Alzheimer's Disease and Related Dementias

STRATEGIC PLAN

Version 1.0
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npaihb.org

Prepared by
Rede Group

NORTHWEST PORTLAND AREA
INDIAN HEALTH BOARD
Indian Leadership for Indian Health

ABOUT BOLD

The Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer project is funded by the Centers for Disease Control and Prevention. Our goal is to promote education around risk reduction (primary prevention), early diagnosis of Alzheimer's Disease and Related Dementias (ADRD) (secondary prevention), prevention and management of comorbidities and avoidable hospitalizations (tertiary prevention), and the role of caregiving for persons with ADRD, and improve and include data for priority setting.

The Elders committee is made up of NW Tribal delegates who serve as our Native Elder Project, BOLD program Tribal Advisory Committee. The advisory committee engages in regular and meaningful discussions with BOLD project staff on the design and implementation of the BOLD strategic plan, and other activities that empower Tribal communities to understand the effects of dementia in our communities.

KERRI LOPEZ, BA
TolowaDee'ni Nation
Director, BOLD and
NW Tribal Elders Project

CHANDRA WILSON, MSW
Klamath, Modoc, Yahooskin-Paiute Tribes
Manager, BOLD and
NW Tribal Elders Project

Cover photo: Barbara Wright, Klamath Tribal Elder
Photo by Stephanie Chavez

VISION

Our Tribal Communities will be aware of what dementias are, the causes, challenges, and what it means to have a dementia-aware community.

MISSION

Improve the quality of life for our Elders and older adults living with dementia, mild cognitive impairment, and traumatic brain injuries. Support the NW Tribes in their workforce capacity to access and deliver culturally appropriate health care services for the prevention, early detection and risk reduction of ADRD, and to develop ADRD and caregiver support programs.

VALUES

Honor and incorporate the sacred knowledge, elders' teachings, and wisdom of our Tribal community's traditional health and wellness ways of living. Our traditional ways are not self-taught, and the knowledge is passed down through life experiences, through teachings from our elders and ancestors.

NPAIHB MEMBER TRIBES

- Burns Paiute Tribe
- Chehalis Tribe
- Colville Tribes
- Coeur d'Alene Tribe
- Confederated Tribes of the Umatilla Indian Reservation
- Confederated Tribes of Coos, Lower Umpqua, and Siuslaw Indians
- Coquille Tribe
- Cow Creek Band of Umpqua
- Cowlitz Tribes
- Grand Ronde Tribes
- Hoh Tribe
- Jamestown S'Klallam Tribe
- Kalispel Tribe
- Klamath Tribes
- Kootenai Tribe
- Lower Elwha Klallam Tribe
- Lummi Nation
- Makah Tribe
- Muckleshoot Tribe
- Nisqually Tribe
- Nez Perce Tribe
- Nooksack Tribe
- NW Band of Shoshone
- Port Gamble S'Klallam Tribe
- Puyallup Tribe
- Quileute Tribe
- Quinault Indian Nation
- Samish Indian Nation
- Sauk-Suiattle Tribe
- Shoalwater Bay Tribe
- Skokomish Tribe
- Snoqualmie Tribe
- Shoshone-Bannock Tribes
- Siletz Tribes
- Spokane Tribe
- Squaxin Island Tribe
- Stillaguamish Tribe
- Suquamish Tribe
- Swinomish Tribe
- Tulalip Tribe
- Upper Skagit Tribe
- Warm Springs Tribes
- Yakama Indian Nation

ADRD PARTNERS

Dementia, Brain Health, Elders, Aging

- BOLD Public Health Centers of Excellence Early Detection of Dementia
- Indian Country Dementia ECHO
- Project ECHO Dementia UW Medicine, Memory & Brain Wellness Center
- Oregon ECHO Network

State Departments - NW Region

- **Idaho** – Division of Human Services and Aging & People with Disabilities Agencies
- **Oregon** – Division of Human Services and Aging & People with Disabilities Agencies
- **Washington** – Division of Human Services and Aging & People with Disabilities Agencies

Colleges and Universities

- Layton Aging and Alzheimer's Disease Center, OHSU
- Oregon Center for Aging and Technology, OHSU
- New York University, Early Detection of Dementia
- University of Minnesota, Dementia Caregiving

National Agencies

- Center for Disease and Control and Prevention
- Indian Health Service
- International Association for Indigenous Aging
- National Indian Council on Aging
- National Indian Health Board
- National Institute on Aging
- National Resource Center Native American Aging
- Savvy Caregiver in Indian Country Training
- Washington State Dept. of Veteran Affairs

CONTENTS

THE PROBLEM

ADRD is underdiagnosed in Indian country; only 31% of AI/ANs aged 65 and older who experience memory loss have talked with their health care provider. AI/AN elders are at risk for ADRD and between 2014 and 2060, the number of AI/ANs aged ≥ 65 years will increase by nearly five-times. In 2015-2017, 1 in 6 AI/AN aged 45 and older reported subjective cognitive decline (SCB) – this is self-reported difficulties in thinking and remembering. Studies have reported that more than 95% of people with ADRD have one or more other chronic conditions; cardiovascular risk factors are associated with 50-60% higher risk of dementia in US. A person with ADRD is more than 4.4 times as likely to have six or more other chronic conditions as someone without ADRD. AI/AN populations have a disproportionate burden of many established modifiable risk factors for ADRD, including diabetes, obesity, depression, commercial tobacco use, binge drinking, hearing loss, hypertension, lack of physical activity, and traumatic brain injuries.

