

HEALTHYBRAIN INITIATIVE

Road Map for Indian Country

alzheimer's 
association®





TABLE OF CONTENTS

- i Overview
- 1 Introduction to Alzheimer's and Other Dementias
- 6 The Challenge of Dementia in Indian Country
- 12 Opportunities for Public Health Strategies to Prepare Communities
- 15 Themes Shaping the Road Map
- 19 Opportunities for Community Action
- 23 Communities in Action
- 30 Conclusion
- 31 Acknowledgments
- 33 References

Suggested Citation

Alzheimer's Association and Centers for Disease Control and Prevention. *Healthy Brain Initiative, Road Map for Indian Country*. Chicago, IL: Alzheimer's Association; 2019.

Published: May 2019

Companion HBI Road Map for State and Local Public Health

This *Road Map for Indian Country* is tailored for leaders of American Indian/Alaska Native (AI/AN) communities as they develop a broad response to Alzheimer's and other dementias. A companion Road Map is available to serve public health leaders in state and local governments — the Healthy Brain Initiative's *State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*.





OVERVIEW

This landmark document — the Healthy Brain Initiative’s *Road Map for Indian Country* — is the first-ever public health guide focused on dementia in American Indian/Alaska Native (AI/AN) communities. It is intended as a tool for leaders of the 573 federally recognized Indian tribes, as well as state-recognized tribes, to engage their communities in addressing this important issue. These leaders include tribal officials, tribal health and aging services professionals, and regional tribal health organizational leaders. This Road Map may also be helpful to administrators in the Indian Health Service and state offices of health equity and minority health.

Development of the *Road Map for Indian Country* was supported by the Centers for Disease Control and Prevention (CDC), the Alzheimer’s Association, and other Healthy Brain Initiative (HBI) national partners. The Road Map can help tribal community leaders understand how dementia and associated caregiving is affecting their community and then consider what approaches, including public health strategies, make sense to pursue. The first four sections of the Road Map:

- » Explain Alzheimer’s disease and dementia, symptoms, and the value of early diagnosis and management;
- » Provide pertinent data on the challenge of dementia in Indian Country: the disease burden,

risk and protective factors, access to diagnosis, and caregiving;

- » Make the case for the role of public health in reducing the burden of dementia, and the value of partnerships to carry out that role effectively; and
- » Share themes from a deliberate process to seek input from stakeholders and experts on addressing dementia in AI/AN communities. These themes describe current knowledge and awareness of dementia and set a context for planning and programmatic guidance.

This Road Map offers eight public health strategies for AI/AN leaders to consider as part of a broad response to dementia. These strategies are based on input from experts, practitioners, tribal health directors, and leaders in Indian Country. They are intentionally flexible, designed to be adapted to a wide array of local priorities. Tailoring and innovation by AI/AN communities is expected and strongly encouraged. ●

This Road Map highlights examples of Native leaders and community partners leveraging local strengths and resources within their tribal communities to address dementia in Indian Country. These examples are by no means a complete picture of the activity currently underway or in planning stages. As more AI/AN communities embrace the challenges of addressing dementia, the collective body of experience will grow and become enriched with lessons learned.



PUBLIC HEALTH STRATEGIES TO CARE FOR AN AGING POPULATION

The Healthy Brain Initiative's *Road Map for Indian Country* is tailored for leaders of American Indian/ Alaska Native (AI/AN) communities as they **develop a broad response to Alzheimer's and other dementias**. The following **eight public health strategies** can inform and shape that response. Tribal leaders are encouraged to discuss these strategies with their community and involve members in planning and implementing these community-wide approaches. See Opportunities for Community Action (page 19) for more information about each of these strategies.

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

5. Support collection and use of local data on dementia and caregiving in AI/AN 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 AI/ANs with dementia.

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.



BACKGROUND ON ROAD MAP DEVELOPMENT

The Healthy Brain Initiative (HBI) is a partnership created by CDC and the Alzheimer’s Association that has been guided by a series of three “Road Maps” for the public health community. These Road Maps outline how public health agencies can help prepare communities for the fast-growing challenges of Alzheimer’s and other dementias.

Early in the development of the third Road Map (2018–2023), the HBI Leadership Committee recommended a separate, parallel document that would focus specifically on American Indian/Alaska Native (AI/AN) communities. AI/AN tribal nations understand their communities, heritage, strengths, and systems of care. Strategies that work for state and local public health agencies likely would need to be tailored by AI/AN communities to their cultures and unique contexts. Further, national, state, and local public health organizations could learn from innovations emerging from Indian Country.

For these reasons, the Alzheimer’s Association, CDC, and International Association for Indigenous Aging (IA²) began the process of developing this *Road Map for Indian Country* by listening to regional tribal health boards, tribal aging services leaders, and tribal government officials. Through these discussions came common themes, including:

- » AI/AN health leaders and tribal leaders are concerned about the growing problem of dementia. This health condition has a heavy impact on families and communities.
- » Tribal communities look internally to understand and solve problems. On many issues, leaders first and foremost seek information and help from their members.
- » Great strengths in the culture and traditions of Indian Country offer unique opportunities to improve the lives of older adults living with dementia and their families. AI/AN communities have a strong commitment to caring for elders.
- » Aging services and health systems serving AI/AN communities have begun to address dementia, in spite of resource constraints.

These themes set the foundation for the Healthy Brain Initiative’s *Road Map for Indian Country*. It can be used to support dialogue within a community about how to promote wellness across the lifespan and best support older adults with dementia, their families, and caregivers. The eight strategies in this Road Map are designed to be part of a broad response to dementia in AI/AN communities. ●



GLOSSARY

Alzheimer's disease: an irreversible, progressive brain disorder that slowly destroys memory and thinking, and eventually, the ability to carry out the simplest tasks. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks. A person may have Alzheimer's for many years before symptoms appear.

Alzheimer's dementia: the point in the Alzheimer's disease continuum when a person has dementia.

Brain health: a concept that involves making the most of the brain's capacity and helping to reduce some risks to the brain that occur with aging. Brain health refers to the ability to draw on the strengths of the brain to remember, learn, play, concentrate, and maintain a clear, active mind.

Caregiver: a spouse, partner, adult child, other relative, or friend providing unpaid help to a person living with dementia who has a difficulty with activities of daily living. Caregivers often assist with personal care or managing household chores, finances, medication, and healthcare.

Cognition: the functioning involved in attention, thinking, understanding, learning, remembering, solving problems, and making decisions. Cognition is essential to a person's ability to participate in activities, accomplish goals, solve problems, and engage fully with the world around her or him.

Cognitive assessment: the process when a healthcare provider tests for possible cognitive impairment, including dementia. Cognitive assessments may be conducted after a healthcare provider observes a possible symptom, the patient mentions having memory problems, or caregivers and family members share a concern. The Medicare Annual Wellness Visit requires healthcare providers to conduct a cognitive assessment.

Cognitive impairment: trouble remembering information, learning new things, concentrating, or making decisions that affect everyday life.

Dementia: the loss of cognitive functioning that is severe enough that it interferes with a person's daily life and activities. Cognitive functioning can include thinking, remembering, and reasoning. Alzheimer's disease is the most common cause of dementia. Other types include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.

Mild cognitive impairment: a small but measurable decline in cognition, including memory and thinking. A person with mild cognitive impairment is at an increased risk of later developing Alzheimer's or another cause of dementia.

Subjective cognitive decline: self-reported confusion or memory loss that is happening more often or is getting worse. •



INTRODUCTION TO ALZHEIMER'S AND OTHER DEMENTIAS



Dementia is a chronic condition that affects a person's brain. People with dementia experience a variety of symptoms related to their loss of brain (or cognitive) function. Contrary to what was once believed, dementia is **not** part of normal aging. In fact, Alzheimer's dementia affects about 200,000 people in their 40s and 50s; this is referred to as early-onset or younger-onset Alzheimer's.¹

Alzheimer's disease is the most common cause of dementia.¹ The course of Alzheimer's and other dementias should be viewed as part of a continuum of cognitive health and function that spans an entire lifetime (see Figure 1). The continuum begins at birth with **healthy cognitive functioning**.

For some people, over a span of many years, physiological changes occur in the brain that do not result in any noticeable symptoms. This **pre-symptomatic stage** can eventually lead to **mild cognitive impairment**, which is when difficulties in memory or thinking become noticeable to people affected and family, colleagues, and friends. A portion of people with mild cognitive impairment eventually develop dementia, but not every person will.

The **dementia** stage is when a person's difficulties with memory, language, problem-solving and other cognitive skills now affect her or his ability to perform everyday activities. Many dementias are progressive, meaning that symptoms start out slowly and gradually get worse. With Alzheimer's disease, dementia is the point during the disease process when cognitive difficulties interfere with daily life and activities.

