



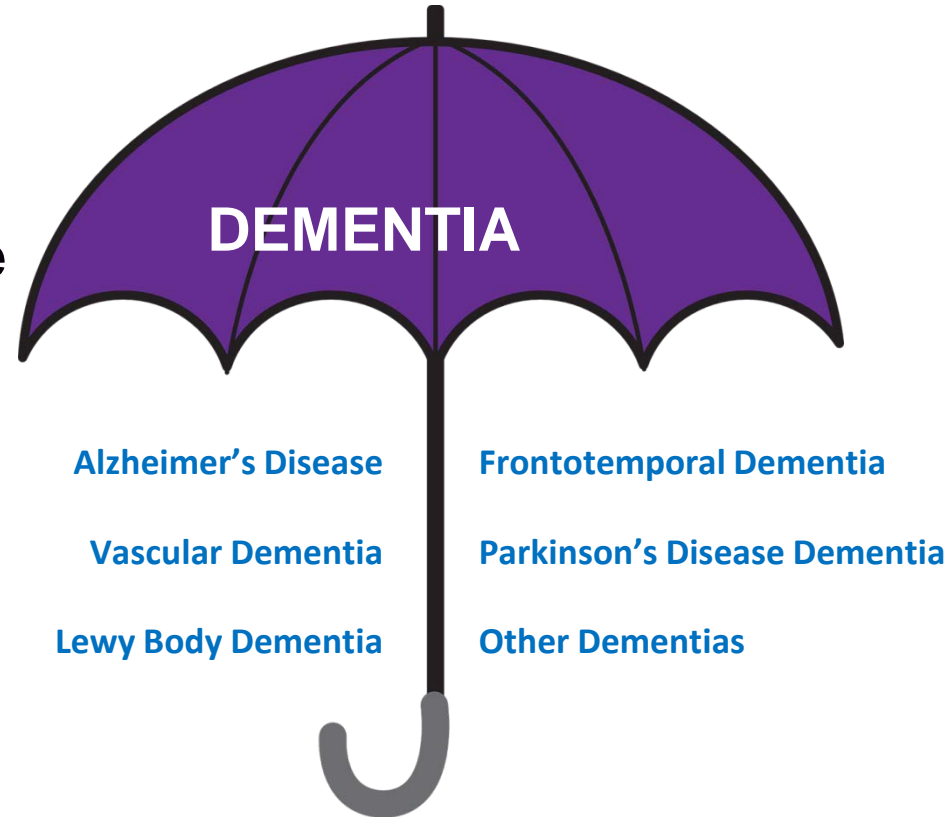
HEALTHYBRAIN INITIATIVE

Alzheimer's and Caregiving in AI/AN Communities: A Public Health Approach

Hosted by NDSU School of American Indian Public Health
November 7, 2019

What is Dementia?

- Dementia is the loss of cognitive functioning and behavioral abilities that interfere with daily life
- **Alzheimer's is the most common cause of dementia**
- Many (maybe majority) of dementia cases have multiple causes



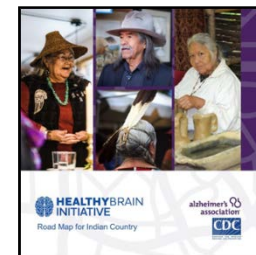
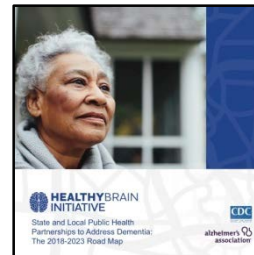
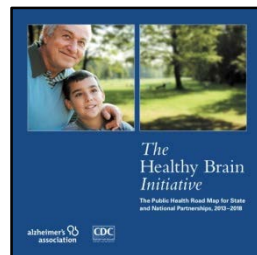
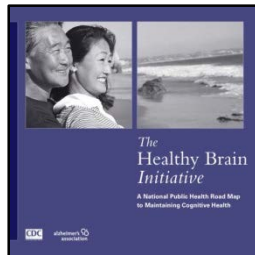
SOURCE: Alzheimer's Disease Facts and Figures, *Alzheimer's & Dementia* (2019)

Healthy Brain Initiative (HBI)

Started in 2005 to build the capacity of public health agencies to act on dementia and support caregiving

HBI Road Maps

- Help public health leaders understand their role
- Offer public health strategies to promote brain health, address dementia, and help support caregivers