SOLUTIONS

There is a need to integrate cultural factors into risk reduction, early diagnosis, clinical research, and caregiving practices that focus on Native American traditional wellness and ways of living. Culturally balanced approaches and resources that address Alzheimer's disease and related dementias to increase awareness and improve outcomes are important to bringing education and awareness to our member Tribes of the Northwest. For example, integrating cultural factors such as including identify words and phrases in our member Tribal languages would better help communicate to elders what ADRD is. What we know about our Tribal communities is that acknowledging and incorporating cultural traditional ways of living, beliefs, and practices influences' our peoples experience with understanding what they may be experiencing within in their health conditions. We envision creating space to bring education and awareness of brain health, dementia risk reduction, early detection and assessments, culturally based caregiving practices, and even clinical research in a way to address health disparities and provide support to NW Tribal community members living with ADRD.

BOLD GOALS

To promote education around risk reduction (primary prevention), early diagnosis of ADRD (secondary prevention), prevention and management of comorbidities and avoidable hospitalizations (tertiary prevention), and the role of caregiving for persons with ADRD, and improve and include data for priority setting.

To support the work with NW Tribes, Tribal health providers, and caregivers to foster understanding about the effects of dementia and to prevent dementia through risk reduction and early detection programs.

INTRODUCTION

ABOUT THE GRANT

The Northwest Portland Area Indian Health Board, Northwest Tribal Epidemiology Center (NPAIHB, NWTEC), is a recipient of the Department of Health and Human Services Centers for Disease Control and Prevention (CDC) cooperative agreement awards for the Healthy Brain Initiative (HBI): BOLD Public Health Programs to Address Alzheimer's Disease and Related Dementias (ADRD) in Indian Country. The project is titled The Northwest Tribal Elder's Project (NTEP).

NTEP is funded on a 3-year cooperative agreement to focus on capacity building, program and policy development, mobilizing partnerships, providing community outreach, health education and promotion, and training and technical assistance to our member Tribes in areas that will enhance community development and health equity. CDC collaborated with Tribal leaders across the nation to develop and implement the Healthy Brain Initiative and the Road Map for Indian Country (RMIC). This is a first-ever public health guide focused on dementia in AI/AN communities. NPAIHB is the first AI/AN CDC funded collaborative grant. The HBI/RMIC is a community engagement tool that can empower Tribal communities to:

- Understand effects of dementia in Tribal communities
- Understand and provide training and resources to caregivers and providers
- Identify prevention, early detection, and preventive strategies for public health approaches

BOLD TIMELINE

2020

April: Resolution Submitted to NPAIHB to support grant submission to the Centers for Disease Control and Prevention BOLD Programs to Address Alzheimer's Disease and Related Dementias.
May: Signed and passed Resolution.
August: Notice of award.
October:

- Award Letter for the 3-year Cooperative Agreement.
- Established Tribal Advisory Committee.
- Identified culturally relevant support resources & services.
- Identified NW Tribes Elder Programs.

2021

January: Letter to Northwest Tribal Leaders Introducing BOLD.
April: Design Community Needs Assessment via partnership with native american graphic designer.
May: Plan ADRD Strategic Plan and identify baseline data through existing and new partners.
June: Identified media outlets and partners.
November: Finalized ADRD Strategic Plan Outline

2022

March: Plan, design and implement a communications media plan with graphic designer.
April:

- Launch Community Needs Assessment
- Partnered with Dr. J. Neil Henderson ADRD Research/Research/Professor
- Year 3 Continuation Application Submitted

June: Launched ADRD Awareness Campaign and disseminated education and awareness materials.
July: Received Year 3 NOA
August: Held first Savvy Caregiver in Indian Country Training
September: Held second Savvy Caregiver in Indian Country Training

HISTORY OF ELDER REPRESENTATION

The Northwest Tribal Elder project is a long standing program of the NPAIHB. In many Tribal communities, elders are sacred, and it is our responsibility as younger generations and as a community to protect our elders. The Native Elder Project supports and advocate for our NW Tribal communities elder programs and services. These programs include Social Security, Medicare and Medicaid, long-term support services, in-home health aide care services, injury prevention, elder abuse, diet and nutrition, transportation, energy assistance and many other programs that support our Native elders with their basic needs.

In 1994 the NPAIHB supported and recommended that our elders be given the opportunity to offer and/or serve in a capacity for the National Congress of American Indians (NCAI) and that an elder from the Northwest be placed at some level at the NCAI meeting starting in Denver, Colorado.

The Board's mission and goals are guided by the Vision for the Seventh Generation, words, and teachings from our elders.

The old people tell us to be careful in the decisions that we make today, as they will impact the seventh generation - our grandchildren's grandchildren. It is the spirit behind this teaching that guides our organization's mission and goals.

The People Spoke: This is their Vision

The seventh generation will have balanced physical, mental, emotional, and spiritual lifestyles. They will have healthy diets, be fit, active, and happy.

- The seventh generation will live in sovereign communities that are politically effective, assertive, goal-oriented, thriving economically, and run by AI/AN people.
- The seventh generation will live in a unified and poverty-free community made up of stable, loving families living in adequate housing.
- Children born to the seventh generation will be healthy and free of chemical substances. They will experience strong parenting, mentorship, and positive role models as youth and will become involved and empowered leaders.
- The seventh generation will live in accordance with their traditional values by knowing their native languages and practicing spiritual and cultural traditions.
- The seventh generation will live in a clean environment, have access to an abundance of natural resources, respect all life, and practice sustainable and socially responsible environmental stewardship.
- Every member of the seventh generation will have access to technologically advanced and culturally appropriate healthcare that includes well-equipped clinics, wellness centers, and health education; a health care delivery system that could serve as a national model.

