**American Indian, Alaska Native, and Culturally Inclusive Language in Alzheimer’s Disease and Related Dementias State Plans**

August 28, 2022

*The International Association for Indigenous Aging (IA2) is dedicated to improving the health and well-being of American Indians, Alaska Natives, and other Native people as they move through the aging spectrum.   
Our work helps people and programs figure out how to engage and effectively serve Native communities. We attempt to advance both knowledge and practice and promote engagement at all levels– local, tribal, regional, and national.  
Our work acknowledges the history, rights, cultures, and values of Indigenous people throughout their lifespans, recognition of tribal sovereignty, and centers the work of Native communities in meaningful partnerships.***www.iasquared.org**

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# Introduction

## Summary

This guide is a resource to aid in Alzheimer’s disease and related dementias (ADRD) policy and planning for American Indian and Alaska Native (AI/AN) tribal communities and their leaders, and state and local public health entities.

**Language about ADRD and engagement practices referencing American Indian and Alaska Native populations and communities were identified in 18 existing states’ Alzheimer’s plans**. **This language forms the context for and the structure of this guide. See the Methods section for explanation of how the 18 state Alzheimer’s plans were selected.**

This document contains word-for-word excerpts (only edited for format) from current state Alzheimer’s and dementia plans that are inclusive of “American Indian” and/or “Alaska Native” and other culturally relevant terms ([see methods section](#_Methods)). While these 18 plans include some type of culturally inclusive language or reference, only 8 of the 18 plans include population-specific language. Specific dementia topics are used to organize the content (see table of contents), and an index of high-frequency keywords and phrases is included. This document is not meant to be guidance or a compilation of best practices. Instead, it indexes current language that is used in existing state plans that may be useful in considering future modifications to such state Alzheimer’s and dementia plans, the development of new state ADRD plans, or the creation of tribal-specific plans. This can also be useful for other efforts to be inclusive of indigenous peoples in Alzheimer’s and dementia-related strategic products.

## Background

Government strategic plansfor addressing dementia have become a common starting point for addressing ADRD within a jurisdiction. Starting in 2007, advocacy organizations (and later government agencies) promoted comprehensive state governmental Alzheimer and dementia plans in the United States (U.S.). Most plans included target implementation dates and built-in renewal processes to stay current with new and expanded knowledge. The National Alzheimer's Project Act (Public Law. 111-375), passed in 2011, called for a National Plan for ADRD that would include input from an Advisory Council. The [National Plan](https://aspe.hhs.gov/napa-national-plans) has been updated annually since its creation in 2012.[[1]](#footnote-2)

The U.S. Constitution acknowledges federally recognized tribes as distinct sovereign nations. “Sovereignty for tribes includes the right to establish their own form of government, determine membership requirements, enact legislation, and establish law enforcement and court systems.”[[2]](#footnote-3) AI/AN people are also generally subject to federal, state, and local laws and policies as both U.S. and state citizens. On federal reservations, only federal and tribal laws apply to members of the tribe unless Congress specifically provides otherwise (U.S. Bureau of Indian Affairs.) As sovereign nations, federally recognized tribes are the inherent public health authorities for their members. As of the summer of 2022, tribal ADRD plans did not exist. Regardless of where AI/AN people reside they should be addressed in and as part of the pertinent state or tribal ADRD plan.

A previous review of existing ADRD plans from states[[3]](#footnote-4) with the highest proportion of AI/AN population was conducted as part of a national tribal policy and law scan (see report: [Tribal Law and Policy: Alzheimer’s Disease and Related Dementia Issues](https://iasquared.org/new-report-tribal-law-policy-alzheimers-disease-and-related-dementia-issues/), 2021)[[4]](#footnote-5). Ten plans reviewed for the initial report included references to American Indians, Alaska Natives or tribal people or populations. This report expands on the initial analysis of plan language in both number of state plans reviewed and approach to identifying relevant content.

The previous report described that most older ADRD plans lacked sections or strategies devoted to AI/AN populations. As dementia and caregiving receive more attention in Indian country and for Alaska Native people, with health equity issues at the forefront, increased future tribal engagement for state ADRD plans may occur. Many states are currently updating or intend to update existing plans. States developing or updating plans can include AI/AN communities in their planning process, embrace more inclusive language, and feature AI/AN population-focused goals and strategies. Tribal leaders may also choose a proactive approach and seek engagement and inclusion in state ADRD plan development processes. Tribes, as sovereign entities, may also consider developing their own ADRD plans.

*This document is not to be considered guidance nor best practices; rather, it highlights current language for informational purposes. The inclusion of plan language in this guide does not imply endorsement. Instead, these excerpts are meant as examples to assist in developing ADRD policies and plans inclusive of AI/AN populations.*

## Methods

This document builds upon a report prepared by Splaine Consulting at the request of IA2. This earlier report was based upon the examination of State ADRD plans from 15 states, including the 14 states with the highest AI/AN population percentages, as well as Hawaii because of its Native Hawaiian population. This document reflects an examination of State ADRD plans from 18 states: the 14 states with the highest AI/AN population percentage, and an additional 4 states[[5]](#footnote-6) with the largest AI/AN population count. A series of terms were used to search plans. These terms included: Native, Indian, Indigenous, Alaska, Tribal, Tribe, Ethnic, Ethnicity, Culture, Cultural, Diverse, Diversity, Race, Racial, Minority, Underserved, Rural, Linguistic. Members of our project team worked in successive sessions to identify ADRD topic areas and themes from the 18 State ADRD plans. These topics were used to categorize plan content and create the table of contents. An index was created including words and phrases by topic and frequency.

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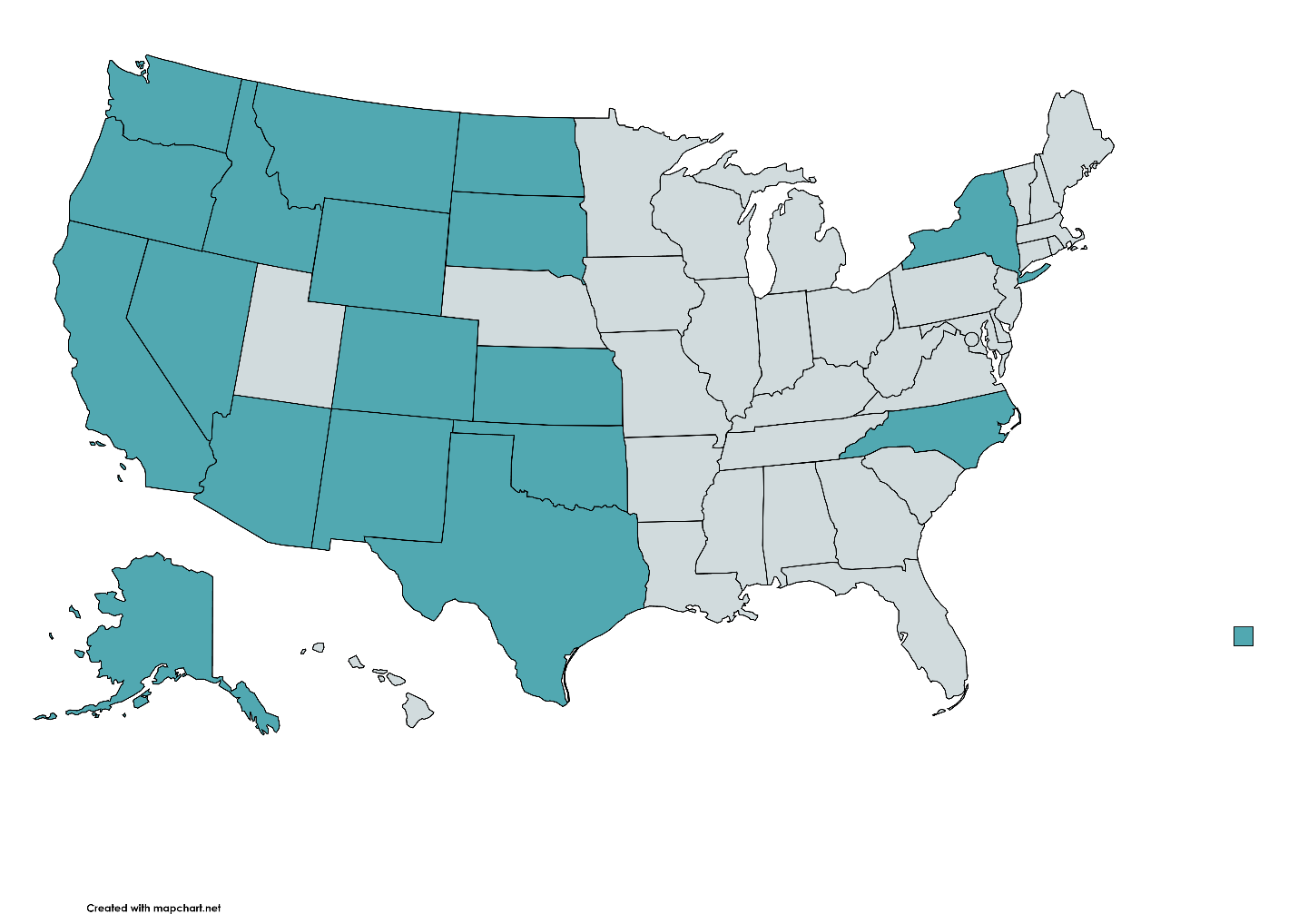
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# State Alzheimer’s Plans Links

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| [Alaska](https://act.alz.org/site/DocServer/Alaska_State_plan_2015.pdf?docID=42541)\* | 2014 | [New York](https://alzimpact.org/uploads/media/state_plans/NY.pdf)\* | 2019 |
| [Arizona](https://azdhs.gov/documents/prevention/tobacco-chronic-disease/healthy-aging/reports-statistics/az-alzheimers-plan-2015.pdf) | 2015 | [North Carolina](https://alzimpact.org/uploads/media/state_plans/NC.pdf) | 2016 |
| [California](https://aging.ca.gov/download.ashx?lE0rcNUV0zZ8r%2fOK1dJ1OQ%3d%3d) | 2011–2021 | [North Dakota](https://ruralhealth.und.edu/assets/4702-20934/alzheimer-dementia-plan-nd.pdf)\* | 2022 |
| [Colorado](https://www.coloradohealthinstitute.org/sites/default/files/file_attachments/CACC_Final_Report.pdf) | 2010 (Update Pending) | [Oklahoma](https://alzimpact.org/uploads/media/state_plans/OK.pdf)\* | 2018 - 2022 |
| [Idaho](https://alzimpact.org/uploads/media/state_plans/ID.pdf) | 2013 | [Oregon](https://www.ohsu.edu/sites/default/files/2019-10/SPADO%20Report%20July%202012.pdf) | 2012 (Update Pending) |
| [Kansas](https://kdads.ks.gov/docs/librariesprovider17/commissions/alzheimer-s-disease-plan-working-group/alzheimer's-disease-plan-final-report/2020-ks-alzheimer's-disease-plan.pdf?sfvrsn=5d3f02ee_2) | 2020 | [South Dakota](https://alzimpact.org/uploads/media/state_plans/SD.pdf)\* | 2018 |
| [Montana](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)\* | 2016 | [Texas](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.) | 2019–2023 |
| [Nevada](https://adsd.nv.gov/uploadedFiles/adsdnvgov/content/Boards/TaskForceAlzheimers/Final_TFAD_2021%20State%20Plan.pdf) | 2021 - 2022 | [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)\* | 2016 |
| [New Mexico](https://nmaging.state.nm.us/uploads/files/Update%20Dementia%20Plan%20LAU-Tracy%20edits.pdf)\* | 2017 | [Wyoming](https://health.wyo.gov/wp-content/uploads/2019/10/wyalzsstateplan-08302018.pdf) | 2018 |

\* State ADRD plans that include the following terms: American Indian, Alaska Native, tribe or tribal.



[**AK**](https://act.alz.org/site/DocServer/Alaska_State_plan_2015.pdf?docID=42541)

[**WA**](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

[**OR**](https://www.ohsu.edu/sites/default/files/2019-10/SPADO%20Report%20July%202012.pdf)

[**CA**](https://aging.ca.gov/download.ashx?lE0rcNUV0zZ8r%2fOK1dJ1OQ%3d%3d)

[**NV**](https://adsd.nv.gov/uploadedFiles/adsdnvgov/content/Boards/TaskForceAlzheimers/Final_TFAD_2021%20State%20Plan.pdf)

[**ID**](https://alzimpact.org/uploads/media/state_plans/ID.pdf)

[**MT**](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)

[**ND**](https://ruralhealth.und.edu/assets/4702-20934/alzheimer-dementia-plan-nd.pdf)

[**SD**](https://alzimpact.org/uploads/media/state_plans/SD.pdf)

[**WY**](https://health.wyo.gov/wp-content/uploads/2019/10/wyalzsstateplan-08302018.pdf)

[**CO**](https://www.coloradohealthinstitute.org/sites/default/files/file_attachments/CACC_Final_Report.pdf)

[**NM**](https://nmaging.state.nm.us/uploads/files/Update%20Dementia%20Plan%20LAU-Tracy%20edits.pdf)

[**AZ**](https://www.azdhs.gov/documents/prevention/tobacco-chronic-disease/healthy-aging/reports-statistics/az-alzheimers-plan-2015.pdf)

[**KS**](https://kdads.ks.gov/docs/librariesprovider17/commissions/alzheimer-s-disease-plan-working-group/alzheimer's-disease-plan-final-report/2020-ks-alzheimer's-disease-plan.pdf?sfvrsn=5d3f02ee_2)

[**OK**](https://alzimpact.org/uploads/media/state_plans/OK.pdf)

[**TX**](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.)

[**NY**](https://alzimpact.org/uploads/media/state_plans/NY.pdf)

[**NC**](https://alzimpact.org/uploads/media/state_plans/NC.pdf)

# Culturally Competent Approaches

## [California](https://aging.ca.gov/download.ashx?lE0rcNUV0zZ8r%2fOK1dJ1OQ%3d%3d)

**GOAL 1 Eliminate Stigma**

**Recommendation 1A:** Heighten public awareness through culturally appropriate public education campaigns.

**Recommendation 1C:** Promote consumer access to established clearinghouses.

**Strategy:** Consider adopting a template for information and educational materials to ensure they are available at appropriate literacy, language and legibility (font size) for a diverse population.

**GOAL 4 Develop an Alzheimer’s Proficient, Culturally Competent Workforce**

## [Idaho](https://portal.alzimpact.org/uploads/media/state_plans/ID.pdf)

**Finding #1: Increase public awareness about Alzheimer’s disease and related dementias (ADRD) and provide comprehensive, practical and timely information related to the disease.**

* Find and use resources to reach out to rural communities, racial and ethnic minorities, and faith-based communities. May or may not include a combined effort with the Alzheimer’s Association in order to increase availability and use of education materials tailored to these groups.
* Ensure information and educational materials are offered at appropriate literacy, language, and legibility (font-size) for a diverse population.

