

PESA SOONAME RESOURCE NOTEBOOK

Assembled by The Dementia Engagement, Education, and Research (DEER) Program, in partnership with the Pesa Sooname Advisory Group, Pyramid Lake Paiute Tribe's Dementia-Friendly Effort



Funding provided by the Nevada Aging and Disability Services Division

Introduction

Dementia Friendly Nevada launched in 2016 as a network of four communities, each passionate about becoming more respectful, educated, supportive, and inclusive of people living with dementia and their care partners. While each community took a different approach to respond to their unique community needs, the statewide effort was unified by a set of shared values, founded upon the fundamental belief that people living with dementia deserve to live in communities that support them in living well.

Since 2016, the number of communities across Nevada that have joined the Dementia Friendly Nevada network has grown to 11. One of those communities is the Pyramid Lake Paiute Tribe, which convened their Pesa Sooname Advisory Group in 2017. "Pesa Sooname" is Northern Paiute for "Good Thought" and "Good Think," because the members of that group feel it is important to promote good thoughts toward people living with dementia while also protecting their own good thinking.

This resource notebook, filled with brain health and dementia resources specifically for American Indian and Alaska Native people, is just one way the Pesa Sooname Advisory Group is working to promote good thoughts and protect good thinking. These resources are meant to support you and the members of your tribe in doing the very same.

Table of Contents

This resource notebook is a collection of resources gathered from multiple sources, and as such, there are no continuous page numbers. However, the notebook has been divided into eight sections according to natural breaks in the material. Also, in many cases, there are multiple resources that cover similar material. We encourage you to add or remove resources to customize the binder to best suit use within your tribe!

Section One:

- Brain Health Action Institute for Tribal Nations Workbook
 - Unit 1: What is Brain Health in Indian Country?
 - Unit 2: The Road Map for Indian Country

Section Two:

- Brain Health Action Institute for Tribal Nations Workbook
 - Unit 3: Cultural Considerations in Brain Health for Indian Country
 - Unit 4: Prioritization of Brain Health in Indian Country
 - Unit 5: Planning for Action- Initial Steps

Section Three:

- Brain Health Action Institute for Tribal Nations Workbook
 - Closing
 - Resources
 - Appendices 1, 3, and 7

Section Four:

- Infographics on Brain Health and Dementia

Section Five:

- What is Dementia? Indigenous Perspectives and Cultural Understandings

Section Six:

- Talking Points for Brain Health Champions

Section Seven:

- Healthy Brain Initiative
 - Learn. Plan. Respond to Dementia.

Section Eight:

- Supporting American Indian and Alaska Native people who Live with Dementia

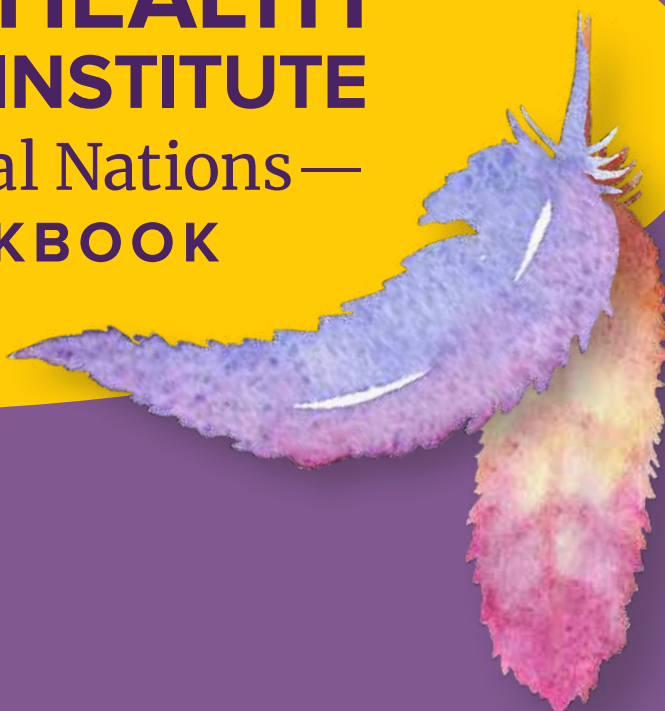
National Indian
Health Board



BRAIN HEALTH ACTION INSTITUTE —for Tribal Nations— WORKBOOK



**BRAIN HEALTH
ACTION INSTITUTE**
—*for Tribal Nations*—
WORKBOOK



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Introduction

BACKGROUND ON THE NATIONAL INDIAN HEALTH BOARD

The National Indian Health Board, or NIHB, is a national non-profit organization based in Washington, DC and was established by Tribal Nations over 45 years ago. NIHB serves all 574 federally-recognized American Indian and Alaska Native Tribes on matters of health and public health.