- The seventh generation will have adequate resources to support healthcare delivery.
- The health of the seventh generation will be a model for the general population. They will experience no preventable illness and no substance abuse or addiction. Old age will be the leading cause of death.
- The seventh generation will respect and care for their elders and celebrate as they live to 100 years or more.

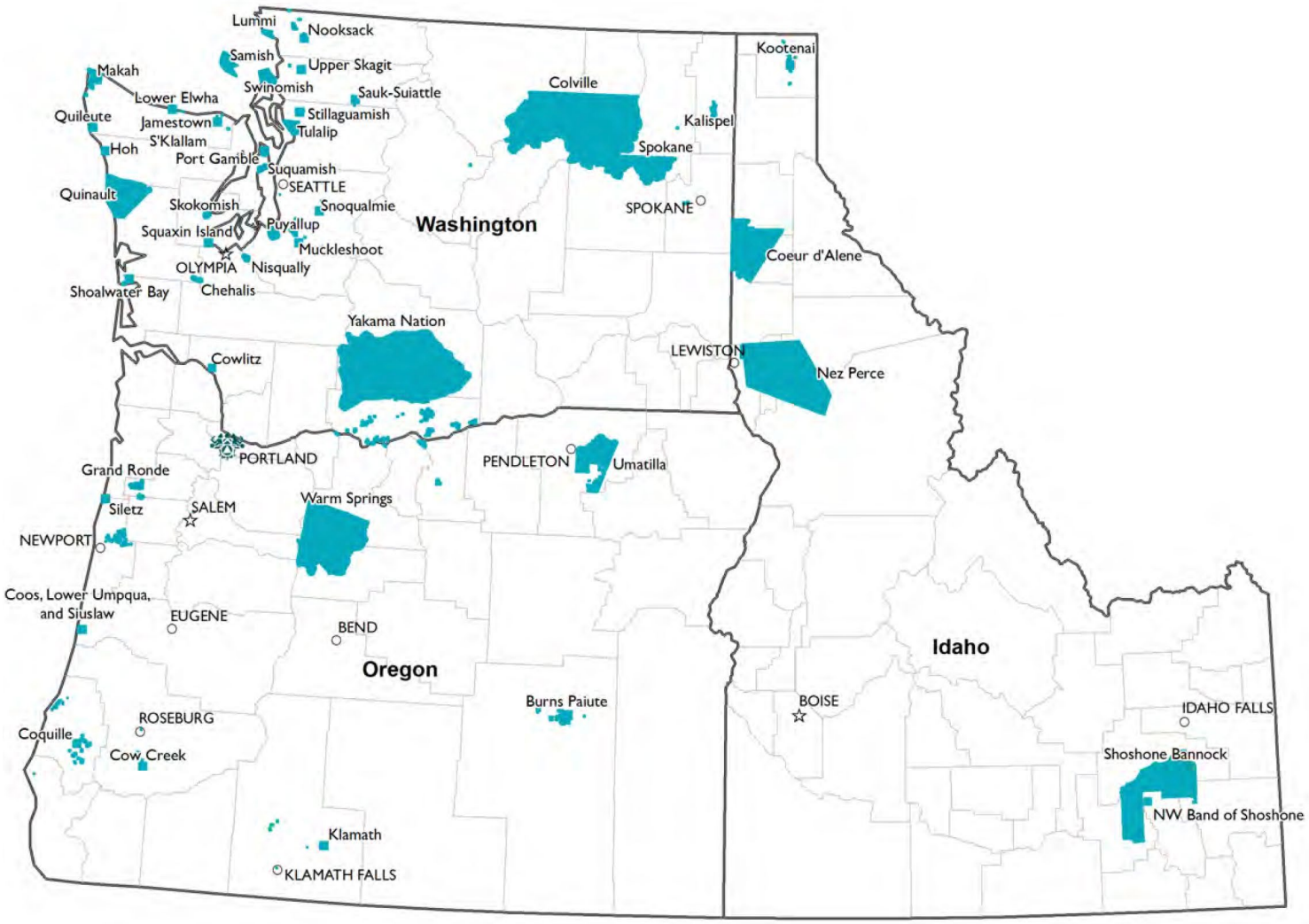
Past and Present Elder Committee members documented from 1997

• Twila Teeman	Burns Tribe
• Dan Gleason	Chehalis Tribe
• Patty Kinswa-Gaiser	Chehalis Tribe
• Denise Ross	Chehalis Tribe
• Norma Peone	Coeur d'Alene Tribe
• Marianne Huley	Coeur d'Alene Tribe
• Andy Joseph, Jr	Colville Tribes
• Beverly Seaman	Confed. Tribes of Coos, Lower Umpqua, and Siuslaw
• Bernadine Shriver	Confed. Tribes of Grand Ronde
• Gladys Hobbs	Confed. Tribes of Grand Ronde
• Cheryle Kennedy	Confed. Tribes of Grand Ronde
• Janice Clements	Confed. Tribes of Warm Springs
• Wilson Wewa	Confed. Tribes of Warm Spring
• Theresa Lechman	Jamestown S'Klallam Tribe
• Leroy Jackson, Jr	Klamath Tribes
• Corrine Hicks	Klamath Tribes
• Natalia Calhoun	Lummi Nation
• Molissa Leyva	Nooksack Indian Tribe
• Rose Purser	Port Gamble S'Klallam Tribe
• Margie Valdez	Quinault Indian Nation
• Marie Gouley	Skokomish Indian Tribe
• Jim Sijohn	Spokane Tribe
• Bonnie Sanchez	Squaxin Island Tribe
• Norma Razote	Tulalip Tribes
• Betty McLean	Confed. Tribes of the Umatilla
• Tina Talley	Upper Skagit Tribe
• Dave Daniels	I.H.S./Yakama
• Ruth Jensen	NPAIHB Staff
• Luella Azule	NPAIHB Staff
• Kerri Lopez	NPAIHB Staff
• Clarice Charging	NPAIHB Staff
• Chandra Wilson	NPAIHB Staff

BACKGROUND

There are more than 390,000 American Indians and Alaska Natives residing in Idaho, Oregon, and Washington and 43 federally recognized Tribes spanning these states.