Advice & Expertise & Collaboration

National Indian Health Board

International Association for Indigenous Aging

Administration for Community Living

Alzheimer's Association

Association of State and Territorial Health Officials

Centers for Disease Control and Prevention

Centers for Medicare & Medicaid Services

Healthy Brain Research Network

Indian Health Service

National Institute on Aging

And many more.....**Thank You!**

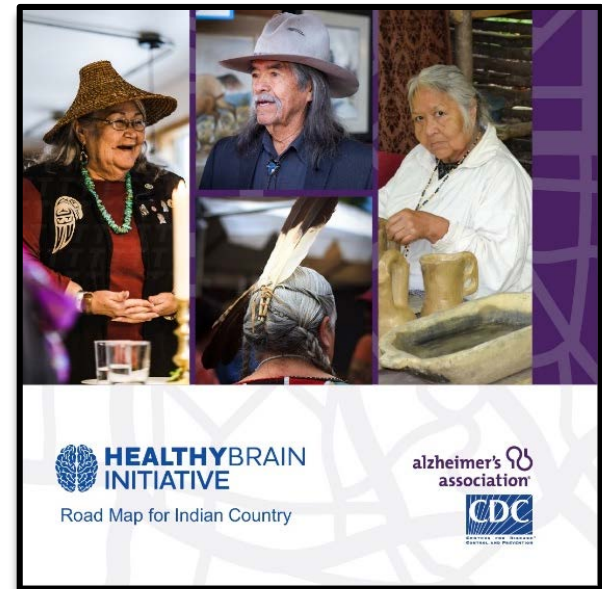
Road Map Intent

Conversation starter

Prompt local planning

Encourage:

- Public health strategies
- Work across and between generations for the good of all



Road Map Strategies

- **Educate and empower community members**
- **Collect and use data**
- **Strengthen the workforce**

<https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>



Educate & Empower Communities

- Educate your community about:
 - Brain health
 - Talking to a doctor about memory problems
- Increase use of programs and services that support health and wellbeing
- Help families plan for the future
- Encourage your leaders to support public health approaches to dementia

Public Health Programs and Resources: Examples

- Good Health and Wellness in Indian Country
- Tribal Epidemiology Centers
- Tribal Practices for Wellness in Indian Country

Healthy Heart, Healthy Brain

Messaging (available at

<http://www.astho.org/Healthy-Aging/Healthy-Heart-Healthy-Brain>)

Healthy Heart, Healthy Brain ...

The River of Life Flows
Through the Heart,
Protecting the Mind and Body



5.7 Million

Americans have
Alzheimer's disease



1 in 10

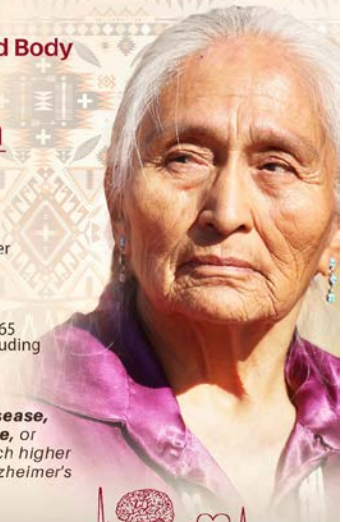
People age 65 and older
has Alzheimer's



1 in 3

American Indians over 65
develop dementia, including
Alzheimer's

Elders with **heart disease**,
high blood pressure, or
diabetes have a much higher
risk of developing Alzheimer's
of other dementias*



Make an appointment with your doctor today to
talk about how to keep your mind and heart healthy.

astho IA² International
Association for Indigenous Aging

This advertisement is supported by grant number 5R01AG032012-01A1, funded by the Center for Disease Control and Prevention. Its contents do not imply the endorsement of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

alz.org/PublicHealth/IndianCountry

10 Warning Signs of Alzheimer's



HEALTHYBRAIN INITIATIVE
Road Map for Indian Country

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.

