Recommendation #:1_	
TFAD Member Lead(s):	_Marco Valera
Current Recommendation as S	Stated:

#### Recommendation #1: Statewide Information and Referral System (2013)

Sustain a statewide information and referral system for people living with Alzheimer's disease and other forms of dementia, their caregivers, and their families to enable them to connect with local case managers and support services. It is the expectation that the approaches, content, and messaging within these resources help promote well-being and preserve dignity. Supportive services would include no wrong door partners, including but not limited to: Nevada 2-1-1, Nevada Care Connection Resource Centers (NCCRC), Family Resource Centers (FRC), and other related informational systems (e.g. websites, helplines, and other technologies).

#### **Indicators**

Monitor collaborations that includes resource centers, including, but not limited to, Nevada Care Connection; Nevada Chapter of the Alzheimer's Association; Southern Nevada Region, Desert Southwest Chapter of the Alzheimer's Association; University of Nevada, Reno; and Nevada Caregiver Support Center, to help facilitate access and streamline processes into services and supports for people living with dementia and their care. The Aging and Disability Services Division (ADSD) will monitor the number of contacts made by outreach programs and the number of inquiries regarding information or services relating to Alzheimer's disease and other forms of dementia received by Nevada Care Connection Resource Centers. In addition, ADSD and partners will monitor and report the number of "hits" on information sites, including nevadacareconnection.org, alz.org, nevadacaregiver.unr.edu,

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Efforts and collaborations will be reported by partners to the TFAD at least once per biennium.

#### **Potential Funding**

Older Americans Act funds. Grants, donations, and/or gifts.

**<u>Determination</u>**: 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

<u>Justification</u>: If you propose revising this recommendation, what is your rationale for your suggested changes: Changes in Yellow – The Alzheimer's Association has seen fit to create a new, statewide chapter – Alzheimer's Nevada

Deleted: the Nevada Chapte

<u>Suggested Revisions</u>: 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:

N/A

#### Indicators:

Develop a collaboration between resource centers, including, but not limited to, Nevada ADRC; Alzheimer's Association Nevada; University of Nevada, Reno; and Nevada Caregiver Support Center, to determine the combined impact of existing information and referral systems. The Aging and Disability Services Division (ADSD) will monitor and report the number of referrals relating to Alzheimer's or dementia from partners to ADSD, and any related Alzheimer's or dementia referrals made by ADSD to partner agencies. In addition, the number of "hits" on information sites, such as an expanded nevadaadrc.com, alz.org, nevadacaregiver.unr.edu, and Alzheimers.gov will be monitored and reported by the respective partners.

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#### Potential Funding:

N/A

# Nevada Task Force on Alzheimer's Disease State Plan Recommendations Planning – prepared by Tina Dortch

Recommendation #: 3	
TFAD Member Lead(s):_Tina Dortch	Current Recommendation as Stated:
Cultural Competency (2013)	

Support efforts to develop and distribute toolkits to assist public and private organizations in their outreach to different cultural communities-culturally diverse and marginalized members of the Alzheimer's community.

**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 expand description of patient base and efforts/means to distribute culturally sensitive care

<u>Justification</u>: If you propose revising this recommendation, what is your rationale for your suggested changes:

Person-centered care has been shown to improve a person's health and the quality of their care

<u>Suggested Revisions</u>: 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:

Promote multiple cultural sensitivity trainings that reflect preferences of culturally diverse and marginalized members of the Alzheimer's community. Including use of (but not limited to) People First Language, maintaining access to interpreters that includes those fluent in American Sign Language, adopting fully expressive pronoun usage and other LGBTQIA concepts (see advocacy recommendations from SAGE - the country's largest and oldest organization dedicated to improving the lives of LGBTQ older people); the Generational Diversity and Sensitivity Training Program

Conduct Listening Sessions facilitated using Culturally and Linguistically Appropriate Standards to gauge impression of quality of care experienced by culturally diverse and marginalized members of the Alzheimer's community

# • Indicators:

Monitor number and diversity of adopted culturally sensitive protocols

Monitor number of service providers taking Implicit Bias Assessments and following up with cultural sensitivity training

# • Potential Funding:

National Resource Center on LGBT Aging

US DHHS Office of Minority Health

Recommendation #:5	
ΓFAD Member Lead(s):Marco Valera	
Current Recommendation as Stated:	

# Recommendation #5: Outreach to Physicians (2017)

# Recommendation

Support collaborations between medical professionals and medical associations to adopt and promote use of best-practice diagnostic guidelines for Alzheimer's disease and other forms of dementia. Support a meaningful and effective communication continuum between these professionals and community-based service organizations, including referrals to community-based resources.