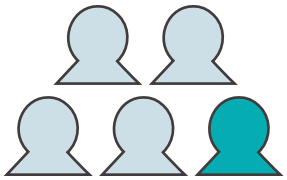
The NW Tribes vary greatly in terms of size, location, culture, language, resources and infrastructure.



Historically, American Indians/Alaska Natives (AI/AN) have had a much younger life expectancy when compared to other racial and ethnic groups.

Alzheimer's Disease and Related Dementias (ADRD) are more common with growing age; therefore, it is imperative that infrastructure is developed to meet the needs of this fast-growing population.

Between 2014-2060, the number of American Indian and Alaska Natives aged 65 and older living with memory loss is projected to grow over five times.



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Today, one of every five AI/AN adults aged 45 and older reported experiencing subjective cognitive decline—increased difficulty in thinking or remembering over the past year—which can be a precursor to dementia.

According to the NPAIHB's 2019 AI/AN Mortality Data report, the leading cause of death for AI/AN populations in Idaho, Oregon, and Washington was major cardiovascular diseases. Among this same group, for adults aged 65 and older, the top five leading causes of death were Cardiovascular Diseases, Cancer, Chronic Lower Respiratory Diseases, Diabetes, and Alzheimer's Disease, respectively

INTRODUCTION TO ALZHEIMER'S DISEASE AND RELATED DEMENTIAS (ADRD)

What is Brain Health?

Brain health refers to the state of brain functioning, your thinking, understanding, and memory abilities. It can refer to the things you to do keep your brain healthy and active, like staying physically active, healthy food choices, and managing risky behaviors such as commercial tobacco use (NIHB.org)

Brain health refers to how well a person's brain functions across several areas. Aspects of brain health include:

- Cognitive health
- Motor function
- Emotional function
- Tactile function

What is normal healthy aging?

Normal Healthy Aging (Common normal aging)

- Simple forgetfulness
- Cognitive Changes
- Delay in recalling names, places, dates and events

What is not healthy aging?

Not normal Healthy Aging (serious memory problem)

- When memory changes begin to interfere with normal daily life and activities
- Forgetting why things are the way they are, or why/how something works the way it does

What is a Mild Cognitive Impairment (MCI)?
MCI is a condition some older adults experience having more memory or other thinking problems than other people their age but can still do their normal daily activities.

Some signs of MCI include:

- Losing things often
- Forgetting to go to important events or appointments
- Having more trouble coming up with specific word usage than other people their age

People with MCI are more likely to develop Alzheimer's disease than those without. However, not everyone with MCI will develop Alzheimer's disease.

What is Dementia?
Dementia is the loss of cognitive functioning — thinking, remembering, and reasoning — to such an extent that it interferes with a person's daily life and activities. Some people with dementia cannot control their emotions, and their personalities may change. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of living.

What are some common types of dementia?
Common types of dementia include Alzheimer's Disease, Lewy Body Dementia, Vascular Dementia, and Frontotemporal Dementia. The table on the following page explains the changes to the brain for each type of dementia. These changes are just one piece of a complex puzzle that scientists are studying to understand the underlying causes of these forms of dementia and others.

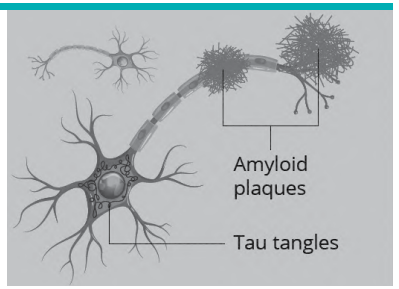
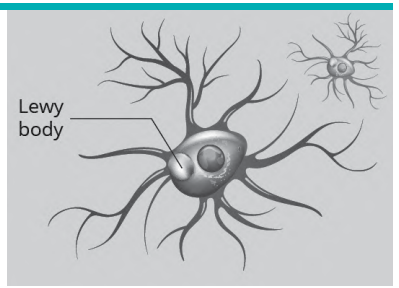
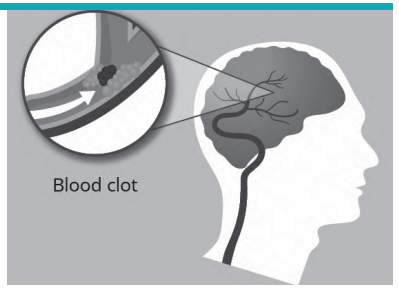
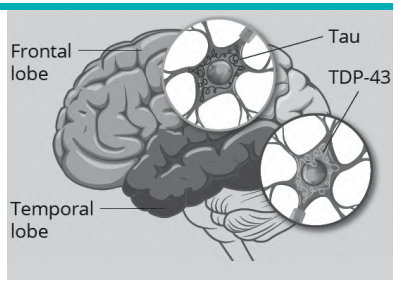
It is also possible to have Mixed Dementia, or a combination of two or more types of dementia. Through autopsy studies involving older adults who had dementia, researchers have identified that many people had a combination of brain changes associated with different forms of dementia.