## [Kansas](https://kdads.ks.gov/docs/librariesprovider17/commissions/alzheimer-s-disease-plan-working-group/alzheimer's-disease-plan-final-report/2020-ks-alzheimer's-disease-plan.pdf?sfvrsn=5d3f02ee_2)

Diversity

Kansas’ population is growing increasingly more diverse. The State of Kansas should encourage partnerships with multicultural coalitions, and other groups that represent underserved populations including rural communities, racial and ethnic minorities, veterans, members of the LGBT community, individuals with younger-onset Alzheimer’s disease, individuals with intellectual and developmental disabilities, and individuals with traumatic brain injuries. These partnerships should be built in order to develop and expand dementia supportive services to diverse individuals and families across the continuum of care (including, but not limited to, adult day care centers, physicians, home-based providers, assisted living communities, skilled nursing facilities, and specialized dementia care entities). It is imperative that the state provide access to diagnosis and quality health care for all individuals affected by Alzheimer’s and other dementias.

## [Montana](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)

**4. Process for Preparing this Plan**

**A. Process**

**Phase I: Establishing the Montana Alzheimer’s/Dementia Work Group –**

The Work Group has more than 40 members representing multiple industries and stakeholder groups [[6]](#footnote-7)including:

* Native Americans

**Phase III: Convening Public Town Hall meetings in Montana**

For a comprehensive Montana Alzheimer’s and Dementia State Plan to be meaningful, it needs to reflect the views, concerns, and recommendations of Montanans from across the state, especially individuals with dementia, their families, caregivers, and advocates.

To ensure this goal was met, in 2015 the Work Group held 13 public Town Hall meetings in 11 urban and rural communities across Montana.

In the same year, public Town Hall meetings were held on seven Native American Reservations and at Indian Health Services centers.

Town Hall meetings at Native American Reservations and at Indian Health Services Centers drew 153 participants.

**C. Diversity Inclusion and Cultural Considerations**

When considering services for Alzheimer’s disease and related dementias in Montana, there are several specific populations requiring special consideration.

To ensure equal access and effectiveness, programs and services must be designed to serve those in rural and frontier communities, racial and ethnic minorities including Native Americans, non-English speaking individuals, veterans, members of the Lesbian, Gay, Bisexual, Transgender (LGBT) community, individuals with younger-onset Alzheimer’s disease, individuals with intellectual and developmental disabilities, individuals with traumatic brain injuries including chronic traumatic encephalopathy (CTE), individuals with mobility and/or sensory impairments, and individuals experiencing post-traumatic stress disorder (PTSD) and co-occurring serious mental illness.

The unique barriers, challenges, and issues affecting these special populations should be part of a larger conversation to ensure fair treatment, dignity, respect, and compassionate care for all people experiencing dementia.

**6. Findings from Montana Alzheimer’s/Dementias Work Group**

The following information is the result of work conducted by the Montana Alzheimer’s/Dementia Work Group from 2014–2016.

This includes an inventory of health care professionals, home and community-based services including residential care, and the summary of information obtained from discussions with Montanans during public Town Hall meetings held across the state.

The meetings also included conversations with Native American populations conducted on Native American Reservations and Indian Health Services Centers. The concerns, fears, and hopes expressed by Montana citizens echo the challenges outlined previously.

**A. Inventory**

**1. Health Care Professionals**

Montana has a shortage of health care professionals, particularly in rural and frontier areas.

**B. Town Hall Meeting Themes**

Thirteen public Town Hall meetings were held in 11 urban and rural communities as well as seven Indian Reservations and Indian Health Services centers to address the current and future needs of people with Alzheimer’s disease and related dementia.

In an article published in The Missoulian on June 2, 2015, Kavan Peterson wrote that the Montana Alzheimer’s/Dementia Work Group’s community meetings are “about how we can transform our communities to embrace people living with dementia,” a sentiment that fully applies to both Native American and non-Native American communities.

**Native American**

Group interviews about Alzheimer’s disease and related dementias and its challenges were conducted on all seven Native American Reservations in Montana and at several urban Indian centers with large Native American populations.

Though some national research exists about American, Alaskan, and Canadian Natives on the subject of dementia, much more work must be done to better understand the needs, challenges, and solutions for Native communities.

The findings of the group interviews point out a stark reality, yet attendees also expressed tremendous hope and ideas for the future. Many of the needs expressed reiterated the themes and points made at the urban/rural Town Hall meetings.

However, several issues were unique to Native American communities.

Issues of particular relevance to Native American communities in Montana include:

* Nursing homes and assisted living facilities are present on some Reservations or in geographic areas with large populations. Other more remote Reservations have either very limited beds available, which are not considered a good choice, or alternatives that are many hours away. Placing a loved one in a nursing home or assisted living facility hours away is not a realistic option because of the challenge of not being able to visit regularly. Based on values of interdependence and reciprocity, there is a strong tradition of family members caring for their elders. Having a loved one in a long-term care facility that is hours away can cause significant family distress.
* Financial issues (particularly because of high poverty levels) are also a barrier to placement in facilities, even when it is obviously needed. The requirements and constraints of Medicare and Medicaid spend down guidelines, and the services available through Indian Health Service are both confusing and limit people’s access. One urban health care service provider explained that more than 200 people on their client list are eligible and had been prequalified for enrollment through Medicaid expansion, yet only a handful had gone through the process to enroll. Furthermore, the cost of between $4,000 and $8,000 a month of institutional care, regardless of the source to pay for it, is prohibitive. In addition, program regulations may make offered services incongruent with cultural values.
* Concern was expressed in some communities about instances of observed elder mistreatment and exploitation, with elders who have dementia being most vulnerable. This was particularly troubling to Town Hall participants who indicated their elders should be honored as carriers of tradition and teachers of wisdom.

**7. Goals and Recommended Action Steps**

**Goal 4: Person-Centered Care**

Ensure that Montana adults with Alzheimer’s disease and related dementias will be able to successfully age in place with dignity and respect regardless of socio-economic status, rural or urban residence, income, race, religious preference, gender identity/expression, or sexual orientation in the least restrictive setting that best fosters his/her current level of cognitive and functional ability, while maintaining a high quality of life.

**Goal 9: Residential Care Facilities**

Promote wellness and maintenance of cognitive function for individuals with dementia living in residential care facilities, including assisted living facilities, personal care homes, adult foster homes, and nursing home facilities, by offering activities tailored to each individual’s needs.

Train staff in non-pharmacological treatment of behavioral issues and person-centered models of care.

**Recommendations:**

9-E. Convene a group of representatives from all the Native American reservations to discuss how to best meet the needs of their citizens so they feel safe, and their cultural expectations are being met in residential care facilities.

## [Nevada](https://adsd.nv.gov/uploadedFiles/adsdnvgov/content/Boards/TaskForceAlzheimers/Final_TFAD_2021%20State%20Plan.pdf)

**Emergency Preparedness**

One of the most important aspects in caring for someone living with dementia during a crisis is to know the person. Person-centered approaches to care and support are vital. Making sure the care setting or community-based program has personal information readily available will allow staff to quickly identify essential information about the person to help them to maintain a stable and comforting environment. Information such as the person’s preferred name (or pronoun), cultural background, names of friends and family, details regarding their preferred routine, what upsets the person, and what calms the person down, are some of the aspects of person-centered care that will help during an emergency.

**Recommendation #3: Cultural Competence**

To help ensure successful processes and outcomes, advocates would benefit from engaging in non-stigmatizing sensitivity training, as well as proactive efforts to gain input from affected communities. Specific activities might include, without limitation:

1. Promoting implicit bias testing. Encourage personnel involved in public-facing engagements with the Alzheimer’s community to take implicit bias assessments;
2. Promoting listening sessions. Before developing campaigns, entities conducting outreach should engage Alzheimer’s community members to gauge impressions on aging services and healthcare experienced by its culturally-diverse and marginalized members; and
3. Promoting development and use of culturally-competent ‘toolkits’ as a resource to support entities providing awareness and outreach campaigns for the Alzheimer’s community.

These activities align with the understanding that person-centered care involves non-stigmatizing, customized outreach approaches to address a multicultural population (i.e., reflecting differences in ability, generation, ethnicity/race, and sexual orientation/gender identity). Adopting this approach has been shown to increase a person’s receptiveness to outreach efforts, improve the quality of their care and minimize their experienced health disparities.

**Indicators**

* Monitor number of created, adopted, and disseminated culturally-sensitive training programs and toolkits, including progress and implementation of Nevada SB 364 and SB 470 (2019).
* Monitor number of service providers that report having participated in cultural-sensitivity training.

**Potential Funding**

Grants, donations and/or gifts. Specific sources may include:

* National Resource Center on LGBT Aging;
* US Department of Health and Human Services (US DHHS) Office of Minority Health
* Nevada Department of Health and Human Services (NV DHHS) – ADSD Collaboration with different cultural and ethnic focused organizations.

## [New Mexico](https://nmaging.state.nm.us/uploads/files/Update%20Dementia%20Plan%20LAU-Tracy%20edits.pdf)

**State Dementia Plan Goals and Strategies Update**

**Goal Two: Raise Public Awareness and Expand Dementia Resource Connections**

In order to reduce the stigma of dementia, support caregivers, increase awareness and encourage advocacy across the state’s diverse cultures and locations, public awareness activities are conducted with a wide range of partners as follows:

1. Coordination, collaboration, and inter-entity communication is encouraged and developed with public, private, local, state, tribal and federal entities to advance Alzheimer’s readiness and dementia capable systems.
2. Public awareness campaigns are conducted, to include New Mexico’s ethnic, cultural, and linguistic diversity.
3. Access to culturally appropriate resources and supports for family caregivers and others caring for, or treating, individuals with Alzheimer’s disease and related dementias is facilitated.

**Goal Three: Support and Empower Caregivers**

In order to create an environment in which the needs of caregivers are addressed, the following activities are conducted:

1. Dissemination of information regarding culturally competent support services, including information on respite, care coordination, and case management services, in a time, manner, and location that meets caregiver and care-recipient needs.
2. Provision of evidence-based caregiver training in a manner that is effective across New Mexico cultures and locations.
3. Advocacy for the development of additional services to support caregivers in urban, rural, frontier and tribal communities throughout New Mexico.

## [New York](https://portal.alzimpact.org/uploads/media/state_plans/NY.pdf)

**Section I. Background**

**Special Populations**

The United States Department of Health and Human Services (HHS) recognizes that AD/D disproportionately impacts racial and ethnic minorities, individuals with younger onset AD/D, and those with Down syndrome. HHS has created the Task Force on Specific Populations to address the needs of these specific populations.

**Racial and Ethnic Minorities**

Disparities are associated with the risk of developing of AD/D among certain racial, ethnic, and socioeconomic groups. Compared to older Caucasians, older African Americans are two times and Hispanics are one and a half times more likely to have AD. More research is needed to estimate the prevalence of AD/D in other racial and ethnic groups. However, a 2016 study which examined electronic health records of individuals from six different racial and ethnic groups found that dementia incidence was highest among African Americans and American Indians, intermediate among Latinos, Pacific Islanders, and Caucasians, and lowest among Asian Americans.

**Goal 5: Address Disparities and Improve Health Equity**

1. Provide support services that target underserved communities, including education on normal aging versus AD/D and the importance of timely diagnosis of AD/D.
2. Increase awareness and understanding among providers about cultural patterns related to family roles and caregiving in underserved communities.
3. Ensuring that educational programs and support services are culturally and linguistically appropriate (e.g., available in multiple languages).
4. Ensuring that care providers consider staffing patterns that reflect the target underserved community, both culturally and linguistically.

## [North Dakota](https://ruralhealth.und.edu/assets/4702-20934/alzheimer-dementia-plan-nd.pdf)

**DIVERSITY, INCLUSION, AND CULTURAL CONSIDERATIONS**

Limited data exists on Alzheimer’s disease and other dementias and caregiving for American Indians and Alaskan Natives, refugees, and New Americans. Overall, there is an underrepresentation of non-White participants in Alzheimer’s disease research. Researchers, working in collaboration with non-White communities of color and marginalized communities, presents opportunity to learn more, aimed at developing best practices for care, education, and support.

**American Indian/Alaskan Native**

As life longevity expectancy increases for American Indians and Alaskan Natives, so does the risk for developing Alzheimer’s disease. According to the Centers for Disease Control and Prevention (CDC), the number of American Indians and Alaskan Natives, age 65 and older living with memory loss, will increase five times between 2014-2060. In response to the growing number of American Indians and Alaskan Natives experiencing memory impairment, the CDC and Alzheimer’s Association developed the tribally informed Healthy Brain Initiative Road Map for Indian Country.

Eight public health strategies were identified for integration and implementation into tribal primary and public health programs and services for Elders and the broader community.

These eight strategies are:

**Educate and Empower Community Members**

1. Work with community members to understand brain health, early warning signs of dementia, and benefits of early detection and diagnosis for persons with dementia and their caregivers.
2. Encourage community members to use effective interventions, best practices, and traditional wellness practices to protect brain health, address cognitive impairment, and support persons with dementia and their caregivers.
3. Provide information and tools to help older adults with dementia and their caregivers anticipate and respond to challenges that typically arise during the course of dementia.
4. Promote engagement among tribal leaders in dementia issues by offering information and education on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health approaches in addressing this priority problem.

**Collect and Use Data**

1. Support collection and use of local data on dementia and caregiving in Indigenous communities to plan programs and approaches.
2. Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to Indigenous communities with dementia.

**Strengthen the Workforce**

1. Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia.
2. Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.

The Alzheimer’s Association Minnesota-North Dakota is also a source of American Indian Alzheimer’s disease and other dementias information. The Alzheimer’s Association Minnesota-North Dakota Chapter is adapting professional, community, and caregiver education to be culturally responsive. Professional and family caregiver care consultation services are available to American Indians, living in urban and tribal communities across North Dakota.

Professional and family caregiver care consultation services are available to African Americans, living in urban and tribal communities across North Dakota.

Professional and family caregiver care consultation services are available to Hispanic people, living in urban and tribal communities across North Dakota.

**Summary of Need**

Based on focus groups, key informant interviews, and research on current infrastructure in North Dakota, several assets were identified, but there was also considerable need. Outside of the three key themes of need identified above, concrete and specific needs included:

* There is a need to identify or develop models for rural and tribal service delivery.

**RECOMMENDATIONS FOR NORTH DAKOTA**

**Goal 1 - Comprehensive Care Over the Full Continuum of the Disease**

It is also imperative to consider the diversity of people across North Dakota in terms of appropriate person-centered care. This attention includes recognizing and understanding the differential needs and preferences of those who are in our tribal, LGBTQ2S+, refugee, and other marginalized communities as well as those who do not fit a “traditional” family structure with a caregiving spouse and/or child.