Types of Dementia

Alzheimer's accounts for a majority (60–80%) of dementia cases.¹ Alzheimer's disease progressively damages and eventually destroys brain cells.

Vascular dementia is the second most common cause of dementia. Initial symptoms are impaired judgment or ability to make decisions, plan, or organize (in contrast to the memory loss often associated with Alzheimer's). Other typical symptoms include difficulty with motor function, especially slow gait and poor balance. Vascular dementia is caused by conditions or lifestyle behaviors that weaken or block blood flow to the brain, depriving brain cells of vital oxygen and nutrients. Depression commonly coexists with vascular dementia and can contribute to cognitive symptoms.

Other types of dementia include **dementia with Lewy bodies** and **frontotemporal dementia**.

More detail can be found at: alzheimers.gov

In the **early stage of dementia**, people may function independently, still drive, work, and be part of social activities. Despite this, they may notice memory lapses, such as forgetting familiar words or the location of everyday objects.

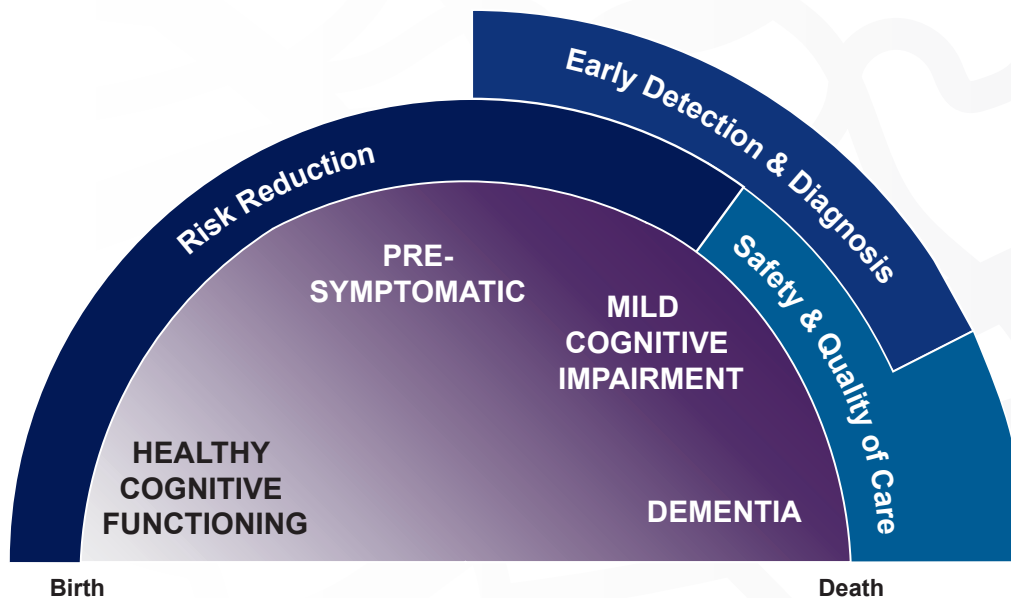
In the **moderate stage**, people may have greater difficulty performing tasks such as paying bills, but they may still remember significant details about their life. As this stage evolves, people may have more trouble communicating and experience mood or behavior changes. They may also have trouble with activities of daily living such as managing medications, dressing, and bathing. They may start to need help from family members or other caregivers.

In the **severe stage** of Alzheimer's, people lose the ability to respond to their environment, have a conversation and, eventually, control movement. They may become bed-bound and require around-the-clock care.

People with Alzheimer's and other dementias do not move through stages consistently or at the same rate. Each person's path along the disease continuum is unique. For example:

- » Not all people with brain changes will progress to dementia. Although a person with mild cognitive impairment is at greater risk of developing dementia, this does not always happen.
- » Some people with Alzheimer's may remain in the moderate stage for many years. On average, a person with Alzheimer's lives four to eight years after diagnosis; some can live as long as 20 years, depending on other health factors.¹

Figure 1: Dementia Life-Course for At-Risk Populations and the Public Health Role²



This illustration provides a life-course view for people who may eventually develop dementia. The semi-circle in purple shows different stages of cognitive functioning from birth to death — beginning with healthy cognition and moving through the pre-symptomatic and mild cognitive impairment stages, and then to dementia. The blue segments show the three major opportunities for public health interventions across the life-course consistent with the stage of cognitive functioning: 1) reduce risk of cognitive decline or progressing to other stages, 2) encourage early detection and diagnosis of cognitive impairment and dementia, and 3) ensure quality of care for and safety of people affected by cognitive impairment and dementia. These essential public health strategies help reduce burden, improve health outcomes, and promote health and well-being throughout the continuum. It is important to note that most older adults do not develop mild cognitive impairment or dementia.

BENEFITS OF EARLY DIAGNOSIS

Early diagnosis is key to a better life path for the older adult affected by dementia. It can help them and their families:

- » Determine if the symptoms are truly due to dementia or some other — perhaps treatable — condition;
- » Have access to available treatments and interventions for symptoms, including potential participation in clinical trials;
- » Build a care team of family, community members, and healthcare and social service providers;
- » Better manage other chronic health conditions;
- » Participate in support services;
- » Plan for future health, financial, and legal needs and end-of-life choices.¹

The earlier in the continuum that a person is diagnosed with dementia, the sooner action can be taken to support him or her. For a small group of people with dementia symptoms, further testing may reveal reversible or treatable causes rather than Alzheimer's disease. Examples of these causes are: depression, obstructive sleep apnea, or vitamin B12 deficiency. In these cases, early diagnosis can lead to treatment and improved cognition and quality of life.

For many others with Alzheimer's and other dementias whose symptoms are not reversible, early diagnosis can help preserve their existing cognitive functioning

for as long as possible. This can be done by managing chronic health conditions and making healthy lifestyle changes to control blood pressure, quit smoking, and promote physical activity. Additionally, early diagnosis lets people make plans for the future, including designating someone to make healthcare decisions, such as a healthcare proxy, for them when they are unable to do so. They can also focus more on spending time with family, friends, and community activities that are meaningful.

As breakthroughs in research happen, early diagnoses may enable people to access effective treatments or cures, even before symptoms appear. ●





10 WARNING SIGNS OF ALZHEIMER'S

Memory often changes as people grow older. Some people notice changes in themselves before anyone else does. For other people, friends and family are the first to see changes in memory, behavior, or abilities. Memory loss that disrupts daily life is not a typical part of aging. People with one or more of these 10 warning signs should see a doctor to find the cause. Early diagnosis gives them a chance to seek treatment and plan for the future.

- 1. Memory loss that disrupts daily life:** forgetting events, repeating yourself or relying on more aids to help you remember (like sticky notes or reminders).
- 2. Challenges in planning or solving problems:** having trouble paying bills or cooking recipes you have used for years.
- 3. Difficulty completing familiar tasks at home, at work, or at leisure:** having problems with cooking, driving places, using a cell phone, or shopping.
- 4. Confusion with time or place:** having trouble understanding an event that is happening later, or losing track of dates.
- 5. Trouble understanding visual images and spatial relations:** having more difficulty with balance or judging distance, tripping over things at home, or spilling or dropping things more often.
- 6. New problems with words in speaking or writing:** having trouble following or joining a conversation or struggling to find a word you are looking for (saying “that thing on your wrist that tells time” instead of “watch”).
- 7. Misplacing things and losing the ability to retrace steps:** placing car keys in the washer or dryer or not being able to retrace steps to find something.
- 8. Decreased or poor judgment:** being a victim of a scam, not managing money well, paying less attention to hygiene, or having trouble taking care of a pet.
- 9. Withdrawal from work or social activities:** not wanting to go to church or other activities as you usually do, not being able to follow football games or keep up with what’s happening.
- 10. Changes in mood and personality:** getting easily upset in common situations or being fearful or suspicious.



THE CHALLENGE OF DEMENTIA IN INDIAN COUNTRY



Addressing dementia in Indian Country begins with a closer look at the specific challenges for AI/AN communities: the burden of disease, risk factors⁰ and protective factors, access to diagnosis, and caregiving. Each of these is explored below from a public health (or population-level) lens.

DEMOGRAPHIC TRENDS

The AI/AN population in the U.S. is growing rapidly.

More than 5.2 million people in the U.S. identify as either American Indian or Alaska Native. From 2000 to 2010, the AI/AN population grew 27%, increasing nearly three times faster than the total U.S. population.^{3,4}

American Indians and Alaska Natives are living longer.