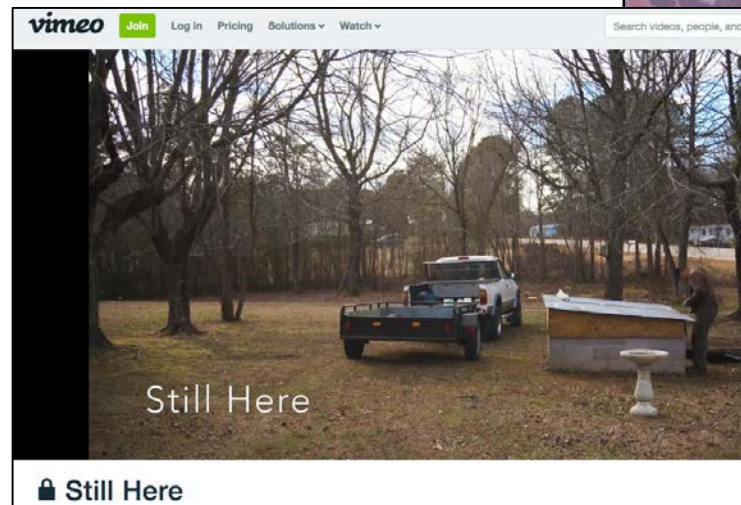
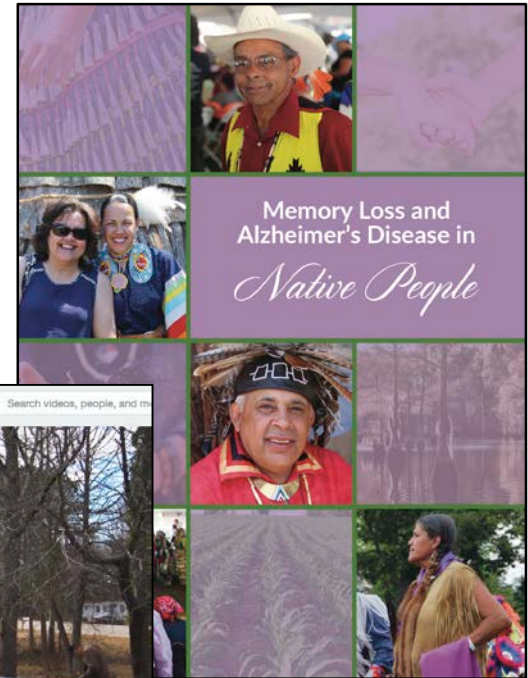
The Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association have created the Healthy Brain Initiative's (HBI) Road Map for Indian Country.

It is designed to help American Indian and Alaska Native (AI/AN) community leaders learn about dementia and start discussions throughout their communities. The Road Map for Indian Country suggests eight public health strategies that embrace community strengths including traditional practices, resilience, and existing services.






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 the Centers for Disease Control and Prevention (CDC) of any particular product, service, or enterprise.



Wyoming Center on Aging

10 Early Signs of Unnatural Memory Changes

Dementia is a general term for a decline in mental ability severe enough to interfere with daily life. Dementia is not a specific disease. It describes a wide range of symptoms associated with a decline in memory or other thinking skills. Alzheimer's disease is the most common type of dementia.

Many dementias are progressive, meaning symptoms start out slowly and gradually get worse. If you or a loved one is experiencing memory difficulties or other changes in thinking skills, don't ignore them. See a doctor soon to determine the cause.

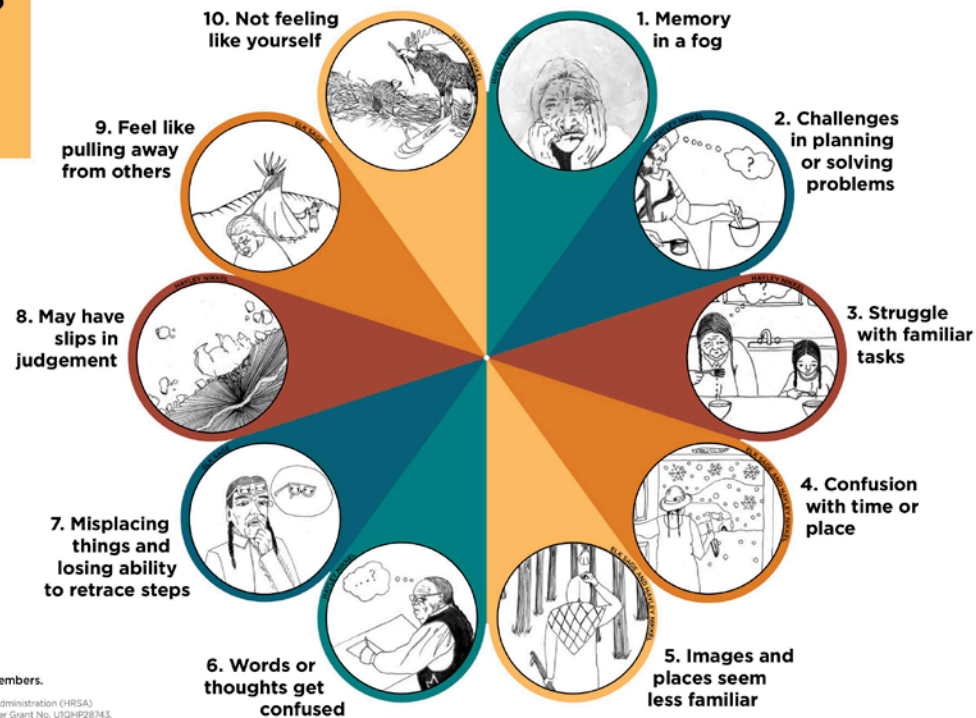
For information, education, referrals, or support, call the Alzheimer's Association 24/7 helpline at 1-800-272-3900 or visit their website at alz.org.