Symptoms can be similar among different types of dementia, and some people have more than one form of dementia, which can make an accurate diagnosis difficult. Symptoms can also vary from person to person. Doctors may ask for a medical history, complete a physical exam, and order neurological and laboratory tests to help diagnose dementia.

Currently, there is no cure for dementia, but some treatments are available.

Common Types of Dementia

Adapted from: National Institute on Aging. Understanding DifferentTypes of Dementia

ALZHEIMER'S DISEASE	The most common and progressive dementia diagnosis among older adults. It is caused by changes in the brain, including abnormal buildups of proteins, known as amyloid plaques and tau tangles.	• Wandering and getting lost • Repeating questions • Problems recognizing friends and family • Impulsive behavior • Cannot communicate	
LEWY BODY DEMENTIA	A form of dementia caused by abnormal deposits of the protein alpha-synuclein, called Lewy bodies.	• Difficulty planning and organizing • Impulsive behaviors • Emotional flatness or excessive emotions • Shaky hands • Problems with balance/walking • Difficulty making or understanding speech	
VASCULAR DEMENTIA	A form of dementia caused by conditions that damage blood vessels in the brain or interrupt the flow of blood and oxygen to the brain. Memory loss in older adults, with high risk of stroke, diabetes, and obesity are impacted more.	• Inability to concentrate, pay attention, or stay alert • Disorganized or illogical ideas • Muscle rigidity • Loss of coordination • Reduced facial expression • Insomnia • Excessive daytime sleepiness • Hallucinations	
FRONTO-TEMPORAL DEMENTIA	A rare form of dementia that tends to occur in people younger than 60. It is associated with abnormal amounts or forms of the proteins tau and TDP-43.	• Forgetting current or past events • Misplacing items • Trouble following instructions or learning new information • Hallucinations or delusions • Poor judgment	

Risk factors:
While advanced aging is considered the greatest known risk factor, Alzheimer's is not typically a part of aging. Hereditary factors, such as family history, can also indicate risk. Most modifiable risk factors for ADRD are related to cardiovascular disease and other chronic health conditions. They include hypertension, not getting enough physical exercise, obesity, diabetes, depression, smoking, hearing loss, and binge drinking.

Prevention:
Maintaining a healthy lifestyle and managing related chronic conditions benefit overall physical health, facilitates and improves brain health, and may help decrease risks of dementia or slow its progression.

- Get Active and Maintain a Healthy Weight: Regular physical activity is important for good health, and when combined with a health diet, can lead to a healthy weight.
- Manage Blood Sugar: Learn how to manage blood sugar if diagnosed with diabetes.
- Prevent and Manage High Blood Pressure: Tens of millions of adults in the United States have high blood pressure, and many do not have it under control. Learn the facts.
- Prevent and Correct Hearing Loss: Communicate with a hearing care professional for treatment and management of hearing loss.
- Find Support: Depression is not just having "the blues" or the emotions we feel when grieving the loss of a loved one. It is a treatable medical condition.

Individuals with risks of dementia or Alzhimers should also consider limiting the following:

- Binge Drinking: Drink in moderation. Learn about the connection between alcohol use and health.
- Smoking: Quitting smoking improves health and reduces the risks of heart disease, cancer, lung disease, and other smoking-related illnesses.

Best practices:
Early diagnosis is the 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.

> The earlier that an individual can be diagnosed, the sooner action can be taken to support them.

Benefits of Early detection and screening

Early detection of symptoms is important, some causes can be identified resulting in improved symptoms. Overall, most instances of dementia do not have a single point of causation. Treatments are limited in their usefulness. Early diagnosis can help with managing the condition and planning ahead.

Early Detection: The ten warning signs of Alzhimers in Indian Country

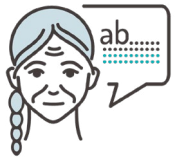
Memory loss that disrupts daily life: Forgetting events, repeating yourself, or relying on more aids to help you remember (like sticky notes or reminders).

Challenges in planning or solving problems: Having trouble paying bills or cooking recipes you have used for years.

Difficulty completing familiar tasks at home, at work, or at leisure: Having problems with cooking, driving places, using a cell phone, or shopping.

Confusion with time or place: Having trouble understanding an event that is happening later, or losing track of dates.

Trouble understanding visual and partial relations: Having more difficulty with balance or judging distance, tripping over things at home, spilling or dropping things more often.



New problems with speaking or writing: Having trouble following or joining a conversation, or struggling to find words you are looking for (saying "that thing on you wrist" instead of "watch").

Misplacing things/unable to retrace steps: Placing car keys in the washer or dryer or not being able to retrace steps to find something.

Decreased or poor judgment: Being victim of a scam, not managing money well, paying less attention to hygiene, or having trouble taking care of pet.

Withdrawal from work or social activities: Not wanting to go to social activities, not being able to follow football games or keep up with what's happening.

Changes in mood and personality: Getting easily upset in common situations or being fearful or suspicious.

Generally, there must be two or more of the symptoms present in a person to label them a case of dementia – and they would be severe enough to cause interference with daily lives.

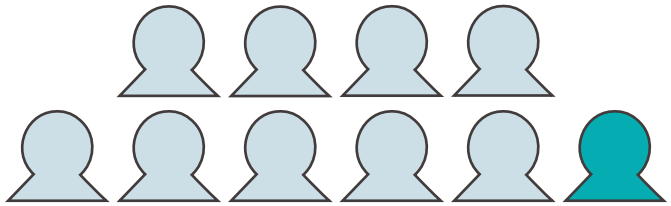
EPIDEMIOLOGICAL OVERVIEW AND DISEASE BURDEN FOR NPAIHB SERVICE AREA

Between 1969-2010, life expectancy has increased nearly 30 years from age 44 to age 73 among AI/AN populations. For previous generations, with life expectancy so low, ADRD were not as common in Native communities.