An AI/AN child born in 2010 can expect to live 73.7 years. This is nearly 30 years longer than an AI/AN child born in 1969. See Figure 2.^{5,6,7}

The number of older adults is increasing. An estimated 569,000 AI/ANs are 65 years or older.⁸ This number is expected to triple over the next three decades. The oldest cohort of adults, ages 85 and older, is projected to increase more than seven-fold by 2050.⁴

Having a larger set of older tribal members is considered a blessing. AI/AN culture has long valued elders for their wisdom, experience, knowledge, and contributions to their communities. Older AI/ANs offer a bridge to the past as keepers of language, history, and traditions. They play a highly revered role in their families and in the tribal community.

BURDEN OF DISEASE

Because dementia is more common with advanced age, as the AI/AN older adult population grows, so too will the impact of cognitive impairment. **Between 2014–2060, the number of AI/ANs aged 65 and older living with dementia is projected to grow over five times.**⁹ Consequently, the impact of an increased number of older adults living with dementia extends well beyond those older adults and affects the vitality of the whole community.

Difficulties with thinking or memory — before they disrupt daily life and activities — are often one of the earliest signs of Alzheimer’s or another dementia. In 2015–2017, one in six AI/ANs aged 45 and older reported subjective cognitive decline (SCD) — that is, self-reported difficulties in memory or thinking.

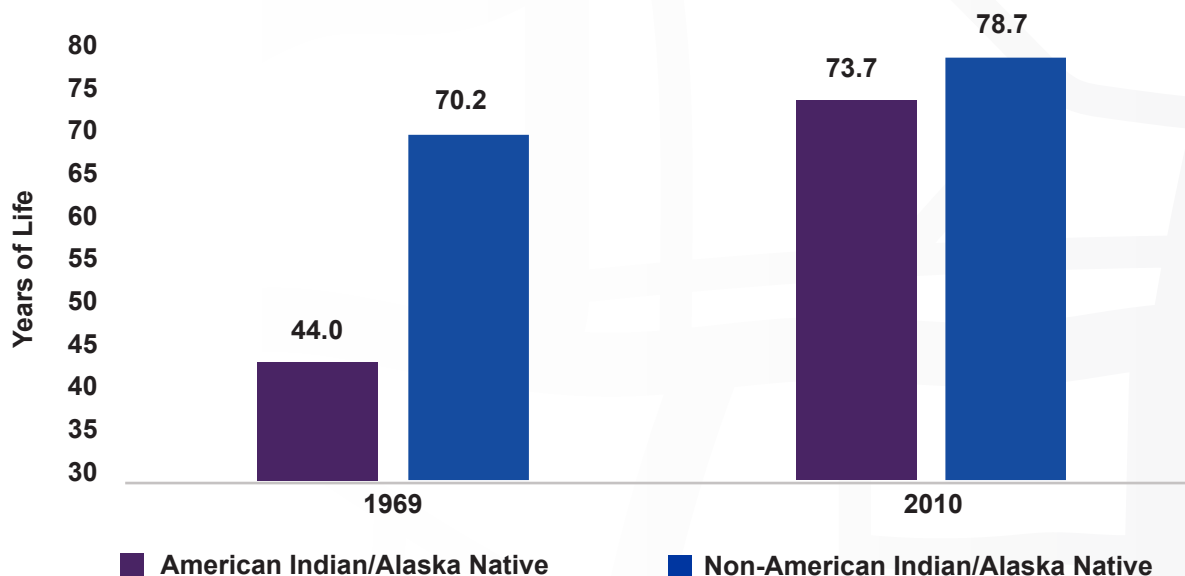
Nearly two-thirds of those with SCD had to give up some day-to-day activities because of these cognitive problems.¹⁰

RISK AND PROTECTIVE FACTORS

While the cause of Alzheimer’s remains largely unknown, there is growing evidence that it may develop as a result of multiple factors over many decades. Some of these factors cannot be changed, including advancing age, family history, and risk genes.

However, **other risk factors can be modified and offer a golden opportunity to change the path of the dementia and keep people healthy longer.**^{11,12,13,14}

Figure 2: Life Expectancy Among American Indians and Alaska Natives, 1969-2010^{5,6,7}



Between 1969 and 2010, life expectancy for American Indian and Alaska Native individuals increased nearly 30 years.

Dementia Incidence in Indian Country

Only a few studies have examined the burden of Alzheimer's and other dementias in the American Indian community. In one study, researchers used 14 years of data from a large Northern California health plan to examine dementia incidence, people who received a new diagnosis of dementia per year, among different racial and ethnic groups. The study found that American Indian members of the health plan had a somewhat higher incidence rate of diagnosed dementia than white plan-members (22.2/1,000 person-years vs. 19.3/1,000 person-years). Based on 14 years of these data, researchers estimate that one in three AI older adults (65 and older) will receive a dementia diagnosis over the next 25 years.¹⁵

Modifiable risk factors for dementia include:

- » Diabetes;
- » High blood pressure;
- » Smoking;
- » Mid-life obesity; and
- » Traumatic brain injuries.

Many of these risk factors are prevalent in AI/AN communities and may result in elevated risks for poor brain health later in life and possibly dementia. AI/ANs have high rates of diabetes, high blood pressure, and heart disease compared to other populations.¹⁶ These

three conditions are the most frequent co-occurring chronic conditions among persons living with Alzheimer's or another dementia.¹ Most experts agree that the higher burden of Alzheimer's in AI/AN communities is not due to any unique genetic predisposition.

- » AI/AN adults are more than twice as likely (2.4 times) to be diagnosed with **diabetes** as non-Hispanic white adults.¹⁷ AI/AN women also are almost twice as likely to die from diabetes as non-Hispanic white women.¹⁷
- » AI/ANs are more likely to be diagnosed with **heart disease** than their white counterparts. Three contributing risk factors for heart disease are more common among AI/AN adults than white adults: **obesity, high blood pressure (30% more likely), and current cigarette smoking (20% more likely).**^{18,19}
- » AI/ANs have the highest prevalence of **cigarette smoking** of all racial/ethnic groups in the United States.²⁰ While the percentage of adults who smoke decreases with age, one in three AI/ANs in their 50s and one in four in their 60s still smoke cigarettes.¹⁰
- » **Mid-life obesity** affects more than one of every three AI/AN adults aged 50 and older.¹⁰
- » AI/ANs have the highest **traumatic brain injury (TBI)** hospitalization rate for all minority groups in the United States. When compared to other populations, TBI death rates are greatest among AI/ANs at any age.²¹

- » Two of every three AI/AN older adults do not engage in even monthly **physical activity**.¹⁰ through focused attention is being given to improving physical activity levels.²² Effective programs rely on such interventions as Tai Chi, walking, yoga, water aerobics, falls prevention, and strength and balance training.²³

While excessive alcohol use over many years can lead to high blood pressure, heart disease, stroke, and other serious problems — and is associated with learning and memory problems including dementia — AI/AN individuals do not consume alcohol more than other groups. In fact, AI/ANs had comparable or lower consumption levels when compared with whites.^{24,25}

Brain health is closely connected to overall physical health and healthy aging. What is good for overall healthy aging may also help keep the brain healthy. There is growing scientific evidence that healthy behaviors — those shown to prevent cancer, diabetes, and cardiovascular disease — may reduce risk for cognitive decline and possibly dementia.^{11,12,13,14}

These “protective factors” include **eating a healthy diet, exercising the body and the mind, staying socially engaged and active, limiting tobacco to ceremonial use, and avoiding secondhand smoke and excess alcohol.**

In addition, **cultural and traditional teachings and practices** build strength and resilience for AI/AN tribes and communities.²⁶ They can help elders retain their valuable knowledge, wisdom, and energy. High levels of social engagement with family and community, which are values deeply embedded in AI/AN traditions, are also associated with reduced risk of cognitive decline.¹

Another protective factor worthy of note is formal education — having more years of **formal education** reduces the risk of cognitive decline and dementia. However, AI/ANs are less likely to have completed high school or attained a college degree than the non-AI/AN population.^{1,4}

ACCESS TO DIAGNOSIS

A substantial portion of people who would meet the diagnostic criteria for Alzheimer’s and other dementias are not diagnosed by a physician. Only one in three (31%) AI/ANs aged 65 and older who experience memory loss have talked with their healthcare provider about it.¹⁰ Less than half of people with dementia in all populations nationwide have been diagnosed.¹ In the absence of specific data for Indian Country, there is no reason to expect that low diagnosis rates are any different for AI/ANs.