## [Oklahoma](https://portal.alzimpact.org/uploads/media/state_plans/OK.pdf)

**Family Objectives**

**F2 Objective:** Emphasize the need to obtain earlier physician referrals to specialists for persons with a working diagnosis of Alzheimer’s dementia.

**Strategy:** Utilize hospital case managers, insurance and drug company field representatives who have routine contact with practicing physician offices to deliver culturally-competent public service campaign information through the Oklahoma State Department of Health. This strategy also includes raising awareness of the websites accessible to specifically-targeted audiences to encourage and obtain earlier referrals to support care planning efforts.

## [Oregon](https://www.ohsu.edu/sites/default/files/2019-10/SPADO%20Report%20July%202012.pdf)

**Goal 1: Enhance Public Awareness and Engagement**

**Recommendation 1A:** Increase public awareness about Alzheimer’s disease, and how to access resources that help those impacted by the disease.

**Strategies**

1. Engage local and statewide organizations to disseminate information to their clients and constituents to raise awareness, with particular focus on reaching multi-cultural, low-income, and rural populations.

**Recommendation 1B:** Create a website that provides a single entry point to link to existing information and resources on Alzheimer’s disease and related dementias.

**Strategies**

1. Website should include up-to-date and culturally appropriate information on the various dementias, as well as local resources and services to support people with dementia throughout the disease process (including newly diagnosed individuals and those with young-onset dementia).

## [South Dakota](https://portal.alzimpact.org/uploads/media/state_plans/SD.pdf)

**Process for Preparing the State Plan**

**Objective 2: Conduct a Statewide Needs Assessment**

**Input 3 | Secondary data collection and analysis:**

Secondary data provided an analysis of indicators for South Dakota, including population projections, social and economic factors, prevalence, health care workforce, and caregiving. An inventory of long-term care providers in South Dakota was included. Additional data sources were contributed to help frame the report. All data was housed in a database with the intent for it to be updated and used to support the state plan ongoing.

**Limitations:** The distribution strategy for the statewide needs assessment survey was intended to reach as many individuals who have a connection with AD as possible. The sample relied heavily on the distribution channels made available by work group members. Less than 2% of the 1,025 survey respondents reported being Native American or American Indian while the U.S. Census estimates 9% of South Dakota’s population was Native American in 2017. In an attempt to make findings more representative of the state’s demographics, an additional survey was designed to gather data from South Dakota’s American Indian population.

This survey was intended to gather information and perspective on needs relating to the experience and care of PWD in South Dakota who identify as American Indian, either in an urban or tribal setting. It was sent out to work group member networks, organizations who work with the American Indian population, and tribal representatives. While criteria for survey respondents was articulated, only 11 of the 71 survey respondents reported being Native American or American Indian. The 11 respondents were somewhat to not familiar with what is available for AD care in South Dakota and identified the availability of services and resources as a pressing need. These limited findings were not admissible into the study’s findings.

After consulting with those well-versed in tribal community study inclusion, it was determined that the timeline did not allow for a revised inclusion strategy prior to state plan publication. A more formalized approach will be pursued at a later date, after which findings will be published and an action plan will be developed.

**South Dakota AD State Plan Goals, Recommendations, and Rationale**

**1. PUBLIC AWARENESS**

**GOAL STATEMENT:**

Highlight dementia as a public health issue and raise public awareness and understanding about Alzheimer’s and other dementias throughout South Dakota. This includes educating the public and family and professional care providers about the importance of early detection and diagnosis, dementia risk factors and lifestyle interventions, and care resources available in the state.

**RECOMMENDATIONS:**

1. Create a centralized online database of resources related to Alzheimer’s and other dementias housed on the Dakota at Home website (dakotaathome.org), formerly known as the ADRC. Form a work group to ensure the information is up-to-date and culturally appropriate.
2. Coordinate culturally-appropriate public awareness campaign efforts with Native American communities, Tribal health agencies, and other underserved and minority population.
3. Adopt and publicize the 25 action items from the CDC’s Healthy Brain Initiative 2018- 2023 Road Map (released in October 2018) and the companion Road Map for Indian Country, which serves as a guide for public health officials. These action items promote brain health, improved care for people with cognitive impairment, and increased attention to caregivers.

## [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

**NEEDED POLICIES AND RESPONSES**

**PLAN DEVELOPMENT PROCESS**

**“Dementia-Capable” States and Communities**

1. Ensure that staff communicate effectively with people with dementia and their caregivers and provide services that: (a) Are person- and family-centered; (b) Offer self-direction of services; and (c) Are culturally appropriate.

**IMPLEMENTATION OF THE ALZHEIMER’S PLAN**

**GROUP RESPONSIBLE FOR IMPLEMENTATION OF THE ALZHEIMER’S DISEASE (AD) PLAN**

**Participation**

The AD/Dementia Action Advisory Group to be convened initially by DSHS, in collaboration with the Steering/Executive Team, with membership to include individuals with dementia, family caregivers, legislators, representatives of the Alzheimer’s Association, Alzheimer Society of Washington, ElderCare Alliance, W4A, AARP, tribal and ethnic communities, long-term care providers, health systems and medical association representatives, universities, and key state agencies including DSHS, DOH, HCA, Department of Veterans Affairs, and the Governor’s Office

**STATE SUPPORT OF ALZHEIMER’S RESEARCH**

**Training and Outreach**

* Reaches out to underserved groups in the Pacific Northwest, both African Americans and Native Americans, to provide opportunities to volunteer for research and to advance knowledge about Alzheimer’s in these diverse groups

**GOAL 2: PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION**

1. **Promote healthy aging and brain health.**
2. Work with UW Healthy Brain Research Network (HBRN) and other partners to develop evidence-based public messages around promoting healthy aging and brain health, while ensuring messages are culturally/ethnically appropriate and designed to reach statewide populations including persons with limited English.
3. Partner with community organizations to disseminate evidence-based educational materials for the public around healthy aging and accessing health care proactively. Include organizations such as tribal centers, community and senior centers, faith-based organizations, hospitals and health plans, YMCAs and parks departments, secondary schools and institutes of higher learning.

# Brain Health and Risk Reduction

## [California](https://aging.ca.gov/download.ashx?lE0rcNUV0zZ8r%2fOK1dJ1OQ%3d%3d)

**GOAL 6 Create a Coordinated State Infrastructure that Enhances the Delivery of Care**

**Recommendation 6B:** Incorporate public health approaches to prepare for significant growth in Alzheimer’s disease.

**Strategy 3.** Promote brain health initiatives to reduce risk factors, especially in ethnically diverse communities.

## [Texas](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.)

**Priority Area 1: Education and Awareness**

**Goal**

Increase the percentage of people with Alzheimer’s disease and other dementias and their family caregivers receiving culturally and linguistically appropriate information and referrals to community resources from health care providers.

**Actions**

1.2 Promote culturally and linguistically appropriate awareness and education campaigns (through television, radio, print, and social media) with common messages to help the general public better understand Alzheimer’s disease and other dementias, provide suggestions on steps to reduce the risk of cognitive decline, and reduce disease stigma. Topics for awareness and education campaigns include, but are not limited to, the following:

* Differences between memory changes related to aging and warning signs of Alzheimer’s disease and other dementias;
* Evidence-based brain health and cognitive aging;
* Risk factors, benefits of early detection, and effective strategies for getting a diagnosis;
* Populations that are at greater risk;
* The role of family caregivers in providing care, participating in care planning with health care providers, and finding support services;
* The health and well-being of family caregivers; and
* Real stories of people living with Alzheimer’s disease and other dementias.

# Early Detection and Diagnosis

## [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

**Goal 5 - IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE**

C. Develop a dementia-capable, culturally competent primary care workforce throughout the state.

# Public Awareness and Education

## [Alaska](https://act.alz.org/site/DocServer/Alaska_State_plan_2015.pdf?docID=42541)

**Goal 1. Promote Public Awareness, Prevention and Early Diagnosis of Alzheimer’s disease and Related Dementias.**

**Recommendation 1.1**: Increase opportunities for public education about Alzheimer’s disease and Related Dementias (ADRD).

**Strategies:**

1. Distribute relevant, targeted materials for people across ethnicities, languages, ages and geographies.

## [Arizona](https://www.azdhs.gov/documents/prevention/tobacco-chronic-disease/healthy-aging/reports-statistics/az-alzheimers-plan-2015.pdf)

**GOAL 1 Maximize Public Awareness and Understanding**

Increase public awareness and understanding of Alzheimer’s disease and related disorders, resources for assistance and ways to help in Arizona. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to all aspects of the diversity of our populations and communities throughout Arizona.

**RECOMMENDATION 1.1** Implement A Public Awareness Campaign Focused On Reducing The Stigma Of The Disease.

**Strategies**

1. Promote realistic, positive, and diverse images of people with Alzheimer’s disease and their care partners to improve societal acceptance and integration

**RECOMMENDATION 1.3** Ensure Accessibility To And Acceptability Of Information About The Disease, Available Health Care Resources, Supportive Services, And Research Opportunities.

**Strategies**

1. Identify, develop and/or update consumer resource materials appropriate for diverse audiences, to be disseminated by community partners.

## [California](https://aging.ca.gov/download.ashx?lE0rcNUV0zZ8r%2fOK1dJ1OQ%3d%3d)

**GOAL 1 Eliminate Stigma**

**Recommendation 1A:** Heighten public awareness through culturally appropriate public education campaigns.

**Recommendation 1C:** Promote consumer access to established clearinghouses.

**Strategy:** Consider adopting a template for information and educational materials to ensure they are available at appropriate literacy, language and legibility (font size) for a diverse population.

## [Idaho](https://portal.alzimpact.org/uploads/media/state_plans/ID.pdf)

**Finding #1: Increase public awareness about Alzheimer’s disease and related dementias (ADRD) and provide comprehensive, practical and timely information related to the disease.**

* Find and use resources to reach out to rural communities, racial and ethnic minorities, and faith-based communities. May or may not include a combined effort with the Alzheimer’s Association in order to increase availability and use of education materials tailored to these groups.
* Ensure information and educational materials are offered at appropriate literacy, language, and legibility (font-size) for a diverse population.

## [Kansas](https://kdads.ks.gov/docs/librariesprovider17/commissions/alzheimer-s-disease-plan-working-group/alzheimer's-disease-plan-final-report/2020-ks-alzheimer's-disease-plan.pdf?sfvrsn=5d3f02ee_2)

**Recommendations**

1. Educating about Alzheimer’s and other dementias

Ensure that the public awareness campaign addresses the diverse ethnic, cultural, linguistic, and literacy differences of Kansans.

## [Montana](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)

**7. Goals and Recommended Action Steps**

Each individual’s health care should be individualized and person-centered, recognizing that everyone experiences dementia differently, with varying symptoms and needs. Montanans living with dementia should be able to transition through their disease with dignity and respect regardless of socio-economic status, rural or urban residence, income, race, or sexual orientation, in a setting that best aligns with the individual’s beliefs, values, and preferences.

**Goal 1: Public Awareness**

Promote awareness and understanding about Alzheimer’s disease and related dementias throughout the state to reduce stigma and enhance care. Educate Montanans about brain health issues and encourage them to institute lifestyle changes where necessary to maintain brain health.

**Recommendations:**

1-C. Coordinate campaign efforts with Native American communities and Tribal health leaders.

1-E. Facilitate outreach and public-private collaborations for individuals with specialized circumstances and needs including those with Down’s syndrome with dementia, traumatic brain injury, high-risk minority populations, people with younger onset dementia, and developmentally disabled individuals.

**Goal 6: Build Dementia-Friendly Communities**

Promote dementia-friendly communities in Montana, where individuals with Alzheimer’s disease and related dementias and their caregivers are treated with respect and dignity, and are actively encouraged to participate in community life. Make it possible for communities to be proactive in assessing community risk for individuals with dementia, such as the potential for wandering, the need for early intervention in crisis situations, and protection from financial and other forms of exploitation.

**Recommendations:**

6-B. Develop a community-based emergency crisis intervention/prevention program that institutes a “course of action” to mitigate dementia issues for families of all cultures and economic means who find themselves at immediate risk.

6-H. Promote a statewide anti-bullying, anti-elder abuse initiative across various care settings, including in-home services, nursing homes, assisted living residences, senior centers, and adult day programs. Such initiatives should also be employed on Native American reservations.

6-G. Assemble a group of Native American representatives to discuss the cultural needs they may experience in their communities and how to address them.

## [Nevada](https://adsd.nv.gov/uploadedFiles/adsdnvgov/content/Boards/TaskForceAlzheimers/Final_TFAD_2021%20State%20Plan.pdf)

**Recommendation #14 Community Awareness**

5) Educational resources to increase awareness about research opportunities and benefits of clinical trials with special consideration for those in underserved, minority communities.

## [New Mexico](https://nmaging.state.nm.us/uploads/files/Update%20Dementia%20Plan%20LAU-Tracy%20edits.pdf)

**State Dementia Plan Goals and Strategies Update**

**Goal Two: Raise Public Awareness and Expand Dementia Resource Connections**

In order to reduce the stigma of dementia, support caregivers, increase awareness and encourage advocacy across the state’s diverse cultures and locations, public awareness activities are conducted with a wide range of partners as follows:

1. Coordination, collaboration, and inter-entity communication is encouraged and developed with public, private, local, state, tribal and federal entities to advance Alzheimer’s readiness and dementia capable systems.
2. Public awareness campaigns are conducted, to include New Mexico’s ethnic, cultural, and linguistic diversity.
3. Access to culturally appropriate resources and supports for family caregivers and others caring for, or treating, individuals with Alzheimer’s disease and related dementias is facilitated.

## [New York](https://portal.alzimpact.org/uploads/media/state_plans/NY.pdf)

**Goal 5: Address Disparities and Improve Health Equity**

Provide support services that target underserved communities, including education on normal aging versus AD/D and the importance of timely diagnosis of AD/D.

21. Increase awareness and understanding among providers about cultural patterns related to family roles and caregiving in underserved communities.

1. Ensuring that educational programs and support services are culturally and linguistically appropriate (e.g., available in multiple languages).
2. Ensuring that care providers consider staffing patterns that reflect the target underserved community, both culturally and linguistically.

## [North Carolina](https://portal.alzimpact.org/uploads/media/state_plans/NC.pdf)

**CHAPTER THREE: RAISING AWARENESS ABOUT ALZHEIMER’S DISEASE AND RELATED DEMENTIAS**

***Promoting Awareness and Education about Alzheimer’s Disease and Related Dementias***

Many advocacy and research organizations support general messaging around the importance of healthy behaviors and lifestyle choices that can improve brain health and potentially have an impact on the likelihood of developing Alzheimer’s disease or related dementias. Other behavior messages focus on the importance of social engagement and participating in cognitive activities such as reading and completing puzzles. Many organizations encourage integrating these messages into broader state and local public health promotion efforts, ensuring that messages are culturally sensitive and relevant to diverse groups, and incorporating appropriate partnerships and collaborations in order to increase awareness of Alzheimer’s disease and related dementias as a public health challenge.