There is growing evidence that access to ADRD diagnosis is unsubstantial. Only 1 in 3 (31%) of AI/AN adults aged 65 and older who experience memory loss actually talk with their health care provider about it

Most Native communities lack services to provide care for individuals with Alzheimer's or other dementia.

The incredible cultural and linguistic diversity across AI/AN communities makes it difficult to design universal clinical assessments and instruments for detecting dementia; it is challenging to translate existing instruments into different languages without altering their meaning (Griffin-Pierce et al., 2008). AI/ANs also experience higher poverty levels and lower educational achievements than any other ethnic group, suggesting a need for alternative cognitive screening tools (Griffin-Pierce et al., 2008).



1/10 One out of ten people age 65 years and older have Alzheimer's disease

> Currently, no culturally appropriate tools exist to measure cognitive function in American Indian/Alaska Native patients
>
> (Jervis & Manson, 2002)

AWARENESS, KNOWLEDGE OF RISK-FACTORS, AND ATTITUDES ABOUT PREVENTION AND EARLY DETECTION

Interview with Dr. Henderson
The following conversation was conducted in November 2022 between Chandra Wilson and Dr. J Neil Henderson.

J. Neil Henderson, PhD is a Choctaw Nation Tribal member, born in southeast Oklahoma and raised in-and-around Oklahoma and Florida. Dr. Henderson's 40+ years of professional work has always addressed prevention of disease, reduction of health disparities, and the building of healthier lives among the youth, adults, and elders in culturally diverse populations. In the more recent 30+ years, his attention has focused on aging. Issues on which he has conducted extensive research include cultural influences on the recognition and treatment of disease, and community health interventions in the context of cultural diversity. He has conducted bio-cultural research on Alzheimer's disease in American Indian Tribes, developed Alzheimer's support groups in African-American and Spanish-speaking populations, developed widely used dementia caregiver support tools designed for Native people, and conducted geriatric health care education for culturally diverse providers across the United States.

"The nature of the full symptoms and care-giving challenges related to ADRD are largely unknown among Tribal members."

What do you think is Tribal members' community awareness level of ADRD?

"On a scale of 1-10, it would be a 3. There is a lot of awareness of ADRD as a name of a memory disease, but that's all that most people actually know about it. The nature of the full symptoms and care-giving challenges related to ADRD are largely unknown among Tribal members."

What knowledge do Tribal members have of the risks of ADRD to themselves or family members?

"Almost none. If a family member has symptoms, then people think that they are more at risk, and while that is technically correct, just having a family member with ADRD causes a low risk but higher than a family without any cases. Also, and importantly for Indian Country, is the connection of diabetes to brain function. That always seems to surprise people. That is correctable by prevention or management. There is also increased risk by having hypertension and other cardiovascular conditions, that is often not clear to the general Tribal citizen."

Do you think Tribal members are aware of ADRD risk factors?

"In general, risk factors that go beyond diabetes and hypertension are not recognized. The main example for the new initiatives on prevention of ADRD is the Standard American Diet of highly processed food, sugar drinks, and transfats as significant lifelong factors that contribute to ADRD risk."

"There is also increased risk by having hypertension and other cardiovascular conditions, that is often not clear to the general Tribal citizen."

COMMUNITY NEEDS ASSESSMENT

The first step toward building community capacity for dementia prevention was to complete a community-wide needs assessment. The assessment was designed to help determine the needs of our Tribal citizens living with Alzheimer's and other dementias and their caregivers. The information gathered through this assessment was used to determine what kind of training and technical assistance around ADRD was most needed by elder programs in our NW Tribal communities.

The following data reflects 23 respondents who identified as Tribal health program staff.

90%

of respondents had no active dementia program in place at their Tribal health program.

90%

of respondents were interested in specific dementia trainings and certifications including CEUs for Tribal members to be caregivers.

Barriers and challenges:

"Lack of education and awareness."

"Lack of staff. Not the right staff."

"Not enough caregivers."

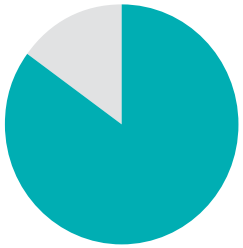
"Lack of transportation."

"Not enough funding."

"We need more support from within...Tribal government, leaders, staff."

"Lack of knowledge about the process of aging and mental health."

"Lack of funding to provide enrichment activities for elders."



85%

said their Tribal community have a program that focuses on elder health and wellness including:

- Elders nutrition programs;
- Wellness classes;
- Swimming classes;
- Unpaid caregiver programs; and
- Home health.

52%

had received dementia-specific training or education, including:

- Alzheimers Association classes;
- Case Manager for Aging & People with Disabilities;
- Training focus on Alzheimers awareness;
- Understanding and Responding to Dementia related behavior,
- Certificate in Gernotology;
- Savvy Caregiver training on Dementia; and
- Sensitivity training.

Program successes:

"Keeping our people home longer."

"We assist adults in need of financial assistance."

"Advocating for our elders and vulnerable adults"

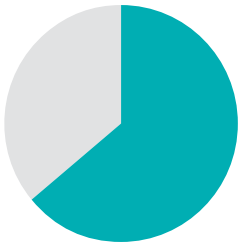
"Congregate meals, meal delivery, outreach, home visits."