wycoa@uwyo.edu
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(307) 766-2829

This resource was created in collaboration with Eastern Shoshone and Northern Arapaho tribal members.

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Collect & Use Data

- Get data about how dementia and caregiving affects your community
- Use quality measures to improve care for people living with dementia



SUBJECTIVE COGNITIVE DECLINE AMONG AMERICAN INDIAN/ALASKA NATIVE ADULTS

2015–2017 Behavioral Risk Factor Surveillance System (BRFSS) Data from American Indian and Alaska Native adults in 49 States*, Puerto Rico, and the District of Columbia: People Aged 45 Years and Older

1 in 6

American Indian/Alaska Native adults aged 45 years and older are experiencing Subjective Cognitive Decline



SCD is self-reported MEMORY PROBLEMS that have been GETTING WORSE over the past year.

63% of people with SCD had to give up day-to-day activities



88% of people with SCD have at least one chronic condition

one in two

of people with SCD say it interfered with social activities, work or volunteering



over half

of people with SCD have discussed their symptoms with a healthcare provider



54% of people with SCD need help with household tasks



* All except Pennsylvania



alzheimer's
association

cdc.gov/aging

CS 300070-A April 2019



Data for Action

<https://www.cdc.gov/aging/data/infographic/2017/american-Indian-alaska-native-cognitive-decline.html>



**HEALTHY BRAIN
INITIATIVE**

Road Map for Indian Country

CAREGIVING AMONG AMERICAN INDIAN/ALASKA NATIVE ADULTS

2015–2017 Behavioral Risk Factor Surveillance System (BRFSS) Data from American Indian and Alaska Native adults in 44 States, Puerto Rico, and the District of Columbia



1 in 4 American Indian/Alaska Native adults are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

CAREGIVING CAN BE

LENGTHY

Half have provided care for at least two years



INTENSE

Almost half have provided care for at least 20 hours per week



HOW DO CAREGIVERS HELP?



Over 80% manage household tasks

Over 50% assist with personal care



WHO ARE CAREGIVERS?