**Recommendation 3.1:**

Increase awareness and promote education about Alzheimer’s disease and related dementias and available resources through incorporating Alzheimer’s disease and related dementia-specific information in current health promotion and education programs.

f) Resources for underserved populations including individuals with intellectual/developmental disabilities, minority populations, homeless, and rural communities.

## [North Dakota](https://ruralhealth.und.edu/assets/4702-20934/alzheimer-dementia-plan-nd.pdf)

**DIVERSITY, INCLUSION, AND CULTURAL CONSIDERATIONS**

**Educate and Empower Community Members**

1. Work with community members to understand brain health, early warning signs of dementia, and benefits of early detection and diagnosis for persons with dementia and their caregivers.
2. Encourage community members to use effective interventions, best practices, and traditional wellness practices to protect brain health, address cognitive impairment, and support persons with dementia and their caregivers.
3. Provide information and tools to help older adults with dementia and their caregivers anticipate and respond to challenges that typically arise during the course of dementia.
4. Promote engagement among tribal leaders in dementia issues by offering information and education on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health approaches in addressing this priority problem.

**RECOMMENDATIONS FOR NORTH DAKOTA**

**Goal 1 - Comprehensive Care Over the Full Continuum of the Disease**

It is also imperative to consider the diversity of people across North Dakota in terms of appropriate person-centered care. This attention includes recognizing and understanding the differential needs and preferences of those who are in our tribal, LGBTQ2S+, refugee, and other marginalized communities as well as those who do not fit a “traditional” family structure with a caregiving spouse and/or child.

**Goal 5 - Identify and Address Diversity in Research, Supports, and Care Access**

One of the limitations of the process of creating this plan was the difficulty in including diverse experiences from traditionally underrepresented and marginalized groups. Thus, Goal 5 recommends identifying and integrating perspectives from groups and cultures that are currently not represented in the plan and are often under-represented in discussions, concerning Alzheimer’s and other dementias. This recommendation includes but is not limited to people of non-White racial and ethnic backgrounds, LGBTQ2S+, Indigenous, migrant, immigrant, and refugee communities. While recommendations, related to diversity and inclusion, have been added to several of the previous goals, they are predicated on this goal to include those communities and groups in order to understand their needs and how they may be different from those who were involved in providing information for this report.

**Stakeholders[[7]](#footnote-8):** Focus Groups and Key Informant Interviews: These individuals included caregivers, providers, social workers, tribal health representatives, educators, persons with lived experience, insurers, and more. These individuals participated in focus groups and key informant interviews anonymously. To protect their identity, below is the list of organizations or the key perspectives they represented.

## [Oregon](https://www.ohsu.edu/sites/default/files/2019-10/SPADO%20Report%20July%202012.pdf)

**Goal 1: Enhance Public Awareness and Engagement**

**Recommendation 1A:** Increase public awareness about Alzheimer’s disease, and how to access resources that help those impacted by the disease.

**Strategies**

1. Engage local and statewide organizations to disseminate information to their clients and constituents to raise awareness, with particular focus on reaching multi-cultural, low-income, and rural populations.

**Recommendation 1B:** Create a website that provides a single entry point to link to existing information and resources on Alzheimer’s disease and related dementias.

**Strategies**

1. Website should include up-to-date and culturally appropriate information on the various dementias, as well as local resources and services to support people with dementia throughout the disease process (including newly diagnosed individuals and those with young-onset dementia).

## [South Dakota](https://portal.alzimpact.org/uploads/media/state_plans/SD.pdf)

**South Dakota AD State Plan Goals, Recommendations, and Rationale**

**1. PUBLIC AWARENESS**

Highlight dementia as a public health issue and raise public awareness and understanding about Alzheimer’s and other dementias throughout South Dakota. This includes educating the public and family and professional care providers about the importance of early detection and diagnosis, dementia risk factors and lifestyle interventions, and care resources available in the state.

**RECOMMENDATIONS:**

1. Create a centralized online database of resources related to Alzheimer’s and other dementias housed on the Dakota at Home website (dakotaathome.org), formerly known as the ADRC. Form a work group to ensure the information is up-to-date and culturally appropriate.
2. Coordinate culturally-appropriate public awareness campaign efforts with Native American communities, Tribal health agencies, and other underserved and minority population.
3. Adopt and publicize the 25 action items from the CDC’s Healthy Brain Initiative 2018- 2023 Road Map (released in October 2018) and the companion Road Map for Indian Country, which serves as a guide for public health officials. These action items promote brain health, improved care for people with cognitive impairment, and increased attention to caregivers.

## [Texas](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.)

**Priority Area 1: Education and Awareness**

**Goal**

Increase the percentage of people with Alzheimer’s disease and other dementias and their family caregivers receiving culturally and linguistically appropriate information and referrals to community resources from health care providers.

**Actions**

**1.1** Provide culturally and linguistically appropriate education on a range of topics to people with Alzheimer’s disease and other dementias and their family caregivers to enhance their health, well-being, and independence. Priority education topics include the following:

* Changes in memory, thinking, or behavior that should be discussed with a health professional;
* Disease management and coexisting conditions;
* The importance of care planning for people with all stages of Alzheimer’s disease and other dementias that includes family caregivers;
* Family caregiver health and well-being; Local caregiver resources and support;
* Clinical trials; and
* Prevention of abuse, neglect, and exploitation.

**1.2** Promote culturally and linguistically appropriate awareness and education campaigns (through television, radio, print, and social media) with common messages to help the general public better understand Alzheimer’s disease and other dementias, provide suggestions on steps to reduce the risk of cognitive decline, and reduce disease stigma. Topics for awareness and education campaigns include, but are not limited to, the following:

* Differences between memory changes related to aging and warning signs of Alzheimer’s disease and other dementias;
* Evidence-based brain health and cognitive aging;
* Risk factors, benefits of early detection, and effective strategies for getting a diagnosis;
* Populations that are at greater risk;
* The role of family caregivers in providing care, participating in care planning with health care providers, and finding support services;
* The health and well-being of family caregivers; and
* Real stories of people living with Alzheimer’s disease and other dementias.

**Priority Area 2: Coordinated Systems of Care and Support**

**Goal**

Increase collaboration between entities and individuals involved in the care of people with Alzheimer’s disease and other dementias to ensure better access to services, quality health care, and support over the lifespan.

**Actions**

**2.1** Identify and address services gaps and priority needs in the care and support of people with Alzheimer’s disease and other dementias, for instance:

Ensure that services are culturally and linguistically appropriate and available in urban and rural communities.

**2.4** Expand the role of community health workers in providing education on care for Alzheimer’s disease and other dementias to reach underserved communities.

**Priority Area 3: Partnerships and Engagement**

**Goal**

Increase collaborative, diverse partnerships to better support and improve access to resources for people diagnosed with Alzheimer’s disease and other dementias and their family caregivers.

**Actions**

**3.7** Engage and collaborate with community and cultural leaders to provide education and referrals to resources for diverse communities and rural populations.

## [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

**GOAL 1: INCREASE PUBLIC AWARENESS, ENGAGEMENT AND EDUCATION**

Dementia affects people of all races, ethnicities, income levels, gender identities, and sexual orientations. Military veterans who experience post-traumatic stress disorder or traumatic brain injury may have a higher risk of developing dementia later in life. Some populations may experience additional health disparities, economic barriers, and challenges to accessing health care and supportive services. The first goal is about a culturally inclusive awareness and outreach plan that intends to increase consumer demand for early detection and diagnosis in order to improve the quality of life for persons with dementia. It considers a spectrum of people with dementia from younger adults to the end of life, those who don’t speak English as their primary language; and it extends from urban to rural areas of Washington State. Goal one proposes to make bite-size pieces of information about best practices available to all Washingtonians.

1. Ensure statewide coordination of information and referral.

3. Offer materials and information to underserved populations, including rural populations; assure material on dementia is multi-cultural, multi-lingual, appropriate for persons with sensory limits (e.g., vision and hearing loss), and tailored to state demographics.

1. Increase public awareness via educational and promotional campaigns developed and implemented collaboratively with the public and private sectors.

5. Promote outreach to Indian Country through health workers, tribal communications and health fairs.

**GOAL 2: PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION**

1. Promote healthy aging and brain health.

2. Work with UW Healthy Brain Research Network (HBRN) and other partners to develop evidence-based public messages around promoting healthy aging and brain health, while ensuring messages are culturally/ethnically appropriate and designed to reach statewide populations including persons with limited English.

5. Partner with community organizations to disseminate evidence-based educational materials for the public around healthy aging and accessing health care proactively. Include organizations such as tribal centers, community and senior centers, faith-based organizations, hospitals and health plans, YMCAs and parks departments, secondary schools and institutes of higher learning.

# Accessibility

## [Arizona](https://www.azdhs.gov/documents/prevention/tobacco-chronic-disease/healthy-aging/reports-statistics/az-alzheimers-plan-2015.pdf)

**GOAL 2 Develop New & Enhance Existing Supports for People with Alzheimer’s Disease and their Families**

Ensure the availability, accessibility, and acceptability of supportive resources for people living with Alzheimer’s disease and related disorders and their caregivers in Arizona. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to the individual and their families to all aspects of the diversity of our populations and communities throughout Arizona.

**RECOMMENDATION 2.1** Increase Education And Skill Training Opportunities

**Strategies**

1. Promote the development of innovative tailored service delivery and outcome tactics to address individual, family and cultural needs.

**GOAL 5 Create a Dementia-Capable System in Arizona**

Create and sustain an innovative dementia-capable system of home and community-based services that are accessible and acceptable to people with dementia and their caregivers. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to all aspects of the diversity of our populations and communities throughout Arizona.

**RECOMMENDATION 5.1** Create and Sustain a Dementia-Capable Home and Community-Based Services System That Is Responsive to The Unique Needs of People with Alzheimer’s Disease and Related Disorders.

**Strategies**

1. Ensure that services, supports, and approaches in a dementia-capable system are available, accessible and acceptable regardless of ethnicity, geography, or culture.

## [Colorado](https://www.coloradohealthinstitute.org/sites/default/files/file_attachments/CACC_Final_Report.pdf)

**DIAGNOSTIC SERVICES**

Unfortunately, many primary physicians in small towns are not trained to diagnose Alzheimer’s disease, meaning these services are lacking in most rural areas of the state.

**REGIONAL AVAILABILITY OF RESOURCES**

Although Colorado state agencies and community-based organizations within the state have tried to provide comprehensive services to people affected by Alzheimer’s disease and other dementia, many gaps still exist. A large gap exists in the services available for individuals living in rural areas. In Colorado, about 15 percent of individuals live in rural communities.40 Many rural populations are geographically isolated, with some counties in Colorado averaging only four individuals per square mile. Because rural populations are much more dispersed than urban, they provide a special challenge to disseminate information and direct services. Further, because of the low population density in rural areas, it is often not cost effective to locate services in rural communities.

Colorado’s 2004-07 State Plan on Aging identified three areas in which the needs and resources for individuals in rural areas differ from those in urban areas: medical care, medical-related transportation and nutrition-related programs. Rural populations tend to experience higher rates of chronic conditions, are uninsured for longer periods of time and have higher health care expenditures. Access to medical care in rural communities is more limited than in urban areas of the state. Lack of public transportation exacerbates this problem as individuals have few, if any, resources available to seek available medical care in more urban areas of the state. Further, nutrition programs such as congregate meals and Meals on Wheels often do not reach individuals living in isolated rural settings.

**Chapter 6: Identified Gaps and Policy Recommendations**

**Recommendation 2.4** Ensure that local Area Agencies on Aging (AAAs) are aware of and promote existing training materials available to family caregivers, especially those located in rural areas.

## [Idaho](https://portal.alzimpact.org/uploads/media/state_plans/ID.pdf)

**Finding #2: Need for Improved Education of Care Providers**

**Initiative #2: Promote existing professional and lay caregiver training programs.**

Based on the finding above from the Statewide Community Needs Assessment, IAPG will incorporate information about family caregiver training programs in the initiative related to Finding #1. This will be accomplished by incorporating information about existing family caregiver trainings in the new statewide information portal. A special effort will be made to reach out to rural areas of the state to inform them of these programs and to promote increased caregiver training. Effectiveness will be measured through call volume data as well as program participation rates.

**Finding #3: Need for Increased Family Support**

**Initiative #2: Link current ADRD support groups and respite care services into a vetted caregiver support network and provide viable options for areas of the state not presently served (i.e., rural areas).**

Based on the finding above, IAPG will work with the Idaho Commission on Aging/Area Agencies on Aging, Alzheimer’s Association and other stakeholders[[8]](#footnote-9) to develop and promote (through the Idaho 211 CareLine) a statewide caregiver support network database, made up of professional, volunteer and community organizations (e.g. churches and service clubs). The mandate of this working group will be to explore any and all legitimate caregiver support options in both rural and urban areas. The group will establish its own measurement of success based on such factors as database usage. It will also report on areas of the state where viable caregiver support is needed and may not exist.

## [Kansas](https://kdads.ks.gov/docs/librariesprovider17/commissions/alzheimer-s-disease-plan-working-group/alzheimer's-disease-plan-final-report/2020-ks-alzheimer's-disease-plan.pdf?sfvrsn=5d3f02ee_2)

**Access to Care**

**Improving access to dementia care and supportive services**

Access to services varies depending on public and provider awareness. There is much confusion about the prognosis of Alzheimer’s disease, and what services may be available to help caregivers and families of those with Alzheimer's and other dementias. Understanding what services are needed at what stage of the disease can add to the confusion in understanding what services are appropriate and available to help caregivers and families along a continuum at the point that services are being sought. It is essential that education about the disease, detection, diagnosis and treatment are available in tandem with the resources to match the needs. Whether in a metropolitan area, such as Kansas City, or in a rural community, such as Hays, Kansans require access to up-to-date information on detection, diagnosis, treatment, and a variety of health services. Many persons with Alzheimer’s disease and their families are not aware of specialized diagnosis of the disease through neurological examination and the availability of care and treatment options. This problem is compounded because of the distance to services or a lack of awareness of specialists to consult. Kansans deserve quality diagnosis and treatment informed by the most current science regardless of where they reside in the state.

As the number of individuals living with Alzheimer’s and other dementias grows, the more difficult accessing care and services can become. Over the past decades, the racial and ethnic composition of the population in Kansas has changed. There has been an increase in the number of minorities and a decrease in the number of white, non-Hispanic Kansans, as well as a population shift from rural areas into urban and semi-urban communities. Changes in the composition of the population could affect health care needs and require the health care system to evolve in order to address social determinants of health that are often distributed differently across population groups.

The availability and scope of support varies widely throughout Kansas, with many rural and frontier Kansas communities having limited access to hospitals, and in home service options.