"Elders attending and making healthier choices."

"The love and care we give our Elders."

"Our luncheons and health walks are the most successful."

9%
of respondents incorporated Tribal traditional best practices of care-giving.



64%
said they need more assistance incorporating traditional best practices in their programs.

71%
said their program receives resources and services, including grant funding and Title VI funding.

Program changes needed:

"More services available."

"Having a shared vision between the departments."

"More elder activities."

"More staff."

"Funds to help with client needs."

"Native Tribal members working with the elders more."

"I think the whole Tribe needs a re-haul, re-do, makeover, with their Elders being the focal point of their programs."

"For the Tribe to take on this program."

CAREGIVERS FOR PEOPLE WITH DEMENTIA

Alzheimers puts an enormous financial and emotional burden on caregivers. Multi-generational housing is common in many AI/AN communities, and subsequently, caregiving is also very common. A caregiver can be anyone, from a family member who has taken the role to care for their family member to a professional who chose to take care of a vulnerable individual as a career. "A caregiver gives care, generally in the home environment, for an aging parent, spouse, other relatives, or unrelated person, or an ill, or disabled person." 40% of medical professionals and 22% of Tribal health program staff are also identified as caregivers; 15% of Tribal health program staff are caregivers to a child or sibling with dementia, according to the NPAIHB Needs assessment.

Effects on caregivers

Family caregivers are under a tremendous amount of stress. Family caregivers go through their "unexpected career" with mixed amounts of help and support; the overall experience tends to be very harmful to their physical and emotional health, as well as their financial stability. Large percentages of caregivers suffer financial losses such as reducing work hours or even leaving the workforce. In addition to the costs to the healthcare system, an average caregiver sees an increase of $550 in his or her own health care costs. This out-of-pocket cost, coupled with increased health issues among the caregiver population intensifies as the population of persons with ADRD increases relative to the main caregiver population.

> Caregivers don't necessarily identify as 'caregivers.' Caring for their own is a way of life for Native people; you have children, you care for them, and when your parents age, you care for them.

1/3

One in three American Indians/Alaska Natives are family caregivers

In reservations, there is often a lack of resources that are readily accessible for caregivers, "Our people don't have easy access to pharmacies, hospitals, or traditional grocery stores. Some people must travel 30 minutes on a dirt road to reach another paved road, where they must travel another 30 minutes, and so on." As many Tribal communities are located in rural areas, access to care for the patient as well as the caregiver is often difficult.

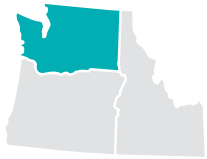
CURRENT PRACTICE

The Savvy Caregiver in Indian Country is a training designed for use by all AI/AN people caring for an elder with memory loss. It is based on the notion that family members who become caregivers assume a role for which they are unprepared and untrained. Although the caregiver role is usually built on their preexisting relationship with the elder, the role is distinct from that relationship, and is likely to change over time as the disease progresses.

The Savvy Caregiver concept teaches caregivers the best skills for achieving *contented involvement* for the elder with dementia, by maintaining their continued involvement in daily life in ways that fit their changing abilities. One of the main themes of the training manual is to teach caregivers the stages of dementia corresponding to their loved ones functioning. The stages of dementia change over time and knowing how to determine the stages allows the caregiver to use activities and tasks that fit the elder's changing abilities.

The Savvy Caregiver training and guide is still be offered to the NW tribes through the BOLD program. The numbers to the right are subject to change over time as more trainings are provided.

17



of the 29 Tribes in Washington received the Savvy Care Giver training

3

of the 9 Tribes in Oregon received the Savvy Care Giver training

CAREGIVER SUPPORTS

Taking Care of You

- What to Expect: As Alzheimer's progresses, your role as caregiver changes. Learn what to expect and how to prepare.
- Getting the Support: As a caregiver, you likely have many responsibilities. It is important to take care of your own well-being and to connect with others that understand.
- Daily Care: By using creativity and caregiving skills, you can adapt routines and activities as needs change.
- Care Options & Planning: There is no one-size-fits all formula when it comes to Alzheimer's care. Each family's situation is unique.
- Respite Care: Respite care can be provided at home — by a friend, other family member, volunteer or paid service — or in a care setting, such as adult day care or long-term care community. In-home and out-of-home care services options include:
  - Companion services to the individual with companionship and supervised activities
  - Personal care or home health aide services to provide assistance with bathing, dressing, toileting, and exercising
  - Homemaker or maid services to help with laundry, shopping, and preparing meals
  - Skilled care services to help with medication and other medical services

Call or Visit:

Alzheimer's Association
24/7 Helpline:
1-800-272-3900
https://www.alz.org/help-support/caregiving

- Adult day centers offer a place where the person with Alzheimer's can be with others in a safe environment. Staff leads planned activities, such as music and art programs. Transportation and meals are often provided.
- Long-term care communities may offer the option for a stay overnight, for a few days or a few weeks. Overnight care allows caregivers to take an extended break or vacation while the person with dementia stays in a supervised, safe environment. The cost for these services varies and is usually not covered by insurance or Medicare.

STRATEGIC PLAN

PURPOSE + AUDIENCE

The purpose of this plan is to support and offer guidance to all NW Tribes as they work to achieve optimal health for all people, by promoting and supporting dementia risk reduction, early detection, and services for those with ADRD and Caregivers.

The audience for this plan includes 43 Tribes, Tribal health programs, Tribal health providers, Tribal elder committees, Tribal councils, clinics, caregivers, Tribal liaisons AAA (state, local regional), families, and Elders.