# **Indicators**

Data gathered by the Alzheimer's Association.

# **Potential Funding**

Alzheimer's Association. Grants, donations, and/or gifts.

**<u>Determination</u>**: 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

<u>Justification</u>: If you propose revising this recommendation, what is your rationale for your suggested changes:

No drastic changes, just updates.

<u>Suggested Revisions</u>: 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:

Support collaborations between medical professionals and medical associations to adopt and promote use of best-practice diagnostic guidelines for Alzheimer's disease and other forms of dementia. Support a meaningful and effective communication continuum between these professionals and community-based service organizations, including referrals to community-based resources. Support our statewide Dementia Director and Coordinator as operated by the Alzheimer's Association through Title XX funds awarded in 2019. Tools that will/should be implemented include: federal companion bills (i.e. the Improving HOPE act), Project ECHO, and distribution of the apps like the Alzheimer's Disease Pocket Card. TFAD will also be in a better position to micro-target physicians and their needs after our BRFSS module findings are returned, modules paid for through the Title XX award.

#### • Indicators:

# Potential Funding:

• Alzheimer's Association. Grants, donations, Title XX funds as allocated by the Department of Public and Behavioral Health, and/or gifts

<b>Recommendation #6:</b> State Match Program for APRNs (2019)	
TFAD Member Lead(s): Senator Valerie Wiener	

# **Current Recommendation as Stated:**

Delete Background.

Historically, we only include "background" section for a recommendation the first year it is included in the State Plan.

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**<u>Determination</u>**: 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:

<u>Suggested Revisions</u>: 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:** remain the same.
- **Indicators:** remain the same.
- **Potential Funding:** remain the same.

# Nevada Task Force on Alzheimer's Disease State Plan Recommendations Planning – prepared by Tina Dortch

<b>Recommendation #:</b>	7					
TFAD Member Lead(	s): Dr. Marwa	an Sabbagh:	This is submitted	by Tina I	Dortch v	who did
not originally voluntee	er to review th	is item				

# **Current Recommendation as Stated:**

# Care Pathways (2013)

Support the adoption of specialized care pathways. Encourage the Nevada Hospital Association (NHA) to develop a best-practices care plan for the management of patients with cognitive impairment entering the hospital. The NHA is strongly encouraged to develop this plan in collaboration with subject matter experts from: the Alzheimer's Association, research and educational organizations, first responders, and healthcare organizations. In addition, TFAD supports the CARE Act, which helps caregivers when for whom they care are hospitalized.

**<u>Determination</u>**: Do you propose that for the 2021 State Plan this recommendation be:

- 7) Retained as is
- 8) Retired to the Appendix (it has been accomplished or is no longer relevant)
- 9) Revised / Updated potential funding source

**Justification:** If you propose revising this recommendation, what is your rationale for your suggested changes:

To expand specialized care pathways through the utilization and/or development of methods, procedures, and rehabilitation technology that maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities.

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	

Subject matter experts (including the Alzheimer's Association, research and educational organizations, first responders, and healthcare organizations) to pursue expansion of specialized care pathways to maximize quality of care

#### ☐ Indicators:

Decrease burn out of care givers (in accordance with 4<sup>th</sup> component "Improved Clinical Experience" of Quadruple Aim practice designed by Institute for Healthcare Improvement) while ensuring patient reports of maximized quality of care

# **☐** Potential Funding:

### DRRP on Assistive Technology to Promote Independence and Community Living:

Under this particular Disability and Rehabilitation Research Projects (DRRP) priority, the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) aims to sponsor research and development activities toward technologies that support community living and independent living of people with disabilities – particularly people who are aging with disabilities. With these DRRP grants, NIDILRR has a interest in funding research and development toward technologies that support people with disabilities in rural, frontier, or tribal communities.