NIHB Mission Statement: Established by the Tribes to advocate as the united voice of federally recognized American Indian and Alaska Native Tribes, NIHB seeks to reinforce Tribal sovereignty, strengthen Tribal health systems, secure resources, and build capacity to achieve the highest level of health and well-being for our People.

Learn more about the National Indian Health Board at www.nihb.org

PURPOSE OF THE WORKBOOK

This workbook is intended for individuals who are already or aspire to be champions of brain health within their communities. This includes, but is not limited to Tribal leaders, health directors, clinicians, Tribal program staff and motivated community members. This workbook can be used individually for self-study or as a resource to replicate a Brain Health Action Institute for Tribal Nations (BHAi) in their community.

By the end of the workbook, participants can expect to:

- Clearly understand the impact of dementia on a community;
- Understand the possible risk factors for dementia;
- Assess their existing Tribal community efforts for Alzheimer's disease and related dementias;
- Prioritize the Healthy Brain Initiative Road Map in Indian Country actions that would have the greatest impact and feasibility in their community;
- Use this opportunity to integrate actions for including dementia, including Alzheimer's disease, as well as caregivers of those with dementia in existing Tribal-wide plans and activities;
- Feel a commitment to and excitement for moving forward with actions that can be taken in your communities.

In addition to this workbook, the following resources available at <https://nihb.org/brain-health/resources/> can be used to support brain health actions in your community:

- Road Map for Indian Country
- Talking Points for sharing with Elders and Families
- Talking Points for sharing with Healthcare Providers and Public Health Professionals
- Talking Points for sharing with Tribal Leaders
- Brain Health Action Institute for Tribal Nations Online Training Module

This workbook is supported by the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$100,000 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

INSTRUCTIONS FOR USING THE WORKBOOK

This workbook can be used individually for self-study or with a group. There are various activities throughout the workbook, each will contain the following:

- Instructions for individual self-study worksheets
- Instructions for group facilitation, including
 - Participant worksheets
 - Facilitator guides (available in the appendix)
- Materials needed to complete each activity
- Materials needed for group facilitation

If you are hosting your own Brain Health Action Institute with a group, it is recommended to invite local subject matter experts or others to help facilitate the activities.

Refer to [appendix 1](#) for a sample agenda and [appendix 2](#) for a sample evaluation for a 2-Day BHA in your community.

Throughout the workbook and in various activities you will be asked to refer to the Health Brain Initiative Road Map for Indian Country (RMIC). The RMIC is available at <https://www.cdc.gov/aging/healthybrain/pdf/HBI-Road-Map-for-Indian-Country-508.pdf>.

BRAIN HEALTH ACTION INSTITUTE FOR TRIBAL NATIONS

The Brain Health Action Institute for Tribal Nations (BHA) took place virtually September 16-17, 2020. The goal of the BHA was for participants to feel a commitment to and excitement for moving forward with actions that can be taken in their own community. It was designed to support Tribes and Tribal organizations

in using the Healthy Brain Initiative Road Map for Indian Country (RMIC) to start conversations, as well as develop and plan strategies for improving brain health in their own communities.