PLAN STRUCTURE

This strategic plan is structured around three main components: goals, strategies, SMART objectives, and metrics.

Goals are broad statements about what NPAIHB wants to achieve, are qualitative in nature, and are linked to the mission.

SMART objectives will follow goals. Objectives are quantifiable, time-specific statements articulating exactly what will be accomplished and by when. SMART is an acronym meaning Smart, Measurable, Achievable, Relevant, and Time-based.

Metrics are a method used to measure your goals and objectives or measures evidence of actual inputs, outputs, and outcomes.

What are SMART objectives?

Specific: A specific objective has a much greater chance of being accomplished than a general objective.

Measurable: When progress is measured, people stay on track and reach target dates.

Achievable: Objectives should be realistic and attainable. Is your objective something your team can reasonably accomplish?

Relevant: Relevant objectives align with your organization's values and broader goals.

Time-based: An objective should be grounded within a time frame. Without a time-frame tied to the goal there is no sense of urgency.

GOAL 1: DEVELOP POLICIES AND MOBILIZE PARTNERSHIPS

Strategy 1.1
Engage partners with diverse knowledge and skills to communicate broadly about dementia prevention.

Period of Performance Outcome
September 30, 2022 - September 29, 2023

SMART Objective & Outcome Measure
- By September 2023, increase the number of ADRD stakeholders engaging in jurisdiction-wide dementia collaboration and action.

Strategy 1.2
Align state, Tribal, and local ADRD goals and objectives with public health approaches in the Road Map for Indian Country.

Period of Performance Outcome
September 30, 2022 - September 29, 2023

SMART Objective & Outcome Measure
- By September 2023, increase the inclusion of RMIC series actions to at least four (4) actions that are reflected in the ADRD state/Tribal/local strategic plan.

Metrics:
- Document review of data sources
- Meeting observation

GOAL 2: EDUCATE AND EMPOWER COMMUNITY MEMBERS

Strategy 2.1
Develop and provide resources to educate about dementia prevention and care.

Period of Performance Outcome
September 30, 2022 - September 29, 2023

SMART Objective & Outcome Measure
- By September 2023, Increase number of Tribal programs that have received materials to raise awareness of ADRD and provide support for families and caregivers.
- By September 2023, Increase inclusion of the areas of dementia risk reductions (primary prevention), early diagnosis of ADRD (secondary prevention), prevention and management of comorbidities and avoidable hospitalizations (tertiary prevention) in program planning and priority setting.

Strategy 2.2
Connect community members to quality care and traditional wellness practices.

Period of Performance Outcome
September 30, 2022 - September 29, 2023

SMART Objective & Outcome Measure
- By September 2023, Increase number Tribal programs, providers, and communities that have been trained in connecting community members

with interventions, best practices, and traditional wellness practices to support brain health.

- By September 2023, Increase inclusion of the areas of dementia risk reductions (primary prevention), early diagnosis of ADRD (secondary prevention), prevention and management of comorbidities and avoidable hospitalizations (tertiary prevention) in program planning and priority setting.

Strategy 2.3

Engage Tribal leaders through education and collaboration on program planning.

Period of Performance Outcome

September 30, 2022 - September 29, 2023

SMART Objective & Outcome Measure

- By September 2023, Increase number Tribal leaders who have received reliable information and education materials available to enhance Tribal leaders' understanding of the challenges encountered by elders with dementia.
- By September 2023, Increase inclusion of the areas of dementia risk reductions (primary prevention), early diagnosis of ADRD (secondary prevention), prevention and management of comorbidities and avoidable hospitalizations (tertiary prevention) in program planning and priority setting.

Metrics:

- Document review of data sources
- Meeting observation

GOAL 3: COLLECT AND USE DATA

Strategy 3.1

Help with the collection and the use of local data on dementia and caregiving in American Indian and Alaska Native communities to plan programs.

Period of Performance Outcome

September 30, 2022 - September 29, 2023

SMART Objective & Outcome Measure

- By September 2023, increase number of Tribes trained in use of local data sources that provide accurate and meaningful information in monitoring ADRD in the community, and designing ADRD programs and policies tailored to the unique needs of Tribal communities.

Strategy 3.2

Research and use available data and the Road Map for Indian Country to set priorities.

Period of Performance Outcome

September 30, 2022 - September 29, 2023

SMART Objective & Outcome Measure

- By September 2023, increase the inclusion of the use of data, including BRFSS, to inform public health priorities and actions in the ADRD state/Tribal/local strategic plan.

Metrics:

- Document review

GOAL 4: STRENGTHEN THE WORKFORCE

Strategy 4.1
Provide education for professionals in healthcare and aging services on how to support families and caregivers of older adults with dementia.

Period of Performance Outcome
September 30, 2022 - September 29, 2023

SMART Objective & Outcome Measure
- By September 2022, Increase the number of Tribes trained in how to provide people with dementia and their caregivers support and facilitate access to services, programs, and interventions
- By September 2023, Increase inclusion of the areas of dementia risk reductions (primary prevention), early diagnosis of ADRD (secondary prevention), prevention and management of comorbidities and avoidable hospitalizations (tertiary prevention) in program planning and priority setting.

Metrics:
- Document review
- Key informant interviews

THIS STRATEGIC PLAN IS THE FIRST STEP IN ADDRESSING THE IMPACT OF ADRD IN OUR TRIBAL COMMUNITIES.

Under the guidance of the Elders Committee, implementation of this strategic plan in collaboration with the NW Tribes will help honor and protect our elders as our wisdom keepers and cultural guides.

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