This new forecasted grant replaces the following:

- DRRP on Assistive Technology to Promote Independent and Community Living (Research)
   Forecast
- DRRP on Assistive Technology to Promote Independent and Community Living (Development) Forecast

Recommendation #:	_9
TFAD Member Lead(s	s):Marco Valera
<b>Current Recommenda</b>	tion as Stated:
Recommendation +	49: Caregiver Support (2019)

# **Background**

Caregivers of people with Alzheimer's disease and other forms of dementia frequently report high levels of stress, which can be emotionally, physically, and psychologically harmful to them. According to the Latest Facts and Figures Report from the Alzheimer's Association, 16.3 million family members and friends provided 18.6 billion hours of unpaid care to those with Alzheimer's disease and other forms of dementia in 2019. That care had an estimated economic value of \$244 billion. Approximately two-thirds of caregivers are women, and 30 percent are age 65 or older. Forty-one percent of caregivers have a household income of \$50,000 or less. On average, care contributors lose more than \$15,000 in annual income as a result of reducing or quitting work to meet the demands of caregiving. Alzheimer's disease and other forms of dementia take a devastating toll on caregivers. Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; about 40 percent suffer from depression. One in five care contributors cut back on their own doctor visits because of their care responsibilities. And, among caregivers, 74 percent report they are "somewhat" to "very" concerned about maintaining their own health since becoming a caregiver.

## Recommendation

Provide caregivers with information about and access to evidence-based education, support services, and resources to: 1) promote knowledge and understanding of Alzheimer's disease and other forms for dementia to best support people living with dementia, 2) provide and expand respite services for family and informal caregivers of persons with dementia and, 3) enhance caregiver well-being. These services include, but are not limited to: family care consultation, solution-focused caregiver support groups, educational programs and services, respite programming, and evidence-based programs in the Nevada Dementia Supports Toolbox. Support efforts to promote and fund comprehensive caregiver services that are provided by many organizations, including, but not limited to: AARP, Alzheimer's Associations, Catholic Charities, the Cleveland Clinic Lou Ruvo Center for Brain Health, Nevada Senior Services, and Nevada Caregiver Support Center.

- 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 Nevada Dementia Friendly 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.

### **Indicators**

Aging and Disability Services Divisions (ADSD) will track and compile data it collects provided in the ADSD-funded programs, as well as data provided by the key partners network and other dementia-related organizations that are working in alignment to support these efforts. ADSD will annually monitor program availability, waitlists, number of consumers, and hours of caregiver support services provided in the ADSD-funded programs and other programs, as feasible. ADSD will also monitor Dementia Friendly Champions, including community action groups throughout Nevada.

### **Potential Funding**

Fund for a Healthy Nevada. Retired and Senior Volunteer Group (RSVP). Older Americans Act Funding. The Alzheimer's Association. Grants, donations, and/or gifts. Explore additional funding opportunities to support caregiver programs once existing funds expire.

**<u>Determination</u>**: 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

<u>Justification</u>: If you propose revising this recommendation, what is your rationale for your suggested changes: \*\*\*\*This particular recommendation update would be best served after our national/state Facts and Figures are released, please see page 4\*\*\*\*

<u>Suggested Revisions</u>: 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:
- Indicators:
- Potential Funding:

### **Nevada Alzheimer's Statistics Graft**



# OF DEATHS FROM ALZHEIMER'S DISEASE (2018)

704

**261%** increase in Alzheimer's deaths since 2000

6<sup>th</sup> leading cause of death

# of geriatricians 40 in 2019 40 increase needed to meet Alzheimer's population needs in 2050



153,000

Number of Caregivers

175,000,000 Total Hours of Unpaid Care

\$2,289,000,000 Total Value of Unpaid Care



1,712

# of emergency department visits per 1,000 people with dementia

34.3%

department visits since 2007

25.4%

hospital readmission rate



2,167

# of people in hospice with a primary diagnosis

**17**%

of people in hospice have a primary diagnosis of dementia

MEDICAID

**\$203** MILLION

Medicaid costs of caring for people with Alzheimer's (2020)

36.5%

change in costs from 2020 to 2025



\$34,875

per capita Medicare spending on people with dementia (in 2019 dollars)



More than **5 million Americans** are living with Alzheimer's. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$305 billion** in 2020, increasing to more than **\$1.1 trillion** (in today's dollars) by mid-century. Nearly **one in every three seniors** who dies each year has Alzheimer's or another dementia.