The National Indian Health Board extends their sincerest thanks to the following individuals for helping ensure the September 16-17, 2020 Brain Health Action Institute for Tribal Nations was a success:

PRESENTERS

- Dr. Blythe Winchester, (Eastern Band of Cherokee Indians), Cherokee Indian Hospital
- Dr. Linda Bane Frizzell, (Eastern Band of Cherokee Indians/Lakota), University of Minnesota
- Heidi Holt, Centers for Disease Control and Prevention
- Nia Reed, ORISE Fellow, Centers for Disease Control and Prevention

FACILITATORS

- Dr. Blythe Winchester, (Eastern Band of Cherokee Indians), Cherokee Indian Hospital
- Dr. Linda Bane Frizzell, (Eastern Band of Cherokee Indians/Lakota), University of Minnesota
- Dave Baldrige, (Cherokee) International Association of Indigenous Aging
- Heidi Holt, Centers for Disease Control and Prevention
- Nia Reed, ORISE Fellow, Centers for Disease Control and Prevention
- David Espey, Centers for Disease Control and Prevention
- Benjamin Olivari, Centers for Disease Control and Prevention
- Mike Splaine, Splaine Consulting
- Karrie Joseph, National Indian Health Board
- Yasmin Zuch, (Navajo Nation), National Indian Health Board
- Nina Martin, National Indian Health Board
- Jessica Dean, National Indian Health Board

Unit 1:

WHAT IS BRAIN HEALTH IN INDIAN COUNTRY?

INTRODUCTION

Unit 1 will take approximately 45 minutes to complete

This unit contains information on brain health and effective strategies for the treatment and prevention or delay of Alzheimer's disease and other dementias. This unit contains a slide deck presentation by Dr. Blythe Winchester, MD, MPH, CMD.

Dr. Winchester is a board certified geriatrician and enrolled member of the Eastern Band of Cherokee Indians in Cherokee, North Carolina. She practices at Cherokee Indian Hospital and is the Certified Medical Director at the Tsali Care Center. She received her MD and MPH at UNC Chapel Hill and did a family medicine residency in Greenville, South Carolina. Her geriatrics fellowship was completed through the Mountain Area Health Education Center in Asheville, North Carolina. She is a mentor for the Jones-Bowman Leadership Award Program and is a current participant in the Right Path Adult Leadership Program through the Ray Kinsland Leadership Institute.

Materials needed for What is Brain Health in Indian Country:

- Self-study
 - Slide deck (following)
- Group facilitation
 - Slide deck (following)

SLIDE DECK



Dr. Blythe Winchester, MD, MPH, CMD

(ENROLLED MEMBER, EASTERN BAND OF CHEROKEE INDIANS)
CERTIFIED MEDICAL DIRECTOR, TSALI CARE CENTER; GERIATRICIAN,
CHEROKEE INDIAN HOSPITAL; AND CHIEF CLINICAL CONSULTANT,
GERIATRICS AND PALLIATIVE CARE, INDIAN HEALTH SERVICE

OBJECTIVES

Upon completion of this unit, participants will be able to describe:

- The current scientific understanding of Alzheimer's disease and other dementia syndromes
- Actions you can take to promote brain health and prevent or delay onset of Alzheimer's disease and related dementias
- Current understanding of effective treatments for Alzheimer's disease and other dementia syndromes

Disclaimer: This information is presented from a healthcare provider and may include technical terminology.

DEMOGRAPHICS

- 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 (AI/AN). From 2000 to 2010, the AI/AN population grew 27%, increasing nearly three times faster than the total U.S. population
- 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
- The number of older adults is increasing. An estimated 569,000 AI/ANs are 65 years or older. 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

Norris T, Vines P, Hoeffel E. (2012). The American Indian and Alaska Native Population: 2010. 2010 Census Briefs, Washington, DC: US Census Bureau.

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.

Johnson L. (1968). The Forgotten American: The President's message to the Congress on goals and programs for American Indians. Indian Record 1-14.

Indian Health Service. (2018). Indian health disparities.

Centers for Disease Control and Prevention. (2018). Deaths: Final Data for 2016. National Vital Statistics Report (67)5, 1-76.