Furthermore, fewer than half of Medicare beneficiaries who have a diagnosis of Alzheimer’s or another dementia in their Medicare records report being told of the diagnosis (or have such a report from their caregiver, if the beneficiary could not respond).¹ Because Alzheimer’s dementia is underdiagnosed and underreported, a large portion of Americans with Alzheimer’s may not know they have it.¹

In Indian Country, geographical, economic, and cultural barriers can reduce access to timely, quality care including services to detect, diagnose, and manage dementia. Older AI/AN adults (aged 65 and older) are more likely to have difficulty accessing healthcare than their peers of the same age in the non-AI/AN U.S. population. They may not have easy access to transportation or have to travel long

distances to healthcare facilities. For some older AI/ANs, the cost of healthcare and prescriptions may be unaffordable. A large majority of AI/ANs aged 65 and older have Medicare coverage, yet an unknown portion may qualify for, but not be enrolled in, programs such as Medicaid or Medicare Savings Programs.²⁷ Providers may be unsure which cognitive assessments are best to use with AI/AN patients.²⁸ Also, available healthcare providers may not speak native languages, be aware of traditions, or address older adults respectfully and in a culturally-sensitive way.

CAREGIVING

Many people living with dementia may need substantial help and caregiving from their family, tribe, and community as Alzheimer's and other dementias progress. This support can become increasingly time-intensive and complex. While caring for an older adult with dementia can have rewarding aspects and help bring families closer, multiple years of looking after all of a person's needs can be challenging. It can also put the caregiver's health at risk.

Dementia caregiving in Indian Country is uniquely challenging for several reasons.

- » **Caregiving is a frequent reality;** one survey of about 5,200 AI adults living in the Northern Plains and in the Southwest found that almost one in five of these adults (17%) cared for other adults.²⁹
- » **AI/ANs are more likely than other populations to live in multi-generational families and raise grandchildren.**²⁹ More AI/ANs aged 50 and older reside in households with three or more

generations than the non-AI/AN population (10% compared with 6.5%). Nearly half of AI/ANs aged 50 and older who have grandchildren in the household are responsible for most of those children's basic needs.²⁹

- » **Proximity to family and caregiving services differs for those living on tribal land, rural reservations, and urban areas.** More than half (56%) of AI/ANs aged 50 and older do not live on tribal land. This may complicate access to culturally-relevant services and supports. It may also mean that family caregivers do not live near their parents, grandparents, and other older relatives. In fact, younger AI/ANs are more likely to reside in urban than rural areas.²⁹

Access to information and formal support services can help caregivers and the older adults they serve in many ways: communicating with the person with dementia, managing other co-existing conditions, and planning for future needs. Availability of these services is an ongoing challenge. Rural tribal communities often face similar obstacles providing supportive programs and services as other communities in rural America: lack of access to healthcare, particularly specialized care; lack of awareness of Alzheimer's in general; lack of high speed internet; and geographic/transportation barriers. In addition, a growing number of AI/ANs live beyond rural reservations and tribal lands, with a majority now settled in urban and metropolitan areas across the nation. For those living beyond tribal lands, culturally-relevant services and supports may not be as readily available. ●



PUBLIC HEALTH PROGRAMS AND RESOURCES TO IMPROVE HEALTH AND WELL-BEING

Several public health efforts are aimed at improving the health and well-being of AI/AN communities. AI/AN leaders can use these efforts to anchor and incorporate into their broad response to Alzheimer's and other dementias.

- » The **Special Diabetes Program for Indians (SDPI)** aims to diagnose, control, and prevent diabetes. Established in 1997, this \$150 million annual grant program provides funds for diabetes treatment and prevention to Indian health programs across the country. It is coordinated by the Indian Health Service (IHS) Division of Diabetes with guidance from the Tribal Leaders Diabetes Committee.
- » Culturally- tailored smoking cessation programs show promise in increasing smoking abstinence. **All Nations Breath of Life (ANBL)** for American Indians is one such program. It has been successful in recruiting, engaging, and retaining American Indian smokers in a randomized controlled trial of smoking cessation.³⁰
- » CDC's largest investment to improve health among AI/ANs is the **Good Health and Wellness in Indian Country (GHWIC)** program. This \$78 million initiative supports prevention activities for heart disease, stroke, diabetes, smoking, nutrition, physical activity, and obesity. The program's prevention activities have expanded to reach over 130 tribes and urban clinics.³¹ Federal funds are also used to support
- 12 **Tribal Epidemiology Centers (TECs)** across the U.S. and one Network Coordinating Center. Their mission is to improve delivery of public health functions to tribes and villages in their region.³¹
- » **Tribal Practices for Wellness in Indian Country** is a three-year, \$15 million program launched by CDC in 2018. Its goal is to strengthen cultural practices and traditions that build resilience and connections to community, family, and culture. Over time, these can reduce risk factors for dementia and many other chronic diseases. The program funds 21 tribes and 14 urban Indian organizations.³²
- » To emphasize the connection between **heart health** and brain health, the Association of State and Territorial Health Officials (ASTHO) and the International Association of Indigenous Aging (IA²), with support from CDC, jointly produced a series of HBI communication materials tailored for Indian Country. These products include radio PSAs, news articles, posters, and fliers intended for community-wide distribution as well as videos that can be shown in clinic settings, and a guide for healthcare providers with culturally-appropriate messaging.³³



OPPORTUNITIES FOR PUBLIC HEALTH STRATEGIES TO PREPARE COMMUNITIES



The public health field seeks to achieve lasting positive change in the health of entire communities. Public health relies on effective partnerships at many levels to achieve meaningful outcomes. Its strategies extend beyond medical treatment of individuals to reach many people at a time using systems and comprehensive approaches. At the core of these partnerships in Indian Country are tribal elected officials, tribal health and aging services professionals, regional tribal health organizational leaders, and administrative leaders in the Indian Health Service (IHS). State public health can also be considered partners in supporting tribal-serving organizations and AI/AN communities. Some of these agencies have a state-tribal liaison housed within the health department to support connections between state public health resources and AI/AN communities.

For any health condition, public health plays a unique and critical role in reducing risk factors for illnesses and injuries, improving early detection and diagnosis, and ensuring safety and quality of care (see Figure 1).² This approach also applies to dementia.

The HBI *Road Map for Indian Country* can be used to engage AI/AN leaders, tribal members, and their partners in a collaborative discussion on the effects of Alzheimer's and other dementias in their communities. With a common understanding, communities can then begin to plan public health strategies to meet the needs of older adults affected by dementia and their caregivers.

Healthy Brain Initiative partners have adapted four public health strategies from other chronic conditions to address Alzheimer's and other dementias.

- » Promoting healthy living to reduce risk of cognitive decline;
- » Encouraging early detection and diagnosis of cognitive impairment and dementia;
- » Ensuring the safety of older adults living with dementia; and
- » Supporting caregivers and improving the quality of care for all people impacted by dementia in their communities.

The underlying values of these public health approaches — promoting wellness and providing care in the community for aging members — are mirrored in the long-standing cultural values and spirit of AI/AN tradition. AI/AN communities already have experience applying public health strategies to diabetes, high blood pressure, and other chronic diseases. These efforts can be leveraged to promote cognitive health as community members reach mid-life and transition into older years.

The IHS is the principal federal healthcare provider for AI/AN people. The agency serves approximately 2.2 million people belonging to 573 federally recognized Indian tribes.³⁵ IHS provides and funds healthcare services through a variety of facilities operated either by IHS itself, tribal entities, or urban Indian health providers (I/T/U).

Primary healthcare service providers who work in the I/T/U systems are a key part of the public health landscape for addressing dementia in Indian Country.³⁴ I/T/U systems are:

- » **Indian Health Service Providers (I).** The majority of IHS facilities serve rural areas typically on or near reservations.
- » **Tribal Health Providers (T).** Under contract with IHS, tribes and tribal organizations operate roughly half of the I/T/U system. Increasingly, tribes are operating these health programs and services.
- » **Urban Indian Health Providers (U).** These providers currently consist of 40 nonprofit programs nationwide, funded through grants and contracts from the IHS.

Leaders in I/T/U work side-by-side with health professionals in other parts of the community. Together, they represent a strong opportunity to pursue potential public health strategies and cultivate action. One such opportunity exists for collaboration between Medicare, Medicaid, the Veterans Health Administration, and IHS to enhance access to care for AI/ANs. Recent initiatives to better coordinate care across these systems is a public health approach that could lead to improved wellness for AI/ANs living with dementia. ●



STARTING THE CONVERSATION: IDEAS FOR INITIAL DISCUSSIONS ABOUT ALZHEIMER'S

Listening and learning are the first steps toward developing a broad response to Alzheimer's and other dementias. The Healthy Brain Initiative's *Road Map for Indian Country* encourages AI/AN leaders to start a conversation within their communities about how dementia affects all generations — individuals living with dementia, their families, other community members who help provide care, and even future generations who may lose cultural traditions or heritage to memory loss associated with Alzheimer's.

An initial community gathering to discuss dementia could begin with an invocation drawing on the community's traditions, such as a prayer or performance of a tribal song. The person leading the discussion may then acknowledge Elders and thank hosts for the space and refreshments. After sharing a personal story about journeying with a loved one who has dementia, the leader could explain the goals of the gathering.