Alzheimer’s and other dementias is exacerbated by multiple factors: An aging and increasingly diverse population, including growing numbers of persons at elevated risk for Alzheimer’s and other dementias; a large proportion of the population living in rural areas where there are fewer health care providers and other resources for persons with Alzheimer’s and other dementias and caregivers; the scarcity of clinicians trained in geriatrics and Alzheimer’s; and the high cost of care borne by individuals and their families. These challenges require a comprehensive response that mobilizes the residents and health care community of Kansas.

**Recommendations**

1. **Telehealth**

Maximize the availability of medical, preventive and home-based support services by promoting use of telemedicine and other technology that brings Alzheimer’s expertise to sites that lack specialized skills or advanced training. The Advisory Council should examine and identify funding streams and ways to expand utilization of telehealth to develop and facilitate the full spectrum of telehealth services to rural communities, including training for providers in rural areas.

## [Montana](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)

**Background**

**F. Health and Social Service Components of Care**

1. Home and Community-Based Services (HCBS)

To remain at home, individuals with dementia, as well as their caregivers, require additional support as their dementia progresses. Such support, often referred to as home and community-based services (HCBS), help relieve caregiver stress and burden by providing assistance and providing respite care.

Transportation is a significant issue due to the frontier nature of most of Montana. Even in more “urban” areas of the state, it can be difficult to find transportation options appropriate for individuals with dementia. Individuals in rural areas often have to travel long distances to service providers with no reliable means of transportation if they can no longer drive. Conversely, service providers have difficulty managing their business costs if they are required to travel long distances to reach clients.

6. Findings from Montana Alzheimer’s/Dementias Work Group

The following information is the result of work conducted by the Montana Alzheimer’s/Dementia Work Group from 2014–2016. This includes an inventory of health care professionals, home and community-based services including residential care, and the summary of information obtained from discussions with Montanans during public Town Hall meetings held across the state. The meetings also included conversations with Native American populations conducted on Native American Reservations and Indian Health Services Centers. The concerns, fears, and hopes expressed by Montana citizens echo the challenges outlined previously

**A. Inventory**

**1. Health Care Professionals**

Montana has a shortage of health care professionals, particularly in rural and frontier areas.

**Native American**

Group interviews about Alzheimer’s disease and related dementias and its challenges were conducted on all seven Native American Reservations in Montana and at several urban Indian centers with large Native American populations. Though some national research exists about American, Alaskan, and Canadian Natives on the subject of dementia, much more work must be done to better understand the needs, challenges, and solutions for Native communities. The findings of the group interviews point out a stark reality, yet attendees also expressed tremendous hope and ideas for the future. Many of the needs expressed reiterated the themes and points made at the urban/rural Town Hall meetings. However, several issues were unique to Native American communities. Issues of particular relevance to Native American communities in Montana include:

* Nursing homes and assisted living facilities are present on some Reservations or in geographic areas with large populations. Other more remote Reservations have either very limited beds available, which are not considered a good choice, or alternatives that are many hours away. Placing a loved one in a nursing home or assisted living facility hours away is not a realistic option because of the challenge of not being able to visit regularly. Based on values of interdependence and reciprocity, there is a strong tradition of family members caring for their elders. Having a loved one in a long-term care facility that is hours away can cause significant family distress.
* Financial issues (particularly because of high poverty levels) are also a barrier to placement in facilities, even when it is obviously needed. The requirements and constraints of Medicare and Medicaid spend down guidelines, and the services available through Indian Health Service are both confusing and limit people’s access. One urban health care service provider explained that more than 200 people on their client list are eligible and had been prequalified for enrollment through Medicaid expansion, yet only a handful had gone through the process to enroll. Furthermore, the cost of between $4,000 and $8,000 a month of institutional care, regardless of the source to pay for it, is prohibitive. In addition, program regulations may make offered services incongruent with cultural values.

**7. Goals and Recommended Action Steps**

**Goal 3: Legal and Financial Issues**

Ensure that Montanans with Alzheimer’s disease and related dementias and their family caregivers are aware of, and have access to, Montana-specific materials regarding legal and financial alternatives, enabling them to execute appropriate legal documents for their circumstances.

**Recommendations:**

**3-H.** Convene a group of representatives from the Native American reservations to determine how to meet the legal and financial issues they experience regarding dementia care and management.

**Goal 4: Person-Centered Care**

Ensure that Montana adults with Alzheimer’s disease and related dementias will be able to successfully age in place with dignity and respect regardless of socio-economic status, rural or urban residence, income, race, religious preference, gender identity/expression, or sexual orientation in the least restrictive setting that best fosters his/her current level of cognitive and functional ability, while maintaining a high quality of life.

**Goal 8: Home and Community-Based Services**

Expand the availability of high-quality, affordable home and community-based services (HCBS) that meet the needs of the individuals living with Alzheimer’s disease and related dementias, allowing them to live in the most appropriate and least restrictive setting.

**Recommendations:**

**8-E.** Develop creative transportation options to serve both rural and urban areas, and explore incentive programs for transportation providers who specialize in services that meet the needs of individuals with dementia.

**8-I.** Explore and support creative approaches to enhancing and providing home and community-based services on the Native American reservations.

## [North Carolina](https://portal.alzimpact.org/uploads/media/state_plans/NC.pdf)

**CHAPTER FOUR: HAVING SUPPORTIVE OPTIONS THAT FOSTER QUALITY OF LIFE**

*Telehealth and Access to Care*

There is opportunity for improved access to quality health care through the expansion of telehealth and other remote-based services for people with Alzheimer’s disease or related dementia. Research has shown that dementia can be reliably diagnosed using detection and assessment tools administered through video conferencing technology. In North Carolina, there are nearly 700,000 people over the age of 60 living in rural areas. For these individuals who live in rural areas with fewer available transportation services or for whom distance to health care providers is a challenge, these types of telehealth services for assessment and diagnosis hold promise.

**Recommendation 4.4:** Improve telehealth services for people with Alzheimer’s disease or related dementias.

Examine and identify funding streams for improved telehealth services for people with Alzheimer’s disease or related dementias, with special attention on rural and underserved communities and the impact on health care costs and caregiver well-being. These services should include:

1. Remote diagnostic capacity and ongoing consultation, medication management, and behavioral management in the context of tele-neurology services when appropriate, and/or at alternate locations (including home locations).
2. Home monitoring of activities of daily living, with local capacity for follow-up.
3. Remote resources for caregivers.
4. Additional non-health care services, such as check in calls, monitoring utilities, falls prevention, and caregiver support services.

*Improving Transportation Options to Improve Access to Care*

Human services transportation and/or public transportation services are available to some extent in all 100 North Carolina counties. North Carolina has a long history of state-level support for the coordination of transportation services across funding sources. Local community transportation networks have been built with the help of federal and state funding from the North Carolina Department of Transportation Public Transportation Division. Especially in rural communities across the state, the availability of public transportation can be traced directly to the immediate need for human service transportation and access to services.

**CHAPTER SEVEN: REACHING THOSE WHO ARE UNDERSERVED**

As discussed in Chapter 2, there are several populations that are disproportionately affected by Alzheimer’s disease and related dementias, including people with intellectual and/or developmental disabilities and a number of minority populations. In addition, in North Carolina, there are geographical disparities in access to care due to the large rural areas of the state.

People in rural areas are about equally as likely to be uninsured as are those in urban areas (16.5% versus 15.7% respectively).5,6 Many rural communities also experience shortages of key health professionals, including primary care, specialty care, mental health care, and allied health care.

Of those designated communities, 48 of the primary care health professional shortage areas (HPSAs) are in rural counties. As discussed in Chapter 4, properly assessing health system capacity, including rural disparities in the health care workforce, is an important step in improving care for people with Alzheimer’s disease or related dementia.

As communities focus resources and efforts on addressing disparities in rates of Alzheimer’s disease and related dementia, they must also keep cultural competency in mind. Cultural competency is defined as understanding different groups’ history, diversity, and culture. As is the case in emphasizing person-centered care within health care settings (see Chapter 4), a culturally competent approach will value others’ experiences, respect their viewpoints, and refrain from judgement.

As discussed above, there are disparities in rates of Alzheimer’s disease and related dementia between many racial and ethnic groups. There is also a disparity among research participants, with fewer minorities participating in clinical trials and other research studies. While the reasons for this vary, contributing factors include higher levels of additional health problems, language barriers, mistrust of clinical research, under-diagnosis, and higher caregiver burdens.

In addition, persons in rural and underserved counties have poorer outcomes than those in urban areas, especially those close to universities and health care systems.

**CHAPTER EIGHT: FULL RECOMMENDATIONS OF THE TASK FORCE ON ALZHEIMER’S DISEASE AND RELATED DEMENTIAS**

**Recommendation 3.1**: Increase awareness and promote education about Alzheimer’s disease and related dementias and available resources through incorporating Alzheimer’s disease and related dementia-specific information in current health promotion and education programs.

f) Resources for underserved populations including individuals with intellectual/developmental disabilities, minority populations, homeless, and rural communities.

**Recommendation 4.4:** Improve telehealth services for people with Alzheimer’s disease or related dementias.

Examine and identify funding streams for improved telehealth services for people with Alzheimer’s disease or related dementias, with special attention on rural and underserved communities and the impact on health care costs and caregiver well-being. These services should include:

a) Remote diagnostic capacity and ongoing consultation, medication management, and behavioral management in the context of tele-neurology services when appropriate, and/or at alternate locations (including home locations).

b) Home monitoring of activities of daily living, with local capacity for follow-up.

c) Remote resources for caregivers.

d) Additional non-health care services, such as check in calls, monitoring utilities, falls prevention, and caregiver support services.

## [Oregon](https://www.ohsu.edu/sites/default/files/2019-10/SPADO%20Report%20July%202012.pdf)

**Goal 4: Improve Access to Quality Care**

**Recommendation 4B:** Increase access to health care providers who serve those with Alzheimer’s disease and related dementia.

**Strategies**

1. Create a work group to identify ways to expand utilization of telemedicine and other technology to keep healthcare providers updated on current treatment developments, and increase access in rural areas to expertise in other areas

**Rationale**

Families and professionals often face challenges in finding medical care for people with dementia. No single comprehensive list exists of healthcare providers who have experience treating dementia in Oregon. Also, rural communities face additional barriers to services and finding providers with expertise, but new technologies could bridge that gap by allowing rural healthcare providers and their patients to consult with healthcare providers in other parts of the state.

**Fiscal Implications**

Costs and possible funding options for expanding technology into rural areas would have to be explored as part of workgroup. Expanding telemedicine and other technological tools can create cost savings and improvements in treatment to offset the cost of investing in these tools.

## [South Dakota](https://portal.alzimpact.org/uploads/media/state_plans/SD.pdf)

**South Dakota AD State Plan Goals, Recommendations, and Rationale**

**2. ACCESS TO CARE**

Ensure that people living with dementia have access to affordable care in all areas of South Dakota including home and community-based services, residential care facilities, and end-of-life care settings.

**RECOMMENDATIONS:**

1. Form strategic partnerships with public and private organizations to bring care services to low-access areas of South Dakota. Capacity-focused workforce development policies could be tailored to incentivize new healthcare professionals to practice in underserved regions.
2. Support policies that expand and fund telehealth capacity in underserved and rural areas.
3. Consult with representatives from Native American reservations to learn how to best meet the needs of their populations and enact the needed services. Additional guidance is available in the CDC’s Healthy Brain Initiative Road Map for Indian Country.

**RATIONALE:**

1. Geographic regions, including Native American reservations, exist within South Dakota without access to certain care services.

**An In-Depth Look at the Five Key Findings**

Disparity in access to health professionals and medical services exists. Shortages are geography and income based.

* Across South Dakota’s 66 counties, there are 47 medically underserved areas.
* Participants living in underserved and shortage areas reported having to travel more than one hour and up to three for initial and follow-up appointments.

## [Texas](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.)

**Priority Area 2: Coordinated Systems of Care and Support**

**Goal**

Increase collaboration between entities and individuals involved in the care of people with Alzheimer’s disease and other dementias to ensure better access to services, quality health care, and support over the lifespan.

**Actions**

**2.1** Identify and address services gaps and priority needs in the care and support of people with Alzheimer’s disease and other dementias, for instance:

Ensure that services are culturally and linguistically appropriate and available in urban and rural communities.

**2.4** Expand the role of community health workers in providing education on care for Alzheimer’s disease and other dementias to reach underserved communities.

**Priority Area 3: Partnerships and Engagement**

**Goal**

Increase collaborative, diverse partnerships to better support and improve access to resources for people diagnosed with Alzheimer’s disease and other dementias and their family caregivers.

**Actions**

**3.7** Engage and collaborate with community and cultural leaders to provide education and referrals to resources for diverse communities and rural populations.

**Priority Area 5: Quality Care and Support**

**Goal**

Increase the use of best practices and care standards for the diagnosis, treatment, and care of people with Alzheimer’s disease and other dementias over the lifespan, as well as to provide for the needs of family caregivers.

**Actions**

**5.4** Improve access to neuropsychologists and standard laboratory and diagnostic imaging, and use technology such as telemedicine to expand patient access in remote rural areas to highly trained neurologists, neuropsychologists, and other specialists.

## [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

**GOAL 2: PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION**

**D. Promote healthy aging and brain health.**

5. Partner with community organizations to disseminate evidence-based educational materials for the public around healthy aging and accessing health care proactively. Include organizations such as tribal centers, community and senior centers, faith-based organizations, hospitals and health plans, YMCAs and parks departments, secondary schools and institutes of higher learning.

## [Wyoming](https://health.wyo.gov/wp-content/uploads/2019/10/wyalzsstateplan-08302018.pdf)

**CHANGING DEMOGRAPHICS**

**Availability of Medical Professionals in Wyoming**

As of 2017, Wyoming ranks 48th nationwide in terms of primary care physicians per capita with 105.7 physicians per 100,000 residents.9 Wyoming’s rural and frontier communities present a unique problem in that physicians are even fewer in these areas and more frequently located in larger communities.

# Workforce Development

## [Alaska](https://act.alz.org/site/DocServer/Alaska_State_plan_2015.pdf?docID=42541)

**Goal 4: Develop a long-term services and supports** **workforce trained in dementia care.**

**Rationale:**

As the older adult population increases and becomes more culturally diverse, cultural competence training becomes even more important to improve care for all Alaskans affected by dementia. Health care professionals and direct service providers need assistance in order to communicate effectively across cultures and languages.

**Recommendation 4.3:** Increase cultural competence among dementia care workers.

**Strategies:**

1. Identify evidence-based national models to address cultural differences within care settings for people with ADRD and their caregivers.
2. Collaborate with ANTHC to develop a cultural competence online training module for caregivers with training hours eligible to satisfy licensing requirements for assisted living homes.
3. Develop and disseminate culturally relevant materials related to ADRD.
4. Link individuals with ADRD with services and care settings that are consistent with their cultural values and beliefs

## [Arizona](https://www.azdhs.gov/documents/prevention/tobacco-chronic-disease/healthy-aging/reports-statistics/az-alzheimers-plan-2015.pdf)

**GOAL 3 Expand Dementia-Capable Workforce in Arizona**

Expand the dementia-capable workforce in Arizona through specialized dementia education and training, and the development and implementation of standardized quality measures of dementia care across long-term-care, community health and other healthcare settings. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to all aspects of the diversity of our populations and communities throughout Arizona.