For more information, view the **2020 Alzheimer's Disease Facts and Figures** report at **alz.org/facts.** 

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Alzheimer's Association is a not-for-profit 501(c)(3) organization.

**Recommendation #: 11 Volunteers** 

TFAD Member Lead(s): Gini Cunningham and Niki Rubarth

Current Recommendation as Stated: Recruit and train community volunteers through collaboration with various organizations including non-profits, service organizations, health care institutions and universities, which have existing programs, education, and practices that address Alzheimer's disease and other forms of dementia. Through these collaborations, volunteers will have the opportunity to expand their own knowledge and awareness about all forms of dementia and learn how to effectively participate in the care and support of persons living with Alzheimer's disease and other forms of dementia, their families, and their caregivers. In supporting age- and dementia-friendly communities, volunteers will learn how to promote each person's well-being, as well as preserve their dignity and respect in every day community life. Also, by implementing "Train the Trainer" programs, volunteer outreach opportunities can be expanded.

Indicators: Monitor non-profits, service organizations, health institutions, and universities that recruit volunteers for the number of volunteers they recruit, the types of training they offer, how many volunteers they train, and what other services are provided. Determine which additional trainings and services might be needed to expand volunteer education and opportunities.

**Potential Funding:** 

Grants, donations, and/or gifts

**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** This Recommendation needs to be revised and updated so that TFAD is actually promoting volunteerism and Train the Trainer models by actively recruiting individuals in every community throughout the state.

<u>Justification</u>: If you propose revising this recommendation, what is your rationale for your suggested changes:

With funding perennially short regardless of the need for far-ranging outreach, it is time to step up our initiatives to educate every Nevada resident about Alzheimer's disease and other forms of dementia through a more visible presence throughout the state. There are so many resources and education opportunities available but often residents are not aware of

these while ongoing community awareness drives are either not present or vanish after one visit. Our TFAD responsibility is to extend outreach to all areas of Nevada, especially to rural community where people live far from many resources that exist in metropolitan areas.

<u>Suggested Revisions</u>: 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:

Recruit and train community volunteers through collaboration with various organizations including non-profits, service organizations, health care institutions, and universities, which have existing programs, education, and practices that address Alzheimer's disease and other forms of dementia. This commitment to education and outreach needs to include rich and abundant Train the Trainer models that then permit and encourage volunteers to share knowledge and information in communities while finding, recruiting, and training local residents to continue to learn more about Alzheimer's disease and other forms of dementia. These additional volunteers can then carry on the drive to provide new knowledge and resource tools to others. Increased outreach and personal connections will help de-stigmatizing the fear and misunderstanding associated with dementia through open-conversations and reliable information. Through these collaborations, volunteers will have the opportunity to expand their own knowledge and awareness about all many forms of dementia and learn how to effectively participate in the care and support of persons living with Alzheimer's disease and other forms of dementia, their families, and their caregivers. This also means ongoing training and support connections for volunteers as they continue to advance personal knowledge to better assist those living with dementia, their families, and caregivers as well as expand community awareness about resources and support tools.

In supporting age- and dementia-friendly communities, volunteers will learn how to promote each person's well-being, as well as preserve their personal dignity and respect in everyday community life. Also, by implementing "Train the Trainer" programs, volunteer outreach opportunities can be expanded. It is essential to de-stigmatize the idea that volunteers lack the knowledge and capabilities to fulfill this critical role.

Indicators: Monitor and correspond with non-profits, service organizations, health institutions, and universities that recruit volunteers to learn the number of volunteers recruited (for the number of volunteers they recruit), the types of training they offer, how many volunteers they train, and what other services are provided. Determine which additional trainings and services might be needed to expand volunteer education and opportunities.

(I am not sure to what degree this monitoring has taken place. While attendees are recorded and reported for items like REST trainings and Dementia Friendly Nevada meetings and events, I am not sure what else is recorded and/or who reports and to whom. And while we do not like to list specific trainings and presentations, it seems that we should do so if we really want to know how much our efforts are impacting others. I propose that we generate a viable list, determine which items on the list have Train the Trainer potential, and then move forward with training and presentations. With input from our group on the best trainings and presentations to promote, I am willing to take on the blanketing of northern Nevada rural communities beginning with senior centers, libraries, Chambers of Commerce...)