The discussion leader asks the community questions, such as:

- » Without identifying individuals, how have persons living with dementia fared in our community?
- » What kinds of people and groups in our community are helping people living with dementia with day-to-day living or getting places? How are these caregivers faring?
- » Do we have traditions about keeping ourselves healthy that include keeping strong our memories, ability to learn, and make decisions?
- » Do our diabetes or heart disease efforts help us learn about dementia and the brain?
- » What kinds of information or training would help family and friends better support our older adults who need care?
- » How could professionals who serve our community (like our doctors, senior centers, van drivers and first responders) better support our older adults who need care?
- » What groups in our community or in nearby communities could help us promote wellness across the lifespan, support caregivers, and enhance the safety and well-being of older adults with dementia?
- » What might we do as a next step? By whom and by when?



THEMES SHAPING THE ROAD MAP



This *Road Map for Indian Country* began by listening to a range of thought leaders in tribal health. The process was jointly sponsored by the Alzheimer's Association, CDC, and IA².

Representatives of Indian Country (including tribal health directors, regional tribal health boards, tribal aging services leaders, and tribal government officials) participated in two national webinars to share their perspectives on:

- » Familiarity with the Healthy Brain Initiative and its series of Road Maps;
- » The impact of Alzheimer's and dementia within their tribes;
- » Ways to address Alzheimer's and cognitive health in Indian Country; and
- » Potential uses for the new Road Map.

Tribal health directors and tribal Title VI (AI/AN-specific services supported by the Older Americans Act) directors participated in other discussions on similar topics, and additional tribal leaders and health experts offered further commentaries.

A focused literature search and outreach to key opinion and research leaders supplemented the expert insights.

COMMON THEMES

Insights from leaders, experts, and the literature were synthesized into two themes. One theme relates to knowledge and awareness of Alzheimer's and other dementias among AI/ANs. Another addresses planning and programmatic guidance to any group trying to address dementia.

Knowledge and Awareness

Gaps in knowledge or awareness about dementia, cognitive health, and caregiving exist throughout the U.S. in all communities. These gaps may be exacerbated in Indian Country because, until recently, national and state level outreach and education to AI/AN communities was patchy and inconsistent. Few leaders in Indian Country, for example, have seen or used the public health HBI Road Maps.

Alzheimer's disease and related cognitive health issues are viewed as serious, growing problems in AI/AN communities. Many leaders felt that Alzheimer's disease and dementia-related issues, including caregiving, are major growing and emerging issues in their tribe or community. They conveyed concern, however, about their own limited knowledge about dementia and the lack of awareness among tribal members.

Healthcare and service providers for tribal members could benefit from more culturally-competent education about dementia and cognitive health. Providers lack knowledge about

Survey Shows Energy on Taking Action

A survey of 327 AI/AN community members (58% female, 43% rural) was conducted at powwows in spring and summer 2016, using the Alzheimer's Disease Knowledge Scale. The survey found that 77% of respondents had heard of Alzheimer's, and 37% had an immediate family member with trouble thinking or memory loss. If personally diagnosed, 61% would agree or strongly agree to donate a blood sample to help researchers find causes and treatments for the condition. This willingness signals energy in the AI/AN community to act on Alzheimer's.³⁶

dementia and caregiving issues, including information on the prevalence of dementia and the importance of early diagnosis. Also, turnover among healthcare professionals can complicate discussions about memory and the process of getting a diagnosis.

AI/AN communities' unique social and cultural attributes may inhibit family caregivers from acknowledging dementia and being willing to seek education or help. Living in rural or frontier areas may foster smaller and close-knit communities. If Alzheimer's is viewed as potentially embarrassing or shameful, family caregivers may be reluctant to seek a diagnosis for parents or other relatives because of fear, denial, or stigma for seeking assistance outside of the family network. Care may not be sought until dementia becomes a crisis.

The stigma of Alzheimer's may also prevent families from seeking services to protect the person with dementia from perceived shame. Family members may lack the time to devote to caregiving, learn about dementia, or look after their own personal health, as well as the needs of children and jobs.

Cultural issues include language considerations and the need to talk about health issues in plain English, or the person's native language, depending on the situation. In Indian Country, a heightened need exists for providers to establish personal connections and trust.

Few tribes and tribal communities are currently addressing dementia as a health planning issue. Many leaders did not know if data about dementia and caregiving were available to them.

For individual tribal members who are aware of Alzheimer's disease, few tribal or other programs offer dementia caregiving education and assistance. One community leader described a volunteer-led local dementia caregiver support group as an example of finding ways to generate solutions from within.

Leaders described AI/AN families as "embracing a 'we take care of our own' philosophy," which discourages use of other available care options. Other barriers may include low levels of educational attainment and health literacy as well as mistrust of the healthcare system.

Planning and Programmatic Guidance

AI/AN leaders also provided planning and programmatic guidance during discussions that helped inform the development of this Road Map. Building

Cultural Stories about Dementia May Impede Understanding

Memory loss, especially when it disrupts everyday life, is **not** a normal part of aging. However, long-held cultural stories may approach Alzheimer's, dementia, and cognitive impairment as something to be expected with older adults, such as in the examples below.

- » A normal/natural condition, a part of the life cycle.
- » A part of the circle of life, or a person has come "full circle."
- » A time of a "second childhood," and a time one is closer to the Creator.
- » A time "out of harmony" due to unresolved grief, historical trauma, cultural disconnect, changes to the environment, or other factors.

Although these descriptions emphasize important cultural values of holistic wellness, the circle of life, and harmony, they may lead families to avoid seeking care when difficulties with memory or thinking become noticeable.

the response to dementia in Indian Country will need involvement from many individuals and organizations, such as clinicians, members of the community, tribal leaders, as well as external groups like state governments, local home- and community-based service providers, the Alzheimer's Association, and CDC. The guidance can help these collaborations set a foundation to reach their goals.

Language and culture are specific to each tribe, yet most materials about dementia and caregiving are in English and frequently written to college literacy levels. Resources are needed to tailor materials to various cultures and languages.

Awareness of and adherence to specific tribal protocols and values may be more important than fluency in the community's native language. If possible, technical jargon should be avoided or carefully explained. Conversations, meetings, and training should emphasize respect for elders. Because cultural protocols differ among tribes, participation of a cultural interpreter or a tribal historian — not just a translator — can be very important in conversations among older adults, families, and communities.

Education, health services, and other community interventions should both be initiated and sustained with tribal leadership and tribal health departments. The path to success relies on involved tribal leaders.

It was acknowledged that tribal health leadership may not be trained in cognitive health. Training for professionals and volunteers who serve older adults may need to precede broader public education initiatives. This would be particularly valuable for

Title VI providers that support delivery of home- and community-based supportive services for older adults, including nutrition services and support for family and unpaid caregivers.

Support for people living with dementia and their caregivers needs to be incorporated into tribal planning. In addition to community education, tribes should also focus on getting quality services to persons with dementia and their families within broader health and social care planning. Programs should include better dementia education for providers, caregivers, and families. Many leaders felt that focusing on the caregiver community is feasible. They also called for improved tribal long-term care options, including more nursing homes that will accept Medicaid and people with dementia. ●



OPPORTUNITIES FOR COMMUNITY ACTION



Eight broad public health strategies are suggested here as ways to respond to the life-course challenges of Alzheimer's and other dementias. With deep respect for tribal tradition and autonomy, these actions are offered as a starting point for discussion, deliberation, and cross-sector collaboration among AI/AN communities, regional tribal health boards, and other public health partners such as state and local health departments. Some actions may be more relevant for a particular AI/AN community than others. Collectively, the strategies aim to improve health and well-being in Indian Country, address cognitive impairment, and help support AI/AN dementia caregivers.

Many of the eight strategies are suitable to cross-sector collaborations. These partnerships across healthcare, public health, and other aspects of community life are increasingly viewed as an essential component of any strategy for improving population health and well-being. Potential partners could include: senior centers; Native American Caregiver Support Program (Title VI C); Indian Health Service, Tribal and urban Indian health programs; Medicaid; the Veterans Health Administration; disease management and wellness programs; and groups of public health nurses and community health representatives (CHRs).

The strategies — grouped in three categories — are written broadly, so that each AI/AN community can tailor implementation to its unique priorities and capacities. (See page 20 for considerations to guide planning efforts.)

Choose Road Map Strategies and Make a Plan

After learning about dementia's impact on the community, the next step is to plan how to build a better future for all. Asking the following questions during the planning process can make it easier to choose which strategies to use and help identify additional interested partners.

1. Which Road Map actions best fit your tribal community's priorities and capabilities?
2. What data and other information can be used to identify a starting place?
3. How can the identified actions best be integrated into existing initiatives? Are new initiatives needed?
4. Who are potential partners? Could any current partnerships be leveraged to implement actions?
5. What are possible funding sources, and how can they be secured?
6. How will implementation and impact be evaluated? How will progress be shared?