56% are women

16% are 65 years old or older

35% are caring for a parent or parent-in-law

7% of caregivers are providing care to someone with dementia



FUTURE CAREGIVERS

Nearly 1 in 5 NON-CAREGIVERS expect to **BECOME CAREGIVERS** within 2 years



cdc.gov/aging

CS 294325-A April 2019



Data for Action

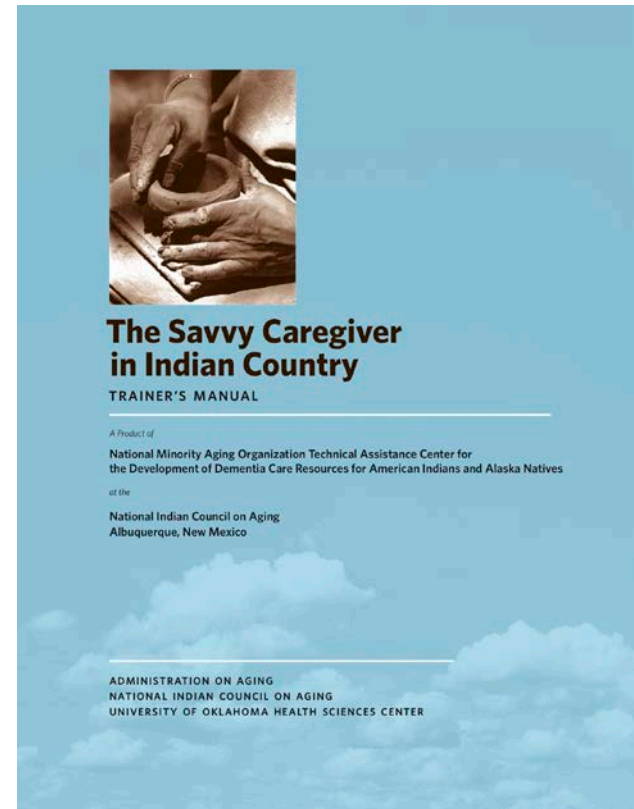
[New Infographic](#)



**HEALTHY BRAIN
INITIATIVE**

State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map

National Indian Council on Aging adapted the Savvy Caregiver model for use in Indian Country



Strengthen the Workforce

- Train people who provide health care or other services about
 - Brain health
 - Alzheimer's and dementia
 - Caregiving
- Give professionals information to share with patients (or clients)



alz.org/Public-Health-Curriculum

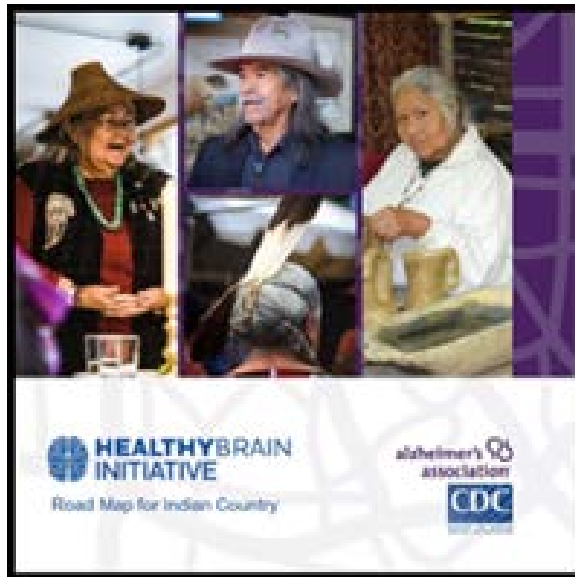
Free curriculum to help educate public health staff and students

A Public Health Approach to Alzheimer's and Other Dementias

An introductory curriculum to increase awareness of the impact of Alzheimer's and other dementias.







Examples and Tools to Get Started

Michael Splaine
Alzheimer's Association

Pyramid Lake Paiute Tribe

Become “dementia-capable”

- Enhance awareness of dementia
- Educate & involve community members
- Increase peer support
- Expand supports, services for caregivers

St. Regis Mohawk Nation

- Community support assist tribal members with dementia and their caregivers
- Alzheimer's Navigator delivers education and coordinate support groups
- Other services: respite care, transportation, caregiver training

Banner Alzheimer's Institute

- Native American Outreach program
- Increase community knowledge and awareness of Alzheimer's and caregiving strategies

In the Road Map....

10 WARNING SIGNS OF ALZHEIMERS

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, etc.
4. **Confusion with time or place:** has trouble understanding an event that is happening or losing track of dates
5. **Trouble understanding visual images and spatial relations:** having more difficulty with balance or judging distance, tripping or falling, getting lost at home, or spilling or dropping things
6. **New problems with words in speaking or writing:** having trouble following or joining a conversation or struggling to find a word when looking for (saying "that thing on your watch" instead of "watch")
7. **Misplacing things and losing the ability to retrace steps:** placing car keys in the trunk or dryer or not being able to retrace steps to find something
8. **Decreased or poor judgment:** being vulnerable to a scam, not managing money well, paying attention to hygiene, or having trouble taking care of a pet
9. **Withdrawal from work or social activities**

GLOSSARY

Alzheimer's disease: an irreversible, progressive brain disorder that slowly destroys memory and thinking and, eventually, the ability to carry out the activities of daily life. Symptoms usually develop slowly and become severe enough to interfere with a person's ability to live independently before symptoms appear.