**RECOMMENDATION 3.1** Develop A Dementia-Capable and Culturally Competent Workforce That Cares for Older Adults and People with Alzheimer’s Disease and Related Disorders Throughout the Continuum of Care

**Strategies**

1. Encourage care providers to partner with multicultural coalitions as they develop dementia-capable services for ethnically diverse clients and residents across the continuum of care.

## [California](https://aging.ca.gov/download.ashx?lE0rcNUV0zZ8r%2fOK1dJ1OQ%3d%3d)

**GOAL 4 Develop an Alzheimer’s Proficient, Culturally Competent Workforce**

**Recommendation 4A:** Build and expand workforce capacity and competency throughout the continuum of care.

**Recommendation 4B:** Improve dementia care capacity and competency of primary care providers

## [Colorado](https://www.coloradohealthinstitute.org/sites/default/files/file_attachments/CACC_Final_Report.pdf)

**LTSS WORKFORCE**

Colorado’s formal LTC workforce is diverse and involves many occupational groups.

A well-documented shortage of long-term care providers exists; high turnover rates, large numbers of job vacancies and difficulties in recruiting new workers challenge the industry. In addition, the demographics of the population are shifting—those needing LTC will be more ethnically diverse, better educated and wealthier than in the past.

## [Idaho](https://portal.alzimpact.org/uploads/media/state_plans/ID.pdf)

**Finding #2: Need for Improved Education of Care Providers**

**Initiative #2: Promote existing professional and lay caregiver training programs.**

Based on the finding above from the Statewide Community Needs Assessment, IAPG will incorporate information about family caregiver training programs in the initiative related to Finding #1. This will be accomplished by incorporating information about existing family caregiver trainings in the new statewide information portal. A special effort will be made to reach out to rural areas of the state to inform them of these programs and to promote increased caregiver training. Effectiveness will be measured through call volume data as well as program participation rates.

**Ideas for Future Consideration**

**Finding #2: Provide ADRD-specific education and training for current and future health care providers, institutional caregivers and family caregivers**

* Ensure that specific needs of applicable minority populations with dementia are included in training modules.

## [Montana](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)

**Background**

**F. Health and Social Service Components of Care**

2. Residential Care Although most people would like to remain at home, this is sometimes not possible, particularly for individuals with Alzheimer’s disease and related dementias. Approximately 30-40% of older adults with dementia live in a facility compared with 2% of older adults without dementia.

On average, nursing homes lose more than $38 per resident per day providing care to Medicaid beneficiaries. These financial losses limit the ability of facilities to attract qualified staff as nursing home wages may not be able to match wages in other health care markets. This results in high turnover rates or inadequate staffing levels, and can lead to an increased of closure [sic] for nursing home facilities, particularly those in rural areas and can also result in poor health outcomes for residents. Although staffing issues have been noticed anecdotally, no real data on this issue is available in Montana.

**6. Findings from Montana Alzheimer’s/Dementias Work Group**

The following information is the result of work conducted by the Montana Alzheimer’s/Dementia Work Group from 2014–2016. This includes an inventory of health care professionals, home and community-based services including residential care, and the summary of information obtained from discussions with Montanans during public Town Hall meetings held across the state. The meetings also included conversations with Native American populations conducted on Native American Reservations and Indian Health Services Centers. The concerns, fears, and hopes expressed by Montana citizens echo the challenges outlined previously

**A. Inventory**

**1. Health Care Professionals**

Montana has a shortage of health care professionals, particularly in rural and frontier areas.

**Native American**

Group interviews about Alzheimer’s disease and related dementias and its challenges were conducted on all seven Native American Reservations in Montana and at several urban Indian centers with large Native American populations. Though some national research exists about American, Alaskan, and Canadian Natives on the subject of dementia, much more work must be done to better understand the needs, challenges, and solutions for Native communities. The findings of the group interviews point out a stark reality, yet attendees also expressed tremendous hope and ideas for the future. Many of the needs expressed reiterated the themes and points made at the urban/rural Town Hall meetings. However, several issues were unique to Native American communities. Issues of particular relevance to Native American communities in Montana include:

* Nursing homes and assisted living facilities are present on some Reservations or in geographic areas with large populations. Other more remote Reservations have either very limited beds available, which are not considered a good choice, or alternatives that are many hours away. Placing a loved one in a nursing home or assisted living facility hours away is not a realistic option because of the challenge of not being able to visit regularly. Based on values of interdependence and reciprocity, there is a strong tradition of family members caring for their elders. Having a loved one in a long-term care facility that is hours away can cause significant family distress.

**7. Goals and Recommended Action Steps**

**Goal 4: Person-Centered Care**

Ensure that Montana adults with Alzheimer’s disease and related dementias will be able to successfully age in place with dignity and respect regardless of socio-economic status, rural or urban residence, income, race, religious preference, gender identity/expression, or sexual orientation in the least restrictive setting that best fosters his/her current level of cognitive and functional ability, while maintaining a high quality of life.

**Goal 5: Workforce Education and Development**

Maintain adequate numbers of direct care workers, aides, nurses, nurse practitioners, physician assistants, physicians, social workers, first responders, and other professionals. Ensure that they receive the appropriate training to meet the needs of the Alzheimer’s disease and related dementias population in all care settings.

**Recommendations:**

**5-H.** Assist hospitals, nursing homes, and home and community-based service agencies with education for their workforce regarding cultural and clinical competencies in caring for individuals with dementia.

**Goal 6: Build Dementia-Friendly Communities**

Promote dementia-friendly communities in Montana, where individuals with Alzheimer’s disease and related dementias and their caregivers are treated with respect and dignity, and are actively encouraged to participate in community life. Make it possible for communities to be proactive in assessing community risk for individuals with dementia, such as the potential for wandering, the need for early intervention in crisis situations, and protection from financial and other forms of exploitation.

Recommendations:

**6-H.** Promote a statewide anti-bullying, anti-elder abuse initiative across various care settings, including in-home services, nursing homes, assisted living residences, senior centers, and adult day programs. Such initiatives should also be employed on Native American reservations.

**Goal 9: Residential Care Facilities**

Promote wellness and maintenance of cognitive function for individuals with dementia living in residential care facilities, including assisted living facilities, personal care homes, adult foster homes, and nursing home facilities, by offering activities tailored to each individual’s needs. Train staff in non-pharmacological treatment of behavioral issues and person-centered models of care.

**Recommendations:**

**9-E.** Convene a group of representatives from all the Native American reservations to discuss how to best meet the needs of their citizens so they feel safe, and their cultural expectations are being met in residential care facilities.

## [North Carolina](https://portal.alzimpact.org/uploads/media/state_plans/NC.pdf)

**CHAPTER FOUR: HAVING SUPPORTIVE OPTIONS THAT FOSTER QUALITY OF LIFE**

*Palliative Care*

In North Carolina, many hospice providers have palliative care specialty programs, with physicians, nurses, physician assistants, and social workers included in care teams. Other models of palliative care include palliative consult teams within hospitals, and home-based palliative care, which can also assist with transitions from acute care settings to home care settings. Throughout the state, access to palliative care specialists varies. Community palliative care services, including outpatient clinics, home-based care, or institutional care, is still the area of greatest need, and rural counties in the east and far west portions of the state have the least access to these services. Large hospitals are most likely to have palliative care consultation and services.

**CHAPTER SIX: PROMOTING MEANINGFUL PARTICIPATION IN COMMUNITY LIFE**

***Public Safety for Individuals with Alzheimer’s Disease or Related Dementia***

Law enforcement personnel and first responders are not currently required by law in North Carolina to be trained on dementia. According to a nationwide survey in 2015, only 10 states were found to have laws requiring dementia training on symptoms and behavioral management for law enforcement personnel, including Colorado, Florida, Indiana, Maryland, New Hampshire, New Jersey, Oklahoma, Oregon, South Carolina, and Virginia. Dementia training standards tend to be general surrounding the dangers of wandering or getting lost, the course of Alzheimer’s disease, and how law enforcement can best handle difficult situations safely. The National Council of Certified Dementia Practitioners has developed a training module for first responders, called the Certified First Responder Dementia Trainer. This module includes an overview of dementia symptoms, stages, common behaviors (including wandering, getting lost, and other safety concerns), communication strategies, and multicultural considerations. The US Department of Justice and Alzheimer’s advocacy organizations have also developed toolkits and training resources for first responders.

## [North Dakota](https://ruralhealth.und.edu/assets/4702-20934/alzheimer-dementia-plan-nd.pdf)

**DIVERSITY, INCLUSION, AND CULTURAL CONSIDERATIONS**

**Strengthen the Workforce**

7. Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia.

8. Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.

## [Oklahoma](https://portal.alzimpact.org/uploads/media/state_plans/OK.pdf)

**Professional Objectives**

**P5 Objective:** Develop systems to provide improved services to underserved areas utilizing guidelines identified by the Oklahoma State Department of Health.

## [South Dakota](https://portal.alzimpact.org/uploads/media/state_plans/SD.pdf)

**South Dakota AD State Plan Goals, Recommendations, and Rationale**

**4. TRAINING AND WORKFORCE DEVELOPMENT**

Support the development of an adequately prepared and dementia-capable interprofessional workforce, including direct care workers, aides, site administrators, nurses, nurse practitioners, physician assistants, physicians, social workers, first responders, and other care providers. Dementia training standards should address the knowledge, skills, and attitudes necessary to meet the needs of people with dementia and their families in all care settings. Increase workforce capacity, particularly in underserved areas, to ensure that all parts of South Dakota are covered.

**RECOMMENDATIONS:**

1. Incentivize advanced education for health care providers, especially in underserved areas, who specialize in geriatrics and dementia care, such as loan forgiveness or repayment options, stipends, scholarships, and relocation expenses.

## [Texas](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.)

**Priority Area 4: Training**

**Goal**

Increase the percent of health care professionals and students receiving quality training regarding best practices for the treatment and care of people with Alzheimer’s disease and other dementias over the lifespan, as well as training on the impact of the disease on family caregivers.

**Actions**

**4.1** Educate health care providers and foster continuing education on the following topics:

Available caregiving information, support programs, and services that are culturally and linguistically appropriate;

**4.13** Create incentives (e.g., tuition assistance, housing subsidies, and stipends) to increase the number of health care professionals who pursue education and training to specialize in gerontology and geriatrics, particularly people who make a commitment to work in underserved communities.

## [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

**Goal 5 - IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE**

1. Develop a dementia-capable, culturally competent primary care workforce throughout the state

## [Wyoming](https://health.wyo.gov/wp-content/uploads/2019/10/wyalzsstateplan-08302018.pdf)

**GOALS AND RECOMMENDATIONS**

**Goal #4: Improve access to long-term care residential facilities, which specialize in care for those with AD/RD.**

**Long-Term**

* Increase the number of long-term residential care communities and the capacity and competency of existing facilities in rural areas through recruitment of facilities.
* Increase the number of long-term residential care communities and the capacity and competency of existing facilities in rural areas through reduction of regulatory barriers to business operations and staffing.

**Goal #8: Develop and maintain a professional workforce that has the awareness, knowledge, and skills to care competently for persons living with AD/RD and their caregivers.**

**Long-Term**

* Develop tuition assistance for rural-based dementia care providers

# Caregiving

## [Arizona](https://www.azdhs.gov/documents/prevention/tobacco-chronic-disease/healthy-aging/reports-statistics/az-alzheimers-plan-2015.pdf)

**GOAL 2 Develop New & Enhance Existing Supports for People with Alzheimer’s Disease and their Families**

Ensure the availability, accessibility, and acceptability of supportive resources for people living with Alzheimer’s disease and related disorders and their caregivers in Arizona. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to the individual and their families to all aspects of the diversity of our populations and communities throughout Arizona.

**RECOMMENDATION 2.1** Increase Education and Skill Training Opportunities

**Strategies**

1. Promote the development of innovative tailored service delivery and outcome tactics to address individual, family and cultural needs.

**GOAL 5 Create a Dementia-Capable System in Arizona**

Create and sustain an innovative dementia-capable system of home and community-based services that are accessible and acceptable to people with dementia and their caregivers. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to all aspects of the diversity of our populations and communities throughout Arizona.

**RECOMMENDATION 5.1** Create and Sustain a Dementia-Capable Home and Community-Based Services System That Is Responsive to The Unique Needs of People with Alzheimer’s Disease and Related Disorders

**Strategies**

1. Ensure that services, supports, and approaches in a dementia-capable system are available, accessible and acceptable regardless of ethnicity, geography, or culture.

## [California](https://aging.ca.gov/download.ashx?lE0rcNUV0zZ8r%2fOK1dJ1OQ%3d%3d)

**GOAL 3 Establish a Comprehensive Approach to Support Family Caregivers**

**Recommendation 3A:** Acknowledge and invest in the informal, unpaid caregiver as a vital participant in care.

**Strategy 3.** Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate offerings.

## [Colorado](https://www.coloradohealthinstitute.org/sites/default/files/file_attachments/CACC_Final_Report.pdf)

**Informal services/Caregiver support**

**Recommendation 2.4.** Ensure that local Area Agencies on Aging (AAAs) are aware of and promote existing training materials available to family caregivers, especially those located in rural areas.

## [Idaho](https://portal.alzimpact.org/uploads/media/state_plans/ID.pdf)

**Finding #2: Need for Improved Education of Care Providers**

**Initiative #2: Promote existing professional and lay caregiver training programs.**

Based on the finding above from the Statewide Community Needs Assessment, IAPG will incorporate information about family caregiver training programs in the initiative related to Finding #1. This will be accomplished by incorporating information about existing family caregiver trainings in the new statewide information portal. A special effort will be made to reach out to rural areas of the state to inform them of these programs and to promote increased caregiver training. Effectiveness will be measured through call volume data as well as program participation rates.

**Finding #3: Need for Increased Family Support**

**Initiative #2: Link current ADRD support groups and respite care services into a vetted caregiver support network and provide viable options for areas of the state not presently served (i.e., rural areas).**

Based on the finding above, IAPG will work with the Idaho Commission on Aging/Area Agencies on Aging, Alzheimer’s Association and other stakeholders[[9]](#footnote-10) to develop and promote (through the Idaho 211 CareLine) a statewide caregiver support network database, made up of professional, volunteer and community organizations (e.g. churches and service clubs). The mandate of this working group will be to explore any and all legitimate caregiver support options in both rural and urban areas. The group will establish its own measurement of success based on such factors as database usage. It will also report on areas of the state where viable caregiver support is needed and may not exist.