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.

Helping tribal members take steps to promote cognitive health, reduce stigmas and myths about dementia, and seek early diagnosis of dementia requires clear and consistent messages delivered by trusted sources. Adding brain health to other efforts to prevent and manage chronic disease has been an effective public health strategy in states and local areas. Tailoring this approach for AI/AN cultures could have far-reaching impact. Engaging tribal regional health boards in educational efforts might be a cost-effective approach.

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.

Well-designed programs have been shown to benefit persons with dementia and caregivers. These programs should be readily accessible to all in need. Access to these programs and tools is particularly crucial for people with dementia who live alone. Other support services for older adults could include transportation for those who are no longer able to drive, programs and practices to keep those living with dementia connected to their community, legal and financial assistance, training for all community

members working with older adults, and long-term care for those whose families live far away. National and regional tribal health groups can support this approach by widely distributing reliable information and tools that feature best practices. They also can develop public health approaches to improve knowledge and access to these services and supports.

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.

The challenges facing people with dementia and their caregivers can be daunting. For example, as dementia progresses, older adults may have trouble recognizing when they are unhealthy or not safe, and they often have problems communicating. Tribal public health initiatives can help raise awareness about these challenges and the need to improve quality of life, safety, and well-being among people with dementia and their caregivers. These can include education on how to use behavioral cues and other strategies to reduce injuries, manage medication, and keep chronic conditions in check to minimize unnecessary hospitalizations.

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.

Access to reliable information and education can enhance tribal community leaders' ability to design effective planning and policy initiatives.

This includes expanding understanding of the challenges encountered by older adults with dementia and caregivers, especially in underserved AI/AN communities. Tribal leaders and their partners, in public and private sectors, will have a strong base to examine potential policies and leverage resources for implementation.

COLLECT AND USE DATA

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

Data specific to local AI/AN communities can be invaluable in shaping priorities, policies, and programs tailored to the unique needs in those areas. Such data can help track the burden of dementia and caregiving on AI/AN communities and monitor progress in addressing that burden. Existing local data can be supplemented with aggregated data on older AI/ANs from CDC's Healthy Aging Data Portal. (cdc.gov/aging/agingdata/index.html)

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

Healthcare quality measures are a useful tool for tracking progress about the use of best practices and clinical guidelines. Measures specific to dementia have been developed by the Physician Consortium for Performance Improvement and American Academy of Neurology and American Psychiatric Association Work Group. The National Quality Forum and other experts may develop or endorse additional quality measures

and measure concepts in the coming years. These measures are relevant to Indian Country and can help monitor progress in delivering quality care.

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.

Healthcare and aging professionals in I/T/U services need not only training on brain health and ways to reduce risk of cognitive decline, but also credible materials they can share with tribal members.

Existing training courses or modules can be used or adapted for these new audiences. Outreach to health professionals can call attention to the importance of supporting caregivers' health and their role in managing dementia and other chronic conditions. Integrating brain health and caregiving into existing health promotion and chronic disease efforts has the potential to increase the reliability of care and improve related outcomes for many older adults.

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

Healthcare and aging services professionals can be instrumental in supporting AI/AN caregivers with information and guidance. They can also facilitate access to affordable, evidence-informed services, programs, interventions, and supports for caregivers to reduce their stress and improve coping, self-efficacy, and overall health. Caregivers would benefit from

Online Resources to Support Implementation

The Alzheimer's Association has an online resource library (alz.org/publichealth) with tools, background information, case studies, and links that may be adaptable for implementation of these strategies.

The CDC Healthy Aging Data Portal (cdc.gov/aging) provides data on key indicators of health and well-being, screenings and vaccinations, caregiving, and cognitive and mental health among older AI/AN populations. Additional resources are available to support implementation of HBI Road Maps.

Communications resources tailored to Indian Country are also available on the Association of State and Territorial Health Officials (ASTHO) website at astho.org/healthy-aging

Additional resources have been developed by a variety of governmental and nonprofit organizations including the Indian Health Service, Administration for Community Living, National Institute on Aging, and National Council of Urban Indian Health.

compelling and easy-to-use materials about how to enhance their own health while caring for older adults. ●



COMMUNITIES IN ACTION



Many programs are currently underway to address dementia in Indian Country. A few examples are featured here as both inspiration and models on which to build.

Many other examples and relevant resources can be found at [alz.org/publichealth](https://www.alz.org/publichealth) and [cdc.gov/aging](https://www.cdc.gov/aging).

Outreach and education

- » Banner Alzheimer's Institute: Native American Outreach Program
- » I-CAARE: Culturally-Grounded Dementia Educational Materials for Indigenous Community-Based Care
- » Pyramid Lake Paiute Tribe: Creating a Dementia-Capable Community

Caregiving

- » St. Regis Mohawk Nation: Community Support for Dementia
- » Wisconsin: Dementia Care Specialist Program
- » CAREGIVERS: Education and Support in Indian Country

BANNER ALZHEIMER'S INSTITUTE: Native American Outreach Program

Customized outreach and educational programs can increase community knowledge and awareness of Alzheimer's and caregiving strategies. One such program is the **Banner Native American Outreach** program, designed to:

- » Foster awareness, care, and scientific understanding of Alzheimer's dementia in Arizona's American Indian communities through education and outreach activities;
- » Support participation among American Indians in the federally-funded Alzheimer's Disease Core Center clinical core, which is a longitudinal study of aging and dementia; and
- » Forge working groups and positive relationships with Arizona tribal and urban Indian communities as well as tribal health organizations.

This unique program began in 2003 as a collaboration between Indian Country organizations and Banner Health, which is also a federally funded Alzheimer's Disease Research Center. The Banner Alzheimer's Institute (BAI) assumed overall oversight for this

program in 2008. The Native American Outreach program features several community and caregiver services. Educational topics include: tips to maintain memory; techniques for caregivers to avoid unnecessary arguments when caring for people with dementia; and meaningful activities for people with dementia. Banner provides the Alzheimer's expertise and travel support, and tribal organizations host and promote participation.

A popular feature of the program is the *BAI Beacon*, a free monthly newsletter for family caregivers featuring practical information about dementia. ●

I-CAARE: Culturally-Grounded Dementia Educational Materials for Indigenous Community-Based Care

Educational materials about dementia are more effective if they respect and value the indigenous cultures of their intended audience. Appropriate and meaningful language, graphics, and photos can reduce cultural barriers between healthcare providers and their patients and increase knowledge and understanding.

In Canada, the **Indigenous Cognition and Aging Awareness Research Exchange** (I-CAARE) is an institute dedicated to exploring and promoting healthy aging with indigenous peoples and raising awareness about cognitive health. It is funded primarily through government research grants and in-kind support.

One of I-CAARE's major activities is developing culturally-grounded materials to fill the information gap and increase education about dementia. The materials are designed using a "two eyed seeing" approach,³⁰ with one eye having an indigenous cultural view and the other eye focused on the non-indigenous culture. Professionals partner with an indigenous audience to ensure cultural appropriateness.

Although materials are geared towards first nations and indigenous peoples in Canada, they are relevant and useful for tribes, tribal members, caregivers, and others seeking to provide services to AI/AN people in the United States. ●

PYRAMID LAKE PAIUTE TRIBE: Creating a Dementia-Capable Community

Increasing basic awareness of dementia and community understanding of people affected by the condition has been a major public health initiative recently. By creating **dementia-capable communities**, these endeavors develop and promote a community that is respectful, educated, supportive, and inclusive of people living with dementia and their caregivers.

Nevada is one of the fastest aging states in the United States. In response, an innovative model is working to ensure the community in and around the **Pyramid Lake Paiute Tribe** becomes dementia-capable. This Northern Nevada tribe received a small grant from the Administration for Community Living Alzheimer's program and additional facilitation support from the Community Health Sciences division and Sanford Center for Aging within the University of Nevada-Reno. An AmeriCorps volunteer also donated time.

Program objectives have been developed through collaborative multi-sector approaches, using the Dementia Friendly America process. This ensured that values central to the Pyramid Lake Paiute Tribe were incorporated throughout the program. Members living with dementia as well as their caregivers were included in the development process.