# • Potential Funding:

Grants, donations, and/or gifts. I'd like information on specific grants to apply for and then I think through community outreach we will have an in for requesting donations and gifts through the organizations and key businesses of each community.

**Recommendation #12:** Guardianship (2019)

**TFAD Member Lead(s): Senator Valerie Wiener** 

# **Current Recommendation as Stated:**

Delete Background.

Historically, we only include "background" section for a recommendation the first year it is included in the State Plan.

**<u>Determination</u>**: 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:

<u>Suggested Revisions</u>: 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:** In paragraph 2, line 5 (following Bar Associations,....ADD: and qualified members of the legal community...
- **Indicators:** ADD after last sentence: Number of courses offered to interested stakeholders by qualified members of the legal community.
- **Potential Funding:** Remains the same

# Nevada Task Force on Alzheimer's Disease State Plan Recommendations Planning – prepared by Tina Dortch

Recommendation #: 16_	<u> </u>
TFAD Member Lead(s):	LeAnne (lead); Tina Dortch (support)
<b>Current Recommendation</b>	as Stated:
<b>Community Outreach (201</b>	3)

Foster the development of Dementia Friendly Communities awareness campaigns to provide information about early signs of dementia and to advance Dementia Friendly Communities across the state. The campaigns should include updates on current research and prevention trials that a delay progression, as well as information about now earlier diagnosis and intervention can lead to a more productive and meaningful life. The campaigns should be designed to help citizens feel better supported and hopeful as well as encourage access to available services. The campaigns should be promoted through public service announcements, broadcast and print interviews, as well as articles in newspapers and magazines, websites, and other Internet venues. The respective target audiences for each public awareness campaign may include, but are not limited to:

- a. Allied health professionals, bankers, emergency first responders....
- b. Caregivers and family members ....
- c. The general public....

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

- 4) Retained as is
- 5) Retired to the Appendix (it has been accomplished or is no longer relevant)
- 6) Revised / Updated develop outreach efforts with the goal to find treatments, cure

**Justification:** If you propose revising this recommendation, what is your rationale for your suggested changes:

The more personalized the study of the disease the more broadly treatments can be applied, thus reducing disparities

<u>Suggested Revisions</u>: 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:

Empower members of the Alzheimer's community and caregiver's by encouraging participation in Clinical Trials

View educational/humanistic film "Turning Point" about importance of Alzheimer's related research

# • Indicators:

Voluntary surveys to determine participation, enrollment in trials related to Alzheimer's

# • Potential Funding:

National Institutes of Health, BrightFocus Foundation

# Nevada Task Force on Alzheimer's Disease State Plan Recommendations Planning – prepared by Tina Dortch

Recommendation #: 16_	<u> </u>
TFAD Member Lead(s):	LeAnne (lead); Tina Dortch (support)
<b>Current Recommendation</b>	as Stated:
<b>Community Outreach (201</b>	3)

Foster the development of Dementia Friendly Communities awareness campaigns to provide information about early signs of dementia and to advance Dementia Friendly Communities across the state. The campaigns should include updates on current research and prevention trials that a delay progression, as well as information about now earlier diagnosis and intervention can lead to a more productive and meaningful life. The campaigns should be designed to help citizens feel better supported and hopeful as well as encourage access to available services. The campaigns should be promoted through public service announcements, broadcast and print interviews, as well as articles in newspapers and magazines, websites, and other Internet venues. The respective target audiences for each public awareness campaign may include, but are not limited to:

- a. Allied health professionals, bankers, emergency first responders....
- b. Caregivers and family members ....
- c. The general public....

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

- 4) Retained as is
- 5) Retired to the Appendix (it has been accomplished or is no longer relevant)
- 6) Revised / Updated develop outreach efforts with the goal to find treatments, cure

**Justification:** If you propose revising this recommendation, what is your rationale for your suggested changes:

The more personalized the study of the disease the more broadly treatments can be applied, thus reducing disparities

<u>Suggested Revisions</u>: 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:

Empower members of the Alzheimer's community and caregiver's by encouraging participation in Clinical Trials

View educational/humanistic film "Turning Point" about importance of Alzheimer's related research

# • Indicators:

Voluntary surveys to determine participation, enrollment in trials related to Alzheimer's

# • Potential Funding:

National Institutes of Health, BrightFocus Foundation