## [Montana](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)

**Background**

**F. Health and Social Service Components of Care**

1. Home and Community-Based Services (HCBS) To remain at home, individuals with dementia, as well as their caregivers, require additional support as their dementia progresses. Such support, often referred to as home and community-based services (HCBS), help relieve caregiver stress and burden by providing assistance and providing respite care.

Transportation is a significant issue due to the frontier nature of most of Montana. Even in more “urban” areas of the state, it can be difficult to find transportation options appropriate for individuals with dementia. Individuals in rural areas often have to travel long distances to service providers with no reliable means of transportation if they can no longer drive. Conversely, service providers have difficulty managing their business costs if they are required to travel long distances to reach clients.

**7. Goals and Recommended Action Steps**

**Goal 4: Person-Centered Care**

Ensure that Montana adults with Alzheimer’s disease and related dementias will be able to successfully age in place with dignity and respect regardless of socio-economic status, rural or urban residence, income, race, religious preference, gender identity/expression, or sexual orientation in the least restrictive setting that best fosters his/her current level of cognitive and functional ability, while maintaining a high quality of life.

**Goal 6: Build Dementia-Friendly Communities**

Promote dementia-friendly communities in Montana, where individuals with Alzheimer’s disease and related dementias and their caregivers are treated with respect and dignity, and are actively encouraged to participate in community life. Make it possible for communities to be proactive in assessing community risk for individuals with dementia, such as the potential for wandering, the need for early intervention in crisis situations, and protection from financial and other forms of exploitation.

**Recommendations:**

**6-B.** Develop a community-based emergency crisis intervention/prevention program that institutes a “course of action” to mitigate dementia issues for families of all cultures and economic means who find themselves at immediate risk.

6-H. Promote a statewide anti-bullying, anti-elder abuse initiative across various care settings, including in-home services, nursing homes, assisted living residences, senior centers, and adult day programs. Such initiatives should also be employed on Native American reservations.

**6-G.** Assemble a group of Native American representatives to discuss the cultural needs they may experience in their communities and how to address them.

**Goal 8: Home and Community-Based Services**

Expand the availability of high-quality, affordable home and community-based services (HCBS) that meet the needs of the individuals living with Alzheimer’s disease and related dementias, allowing them to live in the most appropriate and least restrictive setting.

**Recommendations:**

**8-E.** Develop creative transportation options to serve both rural and urban areas, and explore incentive programs for transportation providers who specialize in services that meet the needs of individuals with dementia.

**8-I.** Explore and support creative approaches to enhancing and providing home and community-based services on the Native American reservations.

**Goal 9: Residential Care Facilities**

Promote wellness and maintenance of cognitive function for individuals with dementia living in residential care facilities, including assisted living facilities, personal care homes, adult foster homes, and nursing home facilities, by offering activities tailored to each individual’s needs. Train staff in non-pharmacological treatment of behavioral issues and person-centered models of care.

**Recommendations:**

**9-E.** Convene a group of representatives from all the Native American reservations to discuss how to best meet the needs of their citizens so they feel safe, and their cultural expectations are being met in residential care facilities.

## [New Mexico](https://nmaging.state.nm.us/uploads/files/Update%20Dementia%20Plan%20LAU-Tracy%20edits.pdf)

**State Dementia Plan Milestones**

**Goal 3: Support and Empower Caregivers**

* Evidence-based caregiver training programs―Savvy Caregiver, Cuidando con Respeto, and Savvy Caregiver in Indian Country―are provided state-wide.
* A cadre of volunteer Savvy Caregiver trainers was, and continues to be, recruited and supported statewide.

**State Dementia Plan Goals and Strategies Update**

**Goal Two: Raise Public Awareness and Expand Dementia Resource Connections**

In order to reduce the stigma of dementia, support caregivers, increase awareness and encourage advocacy across the state’s diverse cultures and locations, public awareness activities are conducted with a wide range of partners as follows:

1. Coordination, collaboration, and inter-entity communication is encouraged and developed with public, private, local, state, tribal and federal entities to advance Alzheimer’s readiness and dementia capable systems.
2. Public awareness campaigns are conducted, to include New Mexico’s ethnic, cultural, and linguistic diversity.
3. Access to culturally appropriate resources and supports for family caregivers and others caring for, or treating, individuals with Alzheimer’s disease and related dementias is facilitated.

## [New York](https://portal.alzimpact.org/uploads/media/state_plans/NY.pdf)

**Caregiver Burden**

**Informal Caregivers**

Most of the contemporary research indicates that the burden of caring for an individual living with AD/D disproportionately affects women and minorities. Women represent 65% of caregivers of individuals with AD and report taking on a higher burden of caregiving responsibilities. According to the 2019 Facts and Figures and a study conducted by AARP, Hispanic and African American caregivers report more time caregiving and higher intensity of caregiving burden compared to non-Hispanic Caucasian caregivers. Other research identifies non-Hispanic Caucasian caregivers as experiencing increased depression and perceived stress when compared to caregivers of other races and ethnicities.

**The Caregiver Support Initiative for Underserved Communities**

The Caregiver Support Initiative for Underserved Communities provides $1.5 million to 15 community-based organizations to provide caregiver support services for targeted underserved communities. Each organization receives $100,000 annually to reach caregivers of individuals living with AD/D, either or both of whom are members of underserved communities.

The programs recognize and address the need for culturally competent support strategies. Program models are designed to serve individuals who may experience challenges related to geographic isolation; English as a second language; minority or ethnic group membership; sexual orientation and gender identity; low socioeconomic status; or cultural isolation.

**New York State Education Department**

This is a significant development since, for persons living with AD/D and their caregivers, the cultural customs and beliefs influence the way health and behavior is understood and health care and social living decisions are made.

## [North Dakota](https://ruralhealth.und.edu/assets/4702-20934/alzheimer-dementia-plan-nd.pdf)

**DIVERSITY, INCLUSION, AND CULTURAL CONSIDERATIONS**

**Educate and Empower Community Members**

1. Work with community members to understand brain health, early warning signs of dementia, and benefits of early detection and diagnosis for persons with dementia and their caregivers.
2. Encourage community members to use effective interventions, best practices, and traditional wellness practices to protect brain health, address cognitive impairment, and support persons with dementia and their caregivers.
3. Provide information and tools to help older adults with dementia and their caregivers anticipate and respond to challenges that typically arise during the course of dementia.
4. Promote engagement among tribal leaders in dementia issues by offering information and education on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health approaches in addressing this priority problem.

## [Texas](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.)

**Priority Area 1: Education and Awareness**

**Goal**

Increase the percentage of people with Alzheimer’s disease and other dementias and their family caregivers receiving culturally and linguistically appropriate information and referrals to community resources from health care providers.

**Actions**

**1.1** Provide culturally and linguistically appropriate education on a range of topics to people with Alzheimer’s disease and other dementias and their family caregivers to enhance their health, well-being, and independence. Priority education topics include the following:

* Changes in memory, thinking, or behavior that should be discussed with a health professional;
* Disease management and coexisting conditions;
* The importance of care planning for people with all stages of Alzheimer’s disease and other dementias that includes family caregivers;
* Family caregiver health and well-being; Local caregiver resources and support;
* Clinical trials; and
* Prevention of abuse, neglect, and exploitation.

**1.2** Promote culturally and linguistically appropriate awareness and education campaigns (through television, radio, print, and social media) with common messages to help the general public better understand Alzheimer’s disease and other dementias, provide suggestions on steps to reduce the risk of cognitive decline, and reduce disease stigma. Topics for awareness and education campaigns include, but are not limited to, the following:

* The role of family caregivers in providing care, participating in care planning with health care providers, and finding support services;
* The health and well-being of family caregivers; and
* Real stories of people living with Alzheimer’s disease and other dementias.

**Priority Area 6: Family inclusion**

**Goal**

Increase the inclusion of family caregivers for people with Alzheimer’s disease and other dementias in the development of care plans, and ensure they receive resources, information, and support regarding diagnosis, treatment, long-term care, and caregiver wellness.

**Actions**

**6.2** Provide educational resources at the time of diagnosis about the diagnosis, treatment, stages of Alzheimer’s disease and other dementias, financial and legal information, clinical trials, community support resources, and respite services. Resources should be culturally and linguistically appropriate, written in plain language, and meet health literacy guidelines.

## [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

**Goal 4 - ENSURE ACCESS TO COMPREHENSIVE SUPPORTS FOR FAMILY CAREGIVERS**

Given the expected increases in the state’s dementia population, and significant funding constraints for new services, we must provide comprehensive supports for family caregivers. Not all caregivers have the same experiences, and the supports individual caregivers need vary widely. There is also a need to make education and supports accessible in terms of language and cultural appropriateness, and to reach caregivers in the rural areas of Washington. The National Plan to Address Alzheimer’s Disease recognizes these challenges. For example, the federal government is working to connect American Indian and Alaska Natives to Alzheimer’s disease resources.

Caregivers also need to know what is “out there” to help them when they need support and they want culturally relevant advice, support, and services.

F. Increase the number of culturally and linguistically diverse caregivers who participate in education and support programs.

1. Identify and engage leaders and organizations of diverse populations to explore needs for education and support.

2. Identify and make educational programs and support services for diverse caregivers more available across the state.

G. Collaborate with tribes to meet unique needs of Native American family caregivers living with dementia.

1. Engage tribal representatives to explore the needs of tribal families caring for people with dementia to develop culturally relevant supports and services.

# Long-Term Services and Supports

## [Alaska](https://act.alz.org/site/DocServer/Alaska_State_plan_2015.pdf?docID=42541)

**Goal 2. Improve access to appropriate housing, services and supports for individuals with ADRD at all stages of the disease.**

**Recommendation 2.1:** Develop service eligibility requirements based on functional, cognitive, and behavioral needs and reimbursement rates based on acuity levels.

**Strategies:**

1. Increase services in rural areas through tribal and other partnerships to provide home and community based services such as PCA and assisted living, and skilled nursing. Assess demand for and supply of services for each region and encourage coordination to maximize efficient service delivery.

**Goal 4: Develop a long-term services and supports workforce trained in dementia care**.

**Rationale:**

As the older adult population increases and becomes more culturally diverse, cultural competence training becomes even more important to improve care for all Alaskans affected by dementia. Health care professionals and direct service providers need assistance in order to communicate effectively across cultures and languages.

## [Colorado](https://www.coloradohealthinstitute.org/sites/default/files/file_attachments/CACC_Final_Report.pdf)

**LTSS WORKFORCE**

Colorado’s formal LTC workforce is diverse and involves many occupational groups.

A well-documented shortage of long-term care providers exists; high turnover rates, large numbers of job vacancies and difficulties in recruiting new workers challenge the industry. In addition, the demographics of the population are shifting—those needing LTC will be more ethnically diverse, better educated and wealthier than in the past.

## [Montana](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)

**7. Goals and Recommended Action Steps**

**Goal 6: Build Dementia-Friendly Communities**

Promote dementia-friendly communities in Montana, where individuals with Alzheimer’s disease and related dementias and their caregivers are treated with respect and dignity, and are actively encouraged to participate in community life. Make it possible for communities to be proactive in assessing community risk for individuals with dementia, such as the potential for wandering, the need for early intervention in crisis situations, and protection from financial and other forms of exploitation.

**Recommendations:**

**6-B.** Develop a community-based emergency crisis intervention/prevention program that institutes a “course of action” to mitigate dementia issues for families of all cultures and economic means who find themselves at immediate risk.

**6-H.** Promote a statewide anti-bullying, anti-elder abuse initiative across various care settings, including in-home services, nursing homes, assisted living residences, senior centers, and adult day programs. Such initiatives should also be employed on Native American reservations.

**6-G.** Assemble a group of Native American representatives to discuss the cultural needs they may experience in their communities and how to address them.

**Goal 8: Home and Community-Based Services**

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Recommendations:

**8-E.** Develop creative transportation options to serve both rural and urban areas, and explore incentive programs for transportation providers who specialize in services that meet the needs of individuals with dementia.

**8-I.** Explore and support creative approaches to enhancing and providing home and community-based services on the Native American reservations.

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**Recommendations:**

**9-E.** Convene a group of representatives from all the Native American reservations to discuss how to best meet the needs of their citizens so they feel safe, and their cultural expectations are being met in residential care facilities.

## [Nevada](https://adsd.nv.gov/uploadedFiles/adsdnvgov/content/Boards/TaskForceAlzheimers/Final_TFAD_2021%20State%20Plan.pdf)

**Recommendation #5: State Match Program for APRNs**

Support the establishment of a state match program between the NV DHHS, collaborating with the State Board of Nursing, and federal partners. This match program is intended to address the state's health provider shortage in rural and frontier communities. Match money, which could be offered as loans or scholarships, would be made available to APRNs, who commit to the specified loan or scholarship terms and required service provisions as they relate to providing health care services to underserved rural and frontier areas in Nevada.

## [Texas](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.)

**Priority Area 5: Quality Care and Support**

**Goal**

Increase the use of best practices and care standards for the diagnosis, treatment, and care of people with Alzheimer’s disease and other dementias over the lifespan, as well as to provide for the needs of family caregivers.

**Actions**

**5.2** Include screening for cognitive function and mood using validated assessment tools as a regular part of Medicare Annual Wellness Visits, and ensure that screening tools are culturally and linguistically appropriate.

**5.3** Develop and sustain care coordination, care planning, education, and support for people with mild cognitive impairment, younger-onset and late onset Alzheimer’s disease, and other dementias in ways that are culturally and linguistically appropriate.

**5.4** Improve access to neuropsychologists and standard laboratory and diagnostic imaging, and use technology such as telemedicine to expand patient access in remote rural areas to highly trained neurologists, neuropsychologists, and other specialists.

## [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

**GOAL 2: PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION**

**D. Promote healthy aging and brain health.**

2. Work with UW Healthy Brain Research Network (HBRN) and other partners to develop evidence-based public messages around promoting healthy aging and brain health, while ensuring messages are culturally/ethnically appropriate and designed to reach statewide populations including persons with limited English.

5. Partner with community organizations to disseminate evidence-based educational materials for the public around healthy aging and accessing health care proactively. Include organizations such as tribal centers, community and senior centers, faith-based organizations, hospitals and health plans, YMCAs and parks departments, secondary schools and institutes of higher learning.

## [Wyoming](https://health.wyo.gov/wp-content/uploads/2019/10/wyalzsstateplan-08302018.pdf)

**GOALS AND RECOMMENDATIONS**

**Goal #4: Improve access to long-term care residential facilities, which specialize in care for those with AD/RD.**

**Long-Term**

* Increase the number of long-term residential care communities and the capacity and competency of existing facilities in rural areas through recruitment of facilities.
* Increase the number of long-term residential care communities and the capacity and competency of existing facilities in rural areas through reduction of regulatory barriers to business operations and staffing.

# Research

## [Alaska](https://act.alz.org/site/DocServer/Alaska_State_plan_2015.pdf?docID=42541)

**Goal 6. Increase monitoring and research into ADRD prevalence, cost of care, prevention and treatment.**

**Recommendation 6.2:** Maintain and expand research of ADRD best practices related to risk reduction, treatment and care.