In and around the Tribe, the goals of the program help encourage and implement tribal action to:

- » Improve and promote opportunities for education, engagement, and peer support among persons living with dementia and family caregivers;
- » Increase community awareness about the warning signs of dementia, promote dementia-related resources, improve general knowledge about dementia, and educate the community about ways to support a member living with dementia; and
- » Expand respite supports and services for caregivers so they can take a break from caregiving. ●

ST. REGIS MOHAWK NATION: Community Support for Dementia

Caregivers of older adults with dementia face challenges in learning about Alzheimer's disease, planning for the immediate and future needs of their loved ones, and locating and arranging care and support. The **St. Regis Mohawk Nation** in upstate New York provides services to assist tribal members with Alzheimer's and other dementias and their caregivers. The services are provided through a collaborative that includes the State University of New York (SUNY)-Plattsburgh and the city of Plattsburgh. Using a portion of grant funding awarded in 2016 by the New York State Department of Health, SUNY-Plattsburgh provides services to residents with dementia in rural counties and the St. Regis Mohawk Nation.

The key feature of the program — an Alzheimer's Navigator, a part-time employee from SUNY-Plattsburgh — delivers education and coordinates support groups throughout this area. Caregivers are offered additional services, which can include respite care, transportation to medical appointments, and training in caregiving methods to decrease caregiver burnout. The St. Regis Mohawk Nation also provides a caregiver support program to assist unpaid caregivers, based on an effective program called Powerful Tools for Caregivers.³⁰

Approximately 20% of the St. Regis Mohawk tribal staff are also unpaid caregivers for their own family members. In the past, tribal staff were reluctant to utilize programs themselves for fear of appearing unfair, but through community education, staff members who are also serving as unpaid caregivers are encouraged to access services by the larger St. Regis Mohawk community. ●

WISCONSIN: Dementia Care Specialist Program

Caregivers of tribal members with dementia often struggle to share their concerns with their community or healthcare providers. Some are confused by the condition and lack understanding about Alzheimer's and the different types of dementias. In response, tribal dementia care specialists in Wisconsin are making a difference by providing information, increasing awareness, developing partnerships with state and county services, and assuring that the rich culture of each tribal member with dementia is included and respected in the services provided.

As of 2019, there are three tribes in Wisconsin operating state-funded dementia specialist programs: the Menominee, the Oneida, and the St. Croix Chippewa. These three sovereign nations differ in language, tribal history, and cultural aspects unique to their members necessitating nation-specific staff. The state of Wisconsin funds salaries for these dementia care specialists, making this program an exemplary model for how state and county governments can partner with American Indian and Alaska Native tribes to best serve the needs of their members.

The dementia care specialist program has three primary goals:

1. Support staff in Area Disability Resource Centers and county programs in order to be better prepared with knowledge and resources that support individuals with dementia and their families;
2. Create dementia-capable communities that include businesses, employers, local organizations, and the general public to raise awareness about the unique needs of people living with dementia and their families; and
3. Assist individuals with dementia so they remain active in the community and can stay in their homes longer.

In addition to providing general education about Alzheimer's, tribal dementia care specialists may perform memory assessments in the community to determine if an individual needs follow-up from other healthcare providers. Specialists connect family caregivers with needed support and assistance for long-term care and future care planning.

These staff may lead memory cafes — gatherings that give individuals affected by dementia with an opportunity to socialize and share family and tribal history. Specialists also offer tips to make homes more dementia-friendly during monthly family information meetings.

One tribal program partners with state and local service providers to deliver a full-range of dementia-specific services. Because of this partnership, families receive accurate and timely information, and specialists get referrals from physicians to ensure thorough coordination. The program also operates an adult day care center that primarily serves tribal members and offers memory assessments with a strong cultural focus.

CAREGIVERS: Education and Support in Indian Country

Savvy Caregiver is a six-week course led by trained volunteers who have been or currently are caregivers. It is designed to: introduce family caregivers of persons with Alzheimer's to the caregiving role; provide them with the knowledge, skills, and attitudes needed to carry out that role; and alert them to self-care issues. The course has been demonstrated to be effective in reducing caregiver stress and improving caregiver satisfaction through a series of randomized controlled trials.³⁹

This caregiver-focused program has been adapted by the National Indian Council on Aging (NICOA) — a nonprofit organization originally founded by the National Tribal Chairmen's Association to promote action on aging in the AI/AN community. **Savvy Caregiver in Indian Country** is designed for various American Indian and Alaska Native communities to support members who are caring for an older adult with memory and thinking issues. The program is available for free download.⁴⁰

The original Savvy Caregiver program demonstrated that the program was a good way to teach caregivers to achieve “contented involvement,” a concept that resonated with tribal members. Contented involvement

occurs when older adults with memory loss are able — as fully as their abilities allow — to engage with their family. Savvy Caregiver in Indian Country emphasizes this “family first” approach, connecting the overall importance of family in their community with tribal core values.

The program manual makes distinctions between the original program and the sections revised for Indian Country. The manual also uses a feather image to note information that is written especially for Indian Country. It provides guidance and examples on how a tribe can adapt the program to meet the unique needs of its members. Examples emphasize the importance and unique aspects of culture, and demonstrate how people view and solve problems based on culture.

REACH into Indian County is another effective training and support program for caregivers. As a partnership between the Indian Health Service, Veterans Health Administration, and Administration for Community Living, the program provides training, certification, and materials to public health nurses, community health representatives, and tribal senior center caregiving support staff. ●



CONCLUSION



The challenges of Alzheimer's and other dementias for Indian Country are complex. Tribal leaders have a unique opportunity to promote and support a broad response to dementia that embraces public health approaches. Potential collaborators include tribal health and aging services professionals, regional tribal health organizational leaders, administrative leaders in the Indian Health Service, and state offices of health equity and minority health. Thoughtful consideration of the Road Map's suggested strategies by AI/AN communities can lead to responses tailored to native languages and built upon cultural strengths. Collective and concerted action to promote health, improve early detection, and provide needed supports can improve the lives of older AI/ANs living with dementia and their caregivers. •



ACKNOWLEDGMENTS

Contributors

SUSAN BAKER, MPH

Consultant
Alzheimer's Association

DAVID BALDRIDGE

Executive Director
International Association for Indigenous
Aging

BILL BENSON

Board President
International Association for Indigenous
Aging

STEVE CHAPMAN

Cultural Consultant
Enrolled member, Minnesota Chippewa
Tribe
White Earth Reservation

LAURA CILMI

Director of Public Policy Media Engagment
& Marketing Alzheimer's Association

ROBERT EGGE

Chief Public Policy Officer
Alzheimer's Association

BRUCE FINKE, MD

Elder Health Consultant, Indian Health
Service
Acting, Chief Medical Officer, Nashville
Area
Indian Health Service

MOLLY FRENCH, MS

Director of Public Health
Alzheimer's Association

LISA GARBARINO

Public Health Analyst
Alzheimer's Disease and Healthy Aging
Program
Centers for Disease Control and Prevention

J. NEIL HENDERSON, PhD

Member, Oklahoma Choctaw
Executive Director, Memory Keepers
Professor, Department of Family Medicine
& Biobehavioral Health
University of Minnesota Medical School

HEIDI HOLT, MPA

Public Health Advisor
Alzheimer's Disease and Healthy Aging
Program
Centers for Disease Control and Prevention

MICHAEL C. JACKSON, MS

Communications Specialist
Alzheimer's Disease and Healthy Aging
Program
Centers for Disease Control and Prevention

LISA C. MCGUIRE, PhD

Lead
Alzheimer's Disease and Healthy Aging
Program
Center for Disease Control and Prevention

BECCA RUBIN

Graphic Designer
Gold Standard Studio

JOHN SHEAN, MPH

Associate Director of Public Health
Alzheimer's Association

MICHAEL SPLAINE, MPA

Founder and Principal
Splaine Consulting

BLYTHE WINCHESTER, MD, MPH, CMD

Certified Medical Director, Tsali Care Center
Geriatrician, Cherokee Indian Hospital
Chief Clinical Consultant, Geriatrics and
Palliative Care
Indian Health Service

Reviewers

BASIA BELZA, PhD, RN, FAAN

Director, de Tornyay Center for Healthy Aging
Lead, Coordinating Center, Healthy Brain Research Network
University of Washington, Seattle

ELLEN BLACKWELL, MSW

Senior Advisor
Center for Clinical Standards and Quality
Centers for Medicare & Medicaid Services

MICHAEL BRUHN

Director of Public Policy
Alzheimer's Association, Wisconsin Chapters

MARIA CARILLO, PhD

Chief Science Officer
Alzheimer's Association

CARMEN CLELLAND, PharmD, MPA, MPH

CAPT, US Public Health Service
Director, Office of Tribal Affairs and Strategic Alliances
Centers for Disease Control and Prevention

GRETCHEN DOBERVICH, BSW, LSW

Public Health Policy Manager
American Indian Public Health Resource Center
North Dakota State University

KELSEY DONNELLAN, MPH

Senior Analyst, Health Improvement
Association of State and Territorial Health Officials

RYAN EAGLE

Member, Mandan, Hidatsa, Arikara Nation
Public Health Research Project Manager
American Indian Public Health Resource Center
North Dakota State University