SCOPE

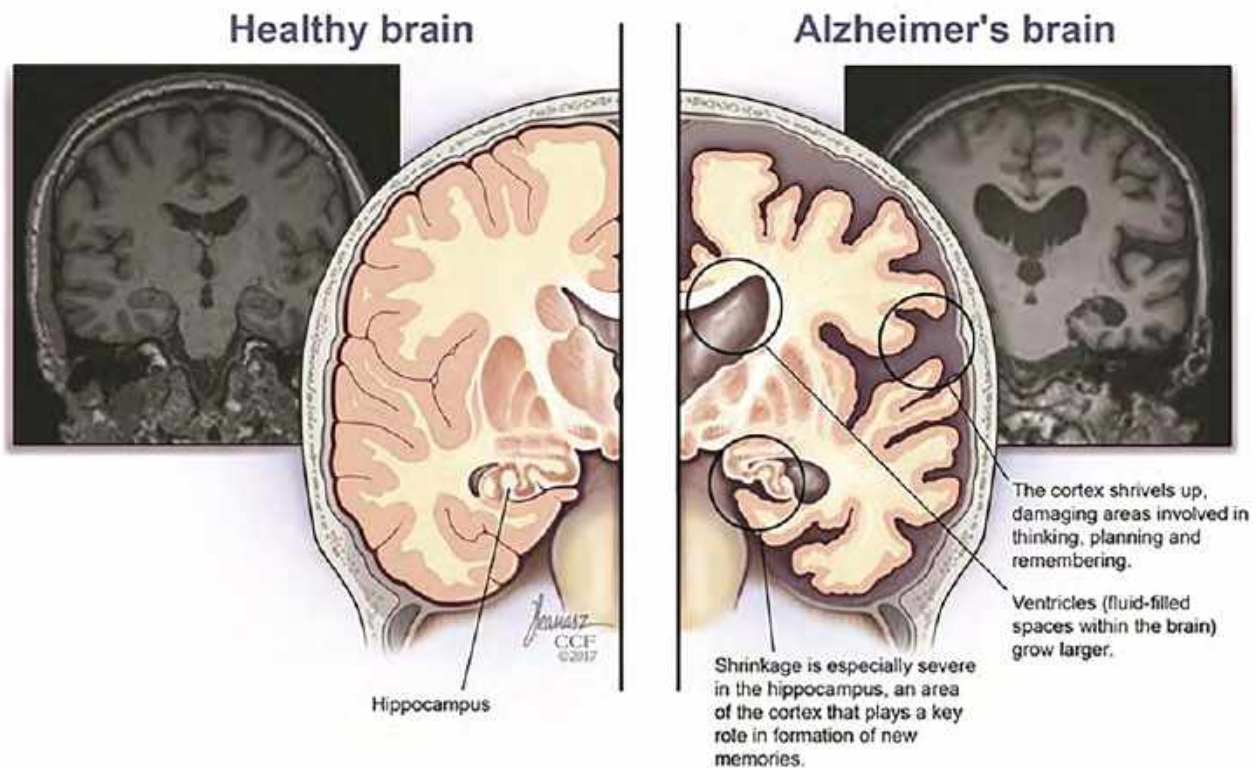
- Between 2014–2060, the number of AI/ANs aged 65 and older living with dementia is projected to grow over five times
- In 2015–2017, one in six AI/ANs aged 45 and older reported subjective cognitive decline (SCD) — that is, self-reported difficulties in memory or thinking
- Nearly two-thirds of those with SCD had to give up some day-to-day activities because of these cognitive problems

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.

Centers for Disease Control and Prevention. (2018). Healthy aging data portal, National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health.

