, as well as one combined summary of findings, have been forwarded to each of you.

Summary of Findings

Nevada's communities vary widely in composition from more densely populated Clark and Washoe Counties to the sparsely inhabited rural and frontier communities that occupy the vast majority of the state. While the challenges differ for each community, common themes emerged from the testimonies, including issues with disease management, early detection and timely diagnosis, and the expansion of dementia-capable resources.

The most pressing needs that were identified can be grouped into five categories:

1. Shortage of Respite – in every community the need for reliable, quality respite care to provide relief for family caregivers was expressed.
2. Insufficient Awareness and Education – even where resources existed, care providers were not always aware of or able to access them.
3. Perceived Lack of Dementia-Competency Training - for providers (medical, respite, and long-term care) as well as for families.
4. Inadequate Availability of Affordable Transportation – providing a barrier to accessing services and sometimes leading to increased isolation
5. Limited Availability of Affordable Long-Term Care – difficult to find and access long-term care at reasonable rates. Also, there are limited incentives for providers to work in rural areas.

Recommendations

In reviewing findings from the Listening Session, the Alzheimer's Association suggests three recommendations to the Interim Committee:

1. Expand Respite – through enhanced/alternate funding sources, increase ease of access to respite resources, bolster programs that recruit and train respite volunteers statewide.
2. Increase Public Awareness of Services - promote use of existing services through a coordinated, statewide public awareness campaign to make Nevadans aware of resources in their community.
3. Review Training and Education Requirements for Providers – Review NRS & NAC for consistency in dementia training requirements amongst all facilities and health professionals, ex: Community Health Workers, Caregivers, Adult Day-Care Programs, etc.

Conclusion

Family and professional care providers shoulder the responsibility of ensuring the safety and wellbeing of individuals living with dementia. Caregiving can be overwhelming, with a corresponding high risk of poor physical and emotional health and even early death. The findings and recommendations from the Listening Session are based on the voices of Nevadans. We heard those voices and now our collective responsibility is to ensure that effective and appropriate supports are in place to help caregivers, and to ensure individuals with dementia live as well, and as safely, as possible with the disease.