DAVID ESPEY, MD

CAPT, US Public Health Services
Director, Healthy Tribes
NCCDPHP/Division of Population Health
Centers for Disease Control and Prevention

JAMES FITZPATRICK

Director of Programs and Advocacy
Alzheimer's Association, Desert Southwest Chapter

GARY GIRON, MDIV

Executive Director
Alzheimer's Association, New Mexico Chapter

CAROLYN HORNBUCKLE, JD

Director of Public Health Policy and Programs
National Indian Health Board

VIJETH IYENGAR, PhD

Aging Services Program Specialist
Administration for Community Living

BETH KALLMYER

Vice President of Care and Support
Alzheimer's Association

SUSAN KAROL, MD

CAPT, US Public Health Services
Division of Tribal Affairs
Centers for Medicare & Medicaid Services

MELINDA KELLEY, PhD

Director
Office of Legislation, Policy and International Activities
National Institute on Aging

CYNTHIA LACOUNTE

Director
Office of American Indian, Alaska Native and Native Hawaiian Programs
Administration for Community Living

SHARI LING, MD

Deputy Chief Medical Officer
Centers for Medicare and Medicaid Services

ERIN LONG, MSW

Office of Supportive and Caregiver Service
Administration for Community Living

DAVID MARQUEZ, PhD

Associate Professor, Kinesiology and Nutrition
University of Illinois at Chicago

JOANNE PIKE, DrPH

Chief Program Officer
Alzheimer's Association

JENNIFER ROSEN

Director of State Affairs
Alzheimer's Association

TALYAH SANDS, MPH

Director, Health Improvement
Association of State and Territorial Health Officials



REFERENCES

1. Alzheimer's Association. (2019). 2019 Alzheimer's disease facts and figures. *Alzheimer's Dement.* 15(3), 321-387. Available at: alz.org/facts.
2. Alzheimer's Association and Centers for Disease Control and Prevention. (2018). *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*. Chicago, IL: Alzheimer's Association.
3. Norris T, Vines P, Hoeffel E. (2012). *The American Indian and Alaska Native Population: 2010*. 2010 Census Briefs, Washington, DC: US Census Bureau.
4. Goins R, Schure M, Crowder J, Baldrige D, Benson W, Aldrich N. (2015). *Lifelong disparities among older American Indians and Alaska natives*. Research Report 2015-08. Washington, DC: AARP Public Policy Institute.
5. Johnson L. (1968). *The Forgotten American: The President's message to the Congress on goals and programs for American Indians*. *Indian Record* 1-14.
6. Indian Health Service. (2018). *Indian health disparities*.
7. Centers for Disease Control and Prevention. (2018). *Deaths: Final Data for 2016*. *National Vital Statistics Report* (67)5, 1-76.
8. US Census Bureau. (2017). *Selected Population Profile in the United States*.
9. Matthews K, Xu W, Gaglioti A, Holt J, Croft J, Mack D, McGuire L. (2019). Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged ≥65 years. *Alzheimer's Dement.* 15(1),17-24.
10. Centers for Disease Control and Prevention. (2018). *Healthy aging data portal*, National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health.
11. Institute of Medicine. (2015). *Cognitive aging: Progress in understanding and opportunities for action*. Washington, DC: The National Academies Press.
12. Baumgart M, Snyder H, Carrillo M, Fazio S, Kim H, Johns H. (2015). Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. *Alzheimer's Dement.* 11(6), 718-726.
13. National Academies of Science, Engineering and Medicine. (2017). *Preventing cognitive decline and dementia: A way forward*. Washington, DC: The National Academies Press.
14. The Lancet Commission on Dementia Prevention, Intervention and Care. (2017). *Dementia prevention, intervention and care*. *The Lancet.* 390(10113), 2673-2734.
15. Mayeda E, Glymour M, Quesenberry C, Whitmer R. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's Dement.* 12(3), 216-224.
16. Centers for Disease Control and Prevention. (2016). *American Indian and Alaska Native heart disease and stroke fact sheet*. Center for Heart Disease and Stroke Prevention.
17. Office of Minority Health. (2016). *Diabetes and American Indians/Alaska Natives*. Department of Health and Human Services.
18. Office of Minority Health. (2016). *Heart Disease and American Indians/Alaska Natives*. Department of Health and Human Services.
19. Office of Minority Health. (2016). *Obesity and American Indians/Alaska Natives*. Department of Health and Human Services.
20. Centers for Disease Control and Prevention. (2018). *American Indians/Alaska Natives and tobacco use*. National Center for Chronic Disease Prevention and Health Promotion.
21. Rutland-Brown W, Wallace L, Faul M, Langlois J. (2005). Traumatic brain injury hospitalizations among American Indians/Alaska Natives. *J Head Trauma Rehabil.* 20(3),205-214.
22. Roanhorse, O. (2017). Physical activity in Indian country. *Preventive Medicine* 95, 151-S153.
23. Indian Health Service. (2014, March). *Tribal Injury Prevention Cooperative Agreement Program Newsletter*.
24. World Health Organization. (2014). *Global status report on alcohol and health—2014*. Geneva, Switzerland: World Health Organization.
25. Cunningham J, Solomon T, Muramoto M. (2016). Alcohol use among Native Americans compared to whites: examining the veracity of the 'Native American elevated alcohol consumption' belief. *Drug Alcohol Depend.* 160,65-75.
26. Tilly J, Hudgins K. (2017). *Community living for American Indian, Alaskan Native, and Native Hawaiian elders*. Administration for Community Living Center for Policy and Evaluation.
27. Boccuti C, Swoope C, Artiga S. (2014). *The role of Medicare and the Indian Health Service for American Indians and Alaska Natives: health, access, and coverage*. Kaiser Family Foundation.
28. Jervis L, Manson S. (2002). *American Indians/Alaska Natives and Dementia*. *Alzheimer's Dement.* 16(2), S89-S95.

29. Goins R, Spencer M, McGuire L, Goldberg J, Wen Y, Henderson J. (2011). Adult caregiving among American Indians: the role of cultural factors. *The Gerontologist* 51(3):310-320.
30. Choi W, Beebe L, Nazir N, Kaur B, Hopkins M, Talawyma M, Shireman T, Yeh H, Grenier K, Daley C. (2016). All nations breath of life: A randomized trial of smoking cessation for American Indians. *Am J Prev Med.* 51(5),743-751.
31. Centers for Disease Control and Prevention. (2018). Good Health and Wellness in Indian Country. National Center for Chronic Disease Prevention and Health Promotion.
32. Centers for Disease Control and Prevention. (2018). Tribal Practices for Wellness in Indian Country. National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health.
33. Association of State and Territorial Health Officials. (2019). Healthy heart, healthy brain.
34. Warne D, Frizzell L. (2014). American Indian health policy: historical trends and contemporary issues. *AJPH*, 104(S3), S263-S267.
35. National Congress of American Indians, Tribal nations and the United States. Washington, DC; 2017.
36. Jernigan M, Buchwald D, Loop K, Boyd A, Domoto-Reilly K. (2018, Nov). Indigenous Aging: Advancing a community-based model to address dementia in tribal clinics. Presentation 4006.0 at APHA's 2018 Annual Meeting and Expo, San Diego, CA.
37. Bartlett C, Marshall M, Marshall A, Iwama M. (2015). Integrative science and two-eyed seeing: enriching the discussion framework for healthy communities in LK Hallstrom, N Guehstorf & M Parkes, *Ecosystems, Society and Health: Pathways through Diversity, Convergence and Integration* (280-326). McGill-Queen's University Press.
38. Powerful Tools for Caregivers. (2019). Portland, OR.
39. Hepburn K, Lewis M, Sherman C, Tornatore J. (2003). The Savvy Caregiver Program: Developing and testing a transportable Dementia family caregiver training program. *The Gerontologist* 43(6), 908-915.
40. National Minority Aging Organization Technical Assistance Center for the Development of Dementia Care Resources for American Indians and Alaska Natives. (2013). *The Savvy Caregiver in Indian Country*. Albuquerque, NM: National Indian Council on Aging.

Disclaimer

The mark “CDC” is owned by the U.S. Department of Health and Human Services (HHS) and is used with permission. Use of this logo is not an endorsement by HHS or CDC of any particular product, service, or enterprise.



The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's disease®.



CDC works 24/7 to protect America from health, safety and security threats, both foreign and in the U.S. Whether diseases start at home or abroad, are chronic or acute, curable or preventable, human error or deliberate attack, CDC fights disease and supports communities and citizens to do the same. CDC increases the health security of our nation. As the nation's health protection agency, CDC saves lives and protects people from health threats. To accomplish our mission, CDC conducts critical science and provides health information that protects our nation against expensive and dangerous health threats, and responds when these arise.