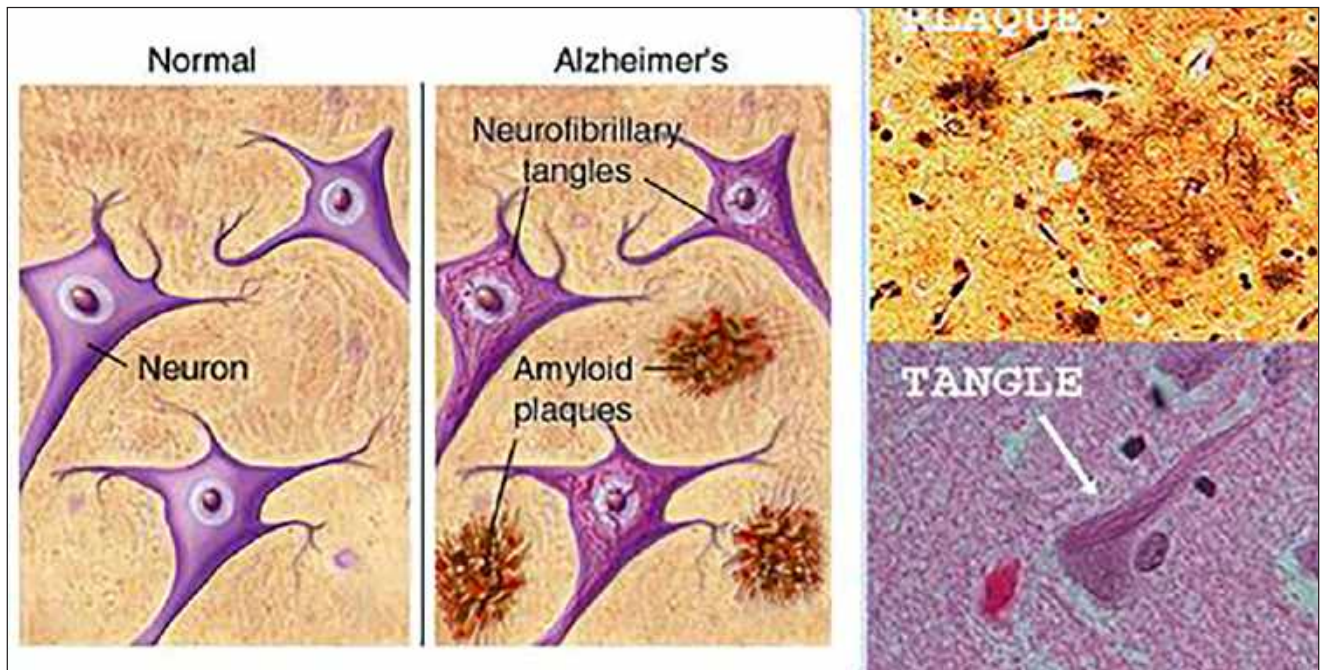
ALZHEIMER'S ASSOCIATION

Brain Tour: https://www.alz.org/alzheimers-dementia/what-is-alzheimers/brain_tour



MRI scans (gray) and illustrations (color) show the differences between a brain affected by Alzheimer's disease and a normal brain.

Source: www.keepmemoryalive.org



<https://www.scientificarchives.com/article/Alzheimers-Disease-A-Brief-Review>

Above Graphic:

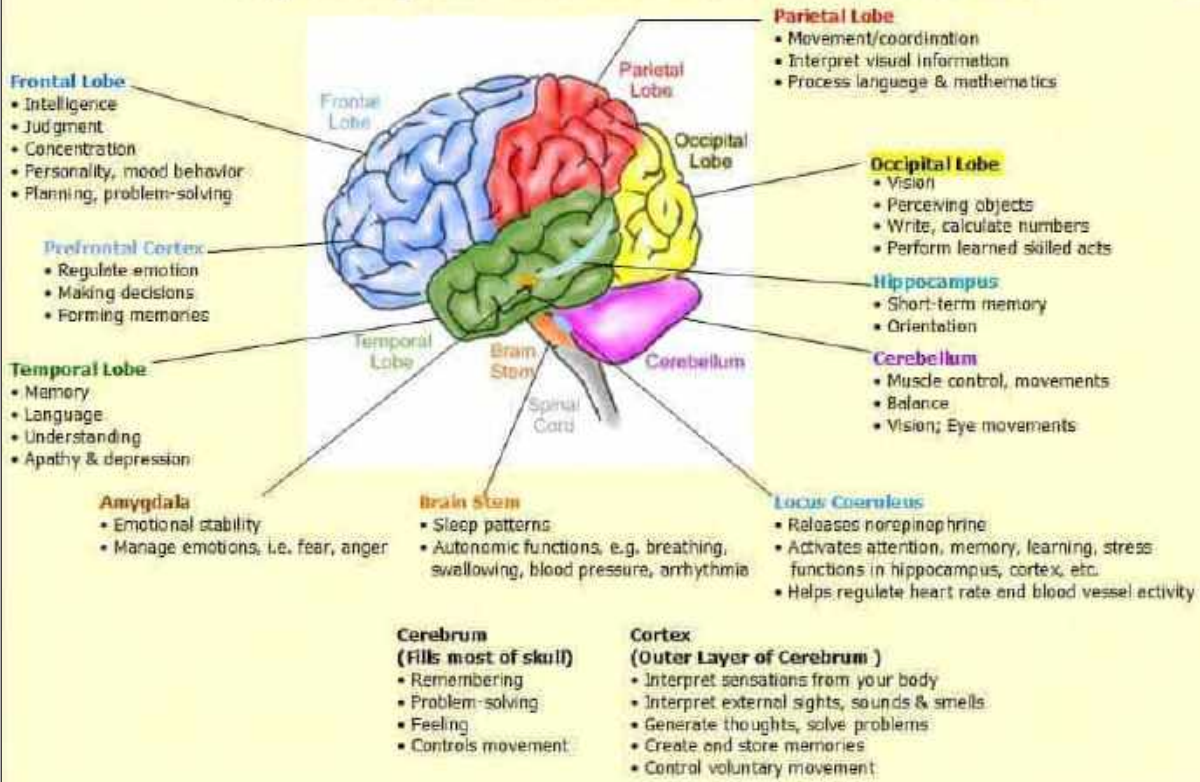
Left: Illustration of neurons in a healthy brain

