

# Nevada Task Force on Alzheimer's Disease State Plan Recommendations Planning Template

## **Recommendation #: 7**

**TFAD Member Lead(s): Chuck Duarte**

**Current Recommendation as Stated: Caregiver Support**

Provide caregivers with information about and access to evidence-based/informed education, support services, and resources to:

- 1) Promote knowledge and understanding of Alzheimer's disease and other forms of dementia
- 2) Increase understanding of effective approaches to care and support;
- 3) Provide and expand respite services for family and informal caregivers of persons with dementia; and
- 4) Enhance caregiver well-being.

These services include, but are not limited to, family care consultations, solution-focused caregiver support groups, educational programs and services, respite programming and evidence-based programs as included in the Nevada Dementia Supports Toolbox. Support efforts to promote and fund comprehensive caregiver education and services that are provided by many organizations, including, but not limited to: AARP, Alzheimer's Association, Catholic Charities, the Cleveland Clinic Lou Ruvo Center for Brain Health, UNR DEER Program, NDVS, Nevada Senior Services, UNR Nevada Caregiver Support Center and UNR Med Sanford Center for Aging.

- Broaden the eligibility requirements for programs and grant funding so that more families may benefit from them regardless of financial status or age.
- Support the Dementia Friendly Nevada initiative and the work of the state's Dementia Friendly Community Action Groups throughout Nevada.
- Improve access to support services and programs by sustaining a statewide information and referral system (recommendation #1) for families, caregivers, and individuals with Alzheimer's disease and other forms of dementia.

**Determination:** Do you propose that for the 2021 State Plan this recommendation be:

- 1) Retained as is
- 2) Retired to the Appendix (it has been accomplished or is no longer relevant)
- 3) Revised / Updated ✓

**Justification:** If you propose revising this recommendation, what is your

rationale for your suggested changes:

According to the 2022 Alzheimer's Disease Facts and Figures report, Nevada has more than 48,000 unpaid caregivers providing 79,000,000 hours of unpaid care annually with an estimated value of almost \$1.35 billion. Nevada has the tenth highest unpaid caregiver hours per caregiver (almost 32 hours per week per caregiver).

In addition, that same report indicates that the caregivers themselves suffer from their own health conditions. More than 80% of Nevada caregivers report at least one chronic medical condition, and more than 18% suffer from depression.

With the anticipated growth of ADRD in Nevada, the burden of unpaid caregiving will only increase. To keep up, the 2022 Alzheimer's Disease Facts and Figures report indicates that Nevada needs to increase the number of caregivers for those living with ADRD by 42% by 2028, from 15,580 home health aids and caregivers to more than 22,000.

Keeping up with this growing demand means we must not only increase the numbers of paid and unpaid caregivers, but must also support those who are already providing care to individuals living with ADRD through respite and training programs.

**Suggested Revisions:** Please provide the text for your suggestions on how to revise the recommendation (and be sure to include each of the following required elements):

- **Recommendation:**

Revise the recommendation adding information on caregiving in Nevada from the 2022 Alzheimer's Disease Facts and Figures report. Revise as follows:

An estimated 48,000 caregivers are providing 79 million hours of unpaid care to Nevadans living with dementia. 80.2% of those caregivers have chronic health conditions and 18.3% have depression. Caregiver support interventions can help improve the health and well-being of dementia caregivers by relieving the negative aspects of caregiving. Effective support for caregivers can also delay nursing home admission of the person with dementia by providing caregivers with skills and resources (emotional, social, psychological and/or technological) to continue helping their relatives or friends at home. (Source: Alzheimer's Association Facts and Figures 2022)

Provide caregivers with information about and access to evidence-based/informed education, support services, and resources to:

- 1) Promote knowledge and understanding of Alzheimer's disease and other forms of dementia
- 2) Increase understanding of effective approaches to care and support; **and thereby help caregivers manage dementia-related symptoms**

The following includes additional language for this recommendation:

The TFAD, ADSD and the Division of Health Care Financing and Policy (DHCFP, or Nevada Medicaid) should explore effective programs in operation in other states, including Structured Family Caregiver Waivers. The current Medicaid Home and Community-Based Waiver for the Frail Elderly, could be modified to based on effective waiver programs, such as in the state of Georgia. Georgia has established a mechanism to identify and deliver individualized training to family caregivers that is based on information collected through the care coordination process. Training may be offered through a home visit, secure electronic communication, web-based training or other ways that are flexible, accessible and meaningful for the caregiver.<sup>1</sup>

In addition, ADSD should consider conducting an awareness campaign around eligibility of current respite care programs.

Finally, a survey of several current and former caregivers affiliated with the Alzheimer's Association suggested language regarding caregiver support programs in the state plan be clarified. As a public-facing document the term used "solution-focused caregiver support groups" was an unfamiliar term and should be clarified.

I also recommend the language changes recommended by Dementia Friendly Nevada as follows in **redline italics**:

**Recommendation #7: ~~Caregiver~~ Care Partner Support TFAD**

**Member Lead: Chuck Duarte**

**Determination: Revised/Updated**

**Suggested Revisions:**

Provide ~~caregivers~~ care partners with information about and access to evidence-based and evidence ~~-~~informed education, support services, and resources to:

1. Promote knowledge and understanding of ~~Alzheimer's disease and other forms for~~ dementia;
2. Increase understanding of effective care-partnering approaches to ~~care and support~~ people living with dementia;
3. Provide and expand respite services for family and informal ~~caregivers~~

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<sup>1</sup> Neva Kaye, Salom Teshale, Medicaid Supports for Family Caregivers, October 2020, National Academy for State Health Policy.

- care partners of persons/people living with dementia;and
4. Enhance caregiver well-being/Emphasize the importance of maintaining care partners' health and well-being.

*These services include, but are not limited to, family care consultations, ~~solution-focused caregiver care partner~~ support groups, educational programs and services (including those focused on the proactive promotion of family care partner health), and respite programming and evidence-based programs as included in the Nevada Dementia Supports Toolbox.*

*Support efforts to promote and fund comprehensive ~~caregiver care partner~~ education and services that are provided by many organizations, including, but not limited to: AARP, Alzheimer's Association, Catholic Charities, ~~the~~ Cleveland Clinic Lou Ruvo Center for Brain Health, UNR DEER Program, NDVS, Nevada Senior Services, UNR Nevada Caregiver Support Center and UNR Med Sanford Center for Aging.*

*Improve access to support services and programs by sustaining a statewide information and referral system (Recommendation #1) for family care partners and people living with dementia. Broaden the eligibility requirements and grant funding for these programs so that more families may benefit regardless of financial status or age.*

~~*Broaden the eligibility requirements for programs and grant funding so that more families may benefit from them regardless of financial status or age. Support the Dementia Friendly Nevada initiative and the work of ~~the state's~~ local Dementia Friendly Nevada Community Action Groups throughout Nevada.*~~

~~*Improve access to support services and programs by sustaining a statewide information and referral system (recommendation #1) for families, caregivers, and individuals with Alzheimer's disease and other forms of dementia.*~~

- **Indicators:**

Current indicators should be retained. However, data from the BRFSS Caregiver Support survey should be incorporated into this section of the recommendation. A longitudinal review of past caregiver surveys can also be used to track progress of this recommendation.

I also recommend changes to this section consistent with the recommendations from Dementia Friendly Nevada in **redline italics**:

- ADSD and DPBH will annually monitor program availability, waitlists, number of consumers/clients served, and hours of ~~caregiver care partner~~ support services provided through ADSD-funded programs.
- ~~Key partners and other d~~ementia-related organizations **that are** working in-

~~alignment~~ to support these efforts will also be asked to report on service delivery and outcomes from ~~caregiver~~ care partner support programs.

- **Potential Funding:**

In addition, to current funding sources, state general fund and Medicaid federal financial participation should be considered in order to enhance current programs and create new effective initiatives.