Figure 2: Life Expectancy Among American Indians and Alaska Natives, 1969-2010

Year	American Indian/Alaska Native	Non-American Indian/Alaska Native
1969	44.0	70.2
2010	73.7	78.7

In the Road Map....



STARTING THE CONVERSATION: IDEAS FOR AN INITIAL DISCUSSION ABOUT ALZHEIMER'S

Listening and learning are the first steps toward developing a holistic 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 to learn how dementia affects all generations. Dementia affects not only people living with the condition, but also their families, community members who are caregivers, and even future generations if memory loss associated with Alzheimer's weakens cultural traditions and heritage.

An initial community gathering to discuss dementia

- » Again, without identifying individuals, who in our community is 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 fragile older adults?

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?

alz.org/PublicHealth/IndianCountry

Find:

- Road Map for Indian Country
- Tools & examples to help you use it
- Data
- More info about key issues

The screenshot displays the Alzheimer's Association website. At the top right, there is a 24/7 HELPLINE number: 800.272.3900. Below the navigation bar, a search bar is visible. The main heading is 'Road Map for Indian Country'. The text below the heading discusses the benefits of American Indians and Alaska Natives living longer and the impact of dementia. It mentions that older people living with Alzheimer's and other dementias progressively depend on caregivers and community resources. The text also states that tribal health and aging leaders become concerned about the growing problem of dementia and can build on strengths in their cultures and traditions. A call to action is provided: 'To offer a tool for tribal leaders, the Alzheimer's Association and the Centers for Disease Control and Prevention, in consultation with the International Association for Indigenous Aging, created the Healthy Brain Initiative: The Road Map for Indian Country. Designed to support discussion about dementia and caregiving within tribal communities, the Road Map for Indian Country encourages a public health approach as part of a holistic response. Publication of the full Road Map for Indian Country will occur later this year.' A sidebar on the right features a graphic titled 'Healthy Brain Initiative Road Map' with the text: 'State and local public health agencies can realize a better future for all communities impacted by Alzheimer's.'

Healthy Heart, Healthy Brain

- Posters
- Flyer
- Provider guide
- Radio announcements
- 5-7 minute videos
- Articles in
Indian Country Today

Discussion: What do
we mean by a public
health approach?
Gretchen Dobervich

Alzheimer's disease a Public Health Issue

The burden is large

5.8 Million Americans are living with Alzheimer's disease

16 million Family caregivers provided 18.5 billion hours of unpaid care in 2018

The impact is major

More Americans die of Alzheimer's disease than breast + prostate cancer

Alzheimer's disease will cost the US \$290 billion in 2019

There are ways to intervene

Early diagnosis and treatment

Caregiver education and supports

Developing Alzheimer's inclusive communities

<https://www.alz.org/alzheimers-dementia/facts-figures>



NDSU AMERICAN INDIAN PUBLIC
HEALTH RESOURCE CENTER

Alzheimer's Disease a Public Health Approach

Assessment

Behavioral Risk Factor Surveillance Survey
National Institutes of Health Epidemiological Studies
Disease registry
Alzheimer's Association Facts & Figures publication
Healthy People 2010, 2020, 2030
Healthy Brain Initiative

Policy

Expansion of Medicare coverage for medications, assessment and care planning
Appropriation of research dollars
Alzheimer's State Plans
National Alzheimer's Plan
Private and publically funded research

Assurance

Evidence based dementia care workforce training
Publication of peer reviewed Alzheimer's disease research articles
Public information materials produced by unbiased sources



For More Information

Centers for Disease
Control and Prevention
(CDC)

Alzheimer's Disease and
Healthy Aging Program

cdc.gov/aging

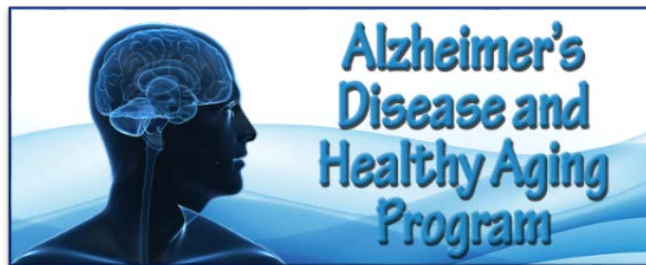
Alzheimer's Association

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alz.org/publichealth/IndianCountry



alzheimer's 
association®