Center: Illustration of neurons in an Alzheimer's brain. Neurofibrillary tangles are apparent within the neuron and there are amyloid plaques surrounding the neurons

Right top: Histological slide under a microscope of amyloid beta-protein deposits labeled "plaque"

Right bottom: Histological slide of neurofibrillary tangle under a microscope

Major Regions of the Brain & Their Functions



www.deathtodisabetes.com

The different kinds of dementia

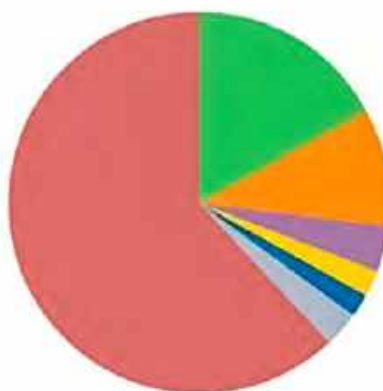
Dementia is not one thing. There are several routes to similar symptoms

ALZHEIMER'S 62%
Causes problems with memory, language and reasoning. 5% of cases start before age 65

VASCULAR DEMENTIA 17%
Impaired judgement, difficulty with motor skills and balance. Heart disease and strokes increase its likelihood

MIXED DEMENTIA 10%
Several types of dementia contribute to symptoms. Most common in people over 85

SOURCE: ALZHEIMERS.ORG.UK



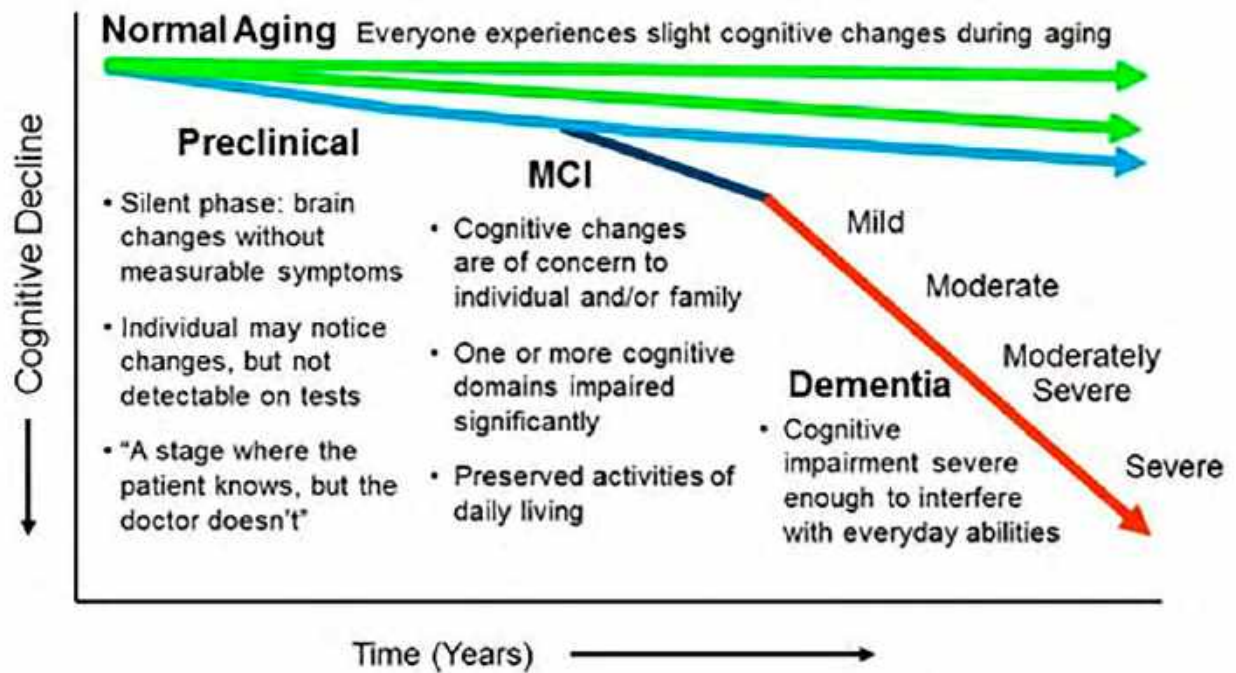
OTHER 3%
Conditions such as Creutzfeldt-Jacob disease; depression; multiple sclerosis