**Strategies:**

1. Collaborate with tribal partners, National Resource Center on American Indians, Alaska Natives, and Hawaiian Alaska Native Elders Resource Center at the University of Alaska Anchorage and ANTHC to better understand impact of ADRD among Alaska Native Elders and communities.

## [Arizona](https://www.azdhs.gov/documents/prevention/tobacco-chronic-disease/healthy-aging/reports-statistics/az-alzheimers-plan-2015.pdf)

**GOAL 4 Advance and Disseminate Research**

Conduct and disseminate cutting-edge research in Alzheimer’s disease and related disorders including research on its impact on Arizona through increased funding and support, expanded collaborations, and a greater understanding of research and its benefits. In keeping with the Task Force’s Guiding Principles, the recommendations and strategies are intended to be inclusive to all aspects of Arizona’s diversity.

**RECOMMENDATION 4.2** Increase Understanding of The Benefits of Research Strategies

**Strategies**

1. Use testimonials of diverse groups of research participants to describe the benefits of research and assist with research recruitment.

**RECOMMENDATION 4.3 Increase Participation in Research Statewide**

**Strategies**

1. Identify and overcome challenges to engaging participants in Alzheimer’s disease and related disorders research, including geographic, socio-economic, cultural or other differences that may discourage participation.

## [California](https://aging.ca.gov/download.ashx?lE0rcNUV0zZ8r%2fOK1dJ1OQ%3d%3d)

**GOAL 5 Advance Research**

**Recommendation 5B:** Increase participation in research.

**Strategy 2.** Collaborate with private, state and federal partners to increase participation of diverse populations in research studies.

## [Montana](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)

**7. Goals and Recommended Action Steps**

**Goal 11: Research**

Improve and grow dementia data collection efforts in Montana, expand Alzheimer’s disease and related dementias research opportunities in Montana and develop new research collaborations with organizations and institutions, and increase participation in research studies and clinical trials.

**Recommendations:**

**11-G.** Identify challenges to engaging participants in dementia research in Montana, including geographic, socio-economic, cultural, or other differences that may discourage participation and implement solutions that will increase participation.

## [New Mexico](https://nmaging.state.nm.us/uploads/files/Update%20Dementia%20Plan%20LAU-Tracy%20edits.pdf)

**State Dementia Plan Goals and Strategies Update**

**Goal Four: Expand Research Opportunities in New Mexico**

In order to address the need for research spanning all aspects of Alzheimer’s disease and related dementias, the two New Mexico-based national laboratories, the University of New Mexico, New Mexico State University, other educational and research-based entities, the NM Department of Health, the Alzheimer’s Association, New Mexico Chapter, and the NM Aging and Long-Term Services Department all work collaboratively to accomplish the following:

1. Study the incidence, impact, and other aspects of Alzheimer’s disease and related dementias in New Mexico with a focus on the underrepresented among New Mexico’s diverse rural, tribal and frontier populations.

## [North Dakota](https://ruralhealth.und.edu/assets/4702-20934/alzheimer-dementia-plan-nd.pdf)

**DIVERSITY, INCLUSION, AND CULTURAL CONSIDERATIONS**

**Collect and Use Data**

5. Support collection and use of local data on dementia and caregiving in Indigenous communities to plan programs and approaches.

6. Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to Indigenous communities with dementia.

## [Oklahoma](https://portal.alzimpact.org/uploads/media/state_plans/OK.pdf)

**Academic/Research Objectives**

**AR1 Objective:** Identify and fund research projects to be conducted in Oklahoma.

**Partners:** tribal nations interested in such research

**AR2 Objective:** Promote Oklahoma as a desirable location for hosting clinical trials

**Partners:** tribal nations

## [South Dakota](https://portal.alzimpact.org/uploads/media/state_plans/SD.pdf)

**Process for Preparing the State Plan**

**Objective 1: Formalize the South Dakota AD State Plan Work Group**

**Input 3 |** Secondary data collection and analysis: Secondary data provided an analysis of indicators for South Dakota, including population projections, social and economic factors, prevalence, health care workforce, and caregiving. An inventory of long-term care providers in South Dakota was included. Additional data sources were contributed to help frame the report. All data was housed in a database with the intent for it to be updated and used to support the state plan ongoing.

**Limitations:** The distribution strategy for the statewide needs assessment survey was intended to reach as many individuals who have a connection with AD as possible. The sample relied heavily on the distribution channels made available by work group members. Less than 2% of the 1,025 survey respondents reported being Native American or American Indian while the U.S. Census estimates 9% of South Dakota’s population was Native American in 2017. In an attempt to make findings more representative of the state’s demographics, an additional survey was designed to gather data from South Dakota’s American Indian population. This survey was intended to gather information and perspective on needs relating to the experience and care of PWD in South Dakota who identify as American Indian, either in an urban or tribal setting. It was sent out to work group member networks, organizations who work with the American Indian population, and tribal representatives. While criteria for survey respondents was articulated, only 11 of the 71 survey respondents reported being Native American or American Indian. The 11 respondents were somewhat to not familiar with what is available for AD care in South Dakota and identified the availability of services and resources as a pressing need. These limited findings were not admissible into the study’s findings. After consulting with those well-versed in tribal community study inclusion, it was determined that the timeline did not allow for a revised inclusion strategy prior to state plan publication. A more formalized approach will be pursued at a later date, after which findings will be published and an action plan will be developed.

## [Texas](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.)

**Priority Area 7: Importance of Data Collection and Evaluation**

**Goal**

Increase surveillance of Alzheimer’s disease, other dementias, and related issues, as well as the evaluation and sharing of effective programs.

**Actions**

**7.2** Collaborate with relevant agencies and organizations in a coordinated and systematic way to identify ongoing data needs, surveillance gaps, population trends, service needs for diverse populations, the capacity of the health care system, common data elements, uniform collection methods, and reporting formats for the range of priority areas for Alzheimer’s disease and other dementias.

**Priority Area 8: Advance Research and Collaboration**

**Goal**

Support ongoing research efforts, increase opportunities for collaboration among researchers, and share the results of Alzheimer’s disease research with the public.

**Actions**

**8.6** Collaborate with private, state, and federal partners to increase participation of diverse populations in research studies.

## [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

**Goal 7 - PROMOTE INNOVATION AND RESEARCH RELATED TO CAUSES OF AND EFFECTIVE INTERVENTIONS FOR DEMENTIA**

B. Develop relationships with key community stakeholders[[10]](#footnote-11) to assess and pilot culturally-specific/relevant service.

1. Identify organizations and institutions in WA involved in providing dementia related psychosocial and medical services, and connect them with AD research to promote research awareness and strategic alliances, and explore using as pilot sites.

**STATE SUPPORT OF ALZHEIMER’S RESEARCH**

**Training and Outreach**

* Reaches out to underserved groups in the Pacific Northwest, both African Americans and Native Americans, to provide opportunities to volunteer for research and to advance knowledge about Alzheimer’s in these diverse groups.

# Resources

## [Alaska](https://act.alz.org/site/DocServer/Alaska_State_plan_2015.pdf?docID=42541)

**Stakeholders10 + Potential Resources**

* Alaska Native Regional Health Corporations
* Alaska Native Tribal Health Consortium
* Cultural organizations active in local communities
* Tanana Chiefs Conference

## [Arizona](https://www.azdhs.gov/documents/prevention/tobacco-chronic-disease/healthy-aging/reports-statistics/az-alzheimers-plan-2015.pdf)

**APPENDIX**

**Glossary of Terms**

**Diversity and Inclusiveness**

The Arizona Alzheimer’s Task Force embraces a broad definition of diversity that relates to people, communities, networks and audiences. Culturally responsive care team members work to bridge the gap between their own sociocultural contexts and those of people they serve. Culturally responsive team members acknowledge the sociocultural context and its influence; actively listen to others’ perspectives; and respectfully communicate similarities and differences across contexts and perspectives to foster understanding and maximize the availability, accessibility, and acceptability of practice, programs, services, policies and research endeavors.

## [Montana](https://mtalzplan.org/wp-content/uploads/2022/09/Montana-Alzheimers-final-print-with-pics3.pdf)

**Appendices**

**Appendix C: Cultural Considerations in Residential Care Facilities**

**Intake Forms and Documentation—**Because the intake process and forms are often a first encounter for individuals and families, they can be powerful tools in creating a safe and affirming space.

In a safe and confidential space, make sure to ask the individual of their race and cultural preferences as well as sexual orientation and gender identity. If they prefer not to disclose, be respectful. In lieu of terminology such as “husband” or “wife,” use “partner,” “significant other,” and/or “domestic partner” in addition to the traditional “husband” and “wife.”

In lieu of terminology for gender restricted to “male” or “female,” also have a box/line dedicated to “they,” “FTM (female to male),” “MTF (male to female),” as well as a blank line for individuals to self-identity. Transgender and gender non-conforming clients should feel that their gender identity is respected. Ask a client’s gender pronoun and make sure to respect the response. Mis-gendering someone can have devastating impacts.

Modify the definition of “family” to extend to non-biological family and allows clients to assign who their family is. This could be a domestic partner, significant other, and/or friends who have been a significant support in their lives.

**Training—**Provide a welcoming and affirming environment by offering culturally competent training to employees to ensure respectful and dignified care is being delivered.

There are many resources available for training programs for specific populations such as lesbian, gay, bisexual, or transgender (LGBT).

**Facility Accommodations—**Policies and practices written into a facility’s by-laws can shape an individual’s sense of safety, and the overall care.

Establish a Non-Discrimination Policy within the facility that declares protections for individuals based on their sexual orientation, gender identity and gender expression, as well as race and other defining characteristics. This can extend to both employees and residents. This sets a precedent for quality care and reaffirms a safe space.

Consider allocating a “Cultural Liaison” to ensure policies are being followed and culturally-appropriate programs are offered. Consider a cultural support group for residents to come together and feel safe.

Specifically for LGBT residents, consider inclusive signage posted on the door/window to signify the facility is LGBT-inclusive and affirming.

Also, gender neutral restrooms for transgender and some gender non-conforming individuals, including the clients and family and friends who may be visiting them provides a safer and more welcoming accommodation.

Allow residents to dress and accessorize in accordance with their gender or race identity. Assess whether a transgender patient is using hormone replacement therapy, and ensure that staff is informed on how to administer it as needed.

Practices should be in place to ensure partners, friends, or family members in minority populations can visit without the fear of discrimination or mistreatment. Assure that all staff and caregivers understand the modified definition of family and understand that all are welcome to visit patients.

**Appendix H: Telehealth Availability Across Montana**

There are several telehealth/videoconferencing networks across Montana, including the Native American reservations. The telehealth networks could be used to improve dementia care in areas with particularly low numbers of health care providers specializing in dementia care. The networks could also be used as a means to provide educational topics on dementia care.

Each of the seven reservations in Montana has video conferencing capabilities, which can be used for telehealth visits. Some, although not all, of the reservations have telehealth equipment that allows checking vital signs, etc.

## [Texas](https://www.dshs.texas.gov/sites/default/files/alzheimers/pdf/Alzheimers-Disease-State-Plan-2019-2023.pdf#:~:text=The%20Texas%20State%20Plan%20for%20Alzheimer%E2%80%99s%20Disease%202019-2023,matter%20experts%2C%20and%20other%20national%20and%20state%20plans.)

**Appendix B. Diversity and Underserved Populations**

Person-centered care involves understanding an individual’s ethnic and cultural backgrounds. Learn about the different experiences of people with Alzheimer’s and other dementias.

**Some Examples:**

* People living in rural areas may not have access to diagnostic facilities, regular doctor visits, or care facilities.
* Lack of insurance or being underinsured may prevent people from seeking diagnosis and care.
* Learn about diversity and cultural awareness
* Learn about the needs and concerns of diverse populations to avoid making assumptions. Help diverse populations describe what they need and the barriers they encounter.
* Learn about the cultural norms and expectations of diverse populations and their attitudes toward health and the medical community.
* Recognize that diverse populations may have different points of view regarding working with health care providers, sharing personal information with others, and asking for help from community organizations.
* Address the stigma. Diverse populations may have different ways of accepting Alzheimer’s disease and other dementias and approaches to managing care.
* Recognize that access to services and compliance with care plans can be affected by such things as socioeconomic concerns, education and reading levels, language, family and work obligations, geographic location, and transportation.
* Diverse populations may be under-represented in research and clinical trials.
* Learn about the role of community health workers and promoters (community health workers in Spanish-speaking communities) and how they can promote education and the importance of getting a diagnosis.
* Learn the principles of writing about health topics in plain language and for lower-literacy audiences to make materials easy to read and understand.
* Learn from diverse populations.
* Conduct focus groups and use surveys.
* Collaborate with community and cultural leaders.
* Have diverse groups provide feedback on education materials and messaging.

**Appendix C. Dementia Friendly Communities**

* Make resources easier to understand and access.
* Recognize and accommodate the needs of diverse populations including culture, language, and economic background.

## [Washington](https://www.dshs.wa.gov/sites/default/files/legislative/documents/2016%20WA%20Alzheimer%27s%20State%20Plan%20-%20Full%20Report%20Final.pdf)

**INVENTORY APPENDIX: ADDITIONAL INFORMATION**

**Aging and Disability Network Services -** The National Aging Network (the Aging Network) was established in 1965 with the passage of the Older Americans Act and is one of the Nation’s largest provider networks of home and community-based care for older persons, adults with disabilities and their caregivers. The Administration on Aging, an agency in the U.S. Department of Health and Human Services, is a lead partner of the Aging Network which consists of 56 State Units on Aging, 629 Area Agencies on Aging, 246 Tribal organizations, 20,000 service providers, and thousands of volunteers.

**Area Agencies on Aging (AAAs) –** local organizations that develop and promote services and options to maximize independence for elders, adults with disabilities, and family caregivers. Washington has thirteen Area Agencies on Aging that are comprised of county governments, regional councils, and tribes. A citizen advisory council guides the work. The Washington Association of Area Agencies on Aging is a membership organization made up of the 13 Area Agencies on Aging in Washington State that seeks to enhance the effectiveness of each AAA through a strong agenda of information, debate, advocacy and education.

**DDC –** Washington State Developmental Disabilities Council. The mission of the Washington State Developmental Disabilities Council is to work collaboratively with people with developmental disabilities, families and guardians, service providers, advocates and policy makers to assure that individuals with developmental disabilities and their families have access to culturally competent, consumer/family-centered supports and other assistance that promote independence, productivity, integration and inclusion into the community of their choice; and to promote this vision in the public policy and planning arena through system change, community capacity building and advocacy at the local, state and national level.

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6. The term “stakeholder” has negative connotations for some tribes and tribal members. The preferred term is “interested groups”. National Library of Medicine. (2016). Banishing Stakeholders. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5020149/ [↑](#footnote-ref-7)
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