DEMENTIA WITH LEWY BODIES 4%
Caused by Lewy body proteins. Symptoms can include hallucinations, disordered sleep

FRONTOTEMPORAL DEMENTIA 2%
Personality changes and language problems. Most common onset between the ages of 45 and 60

PARKINSON'S DISEASE 2%
Can give rise to dementia symptoms as the condition progresses

Source: <https://guidetolongtermcare.wordpress.com/2017/04/26/dementia-isnt-just-one-thing/>



Source: UC Mind: <https://www.mind.uci.edu/about/>

MILD COGNITIVE IMPAIRMENT

- Have noticeable problems that DON'T interfere with daily life
- May show up on testing
- Some progress to dementia, some don't
- Excellent time to talk about risk factors, encourage exercise, quit smoking, brain health
- Monitor progression

DIABETES AND THINKING/COGNITION

- Decreased insulin concentrations = deficits in cognition, memory, learning abilities
- Well known negative association with poor glycemic control and cognitive function
- Diabetes exacerbates age-related impairments in several cognitive functions- attention- processing speed, episodic memory, visuospatial abilities
- People with diabetes = nearly twice risk of developing Neurocognitive Disorders
- Additional risk: advanced complication, long duration, take insulin

PATHOPHYSIOLOGY

Insulin enters the central nervous system (CNS) through the blood-brain barrier by receptor-mediated transport to regulate food intake

- Overproduced amylin, peptide hormone
- Impaired brain insulin signal, vascular damage
- Elevated il6, crp, 1 antichymotrypsin
- Oxidative stress
- Insulin signal gets impaired, deposition of amyloid plaques, mitochondrial dysfunction, inflammatory stress in peripheral tissue

Mittal, Khyati, Ruchi Jakhmola Mani, and Deepshikha Pande Katare. "Type 3 diabetes: cross talk between differentially regulated proteins of type 2 diabetes mellitus and Alzheimer's disease." Scientific reports 6 (2016): 25589.

DIABETES AND DEMENTIA

- Infarcts / tissue death due to inadequate blood supply
- Non-infarct ischemic lesions that affect white matter
- Chronic hypoperfusion (reduced amount of blood flow)
- Hemorrhage /blood loss
- Inflammation

Association of type 2 diabetes with brain atrophy and cognitive impairment. Rosebud O. Roberts, David S. Knopman, Scott A. Przybelski, Michelle M. Mielke, Kejal Kantarci, Gregory M. Preboske, Matthew L. Senjem, Vernon S. Pankratz, Yonas E. Geda, Bradley F. Boeve, Robert J. Ivnik, Walter A. Rocca, Ronald C. Petersen, Clifford R. Jack Neurology Apr 2

Biesself GJ, Stackenbroug S, Brunner E, Brayne C, Scheltens P. Risk of dementia in diabetes mellitus : a systematic review. Lancet Neurology. 2006; 5(1) 64-74.

HEALTHY HEART, HEALTHY BRAIN

- ASTHO, CDC, IA2
- <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



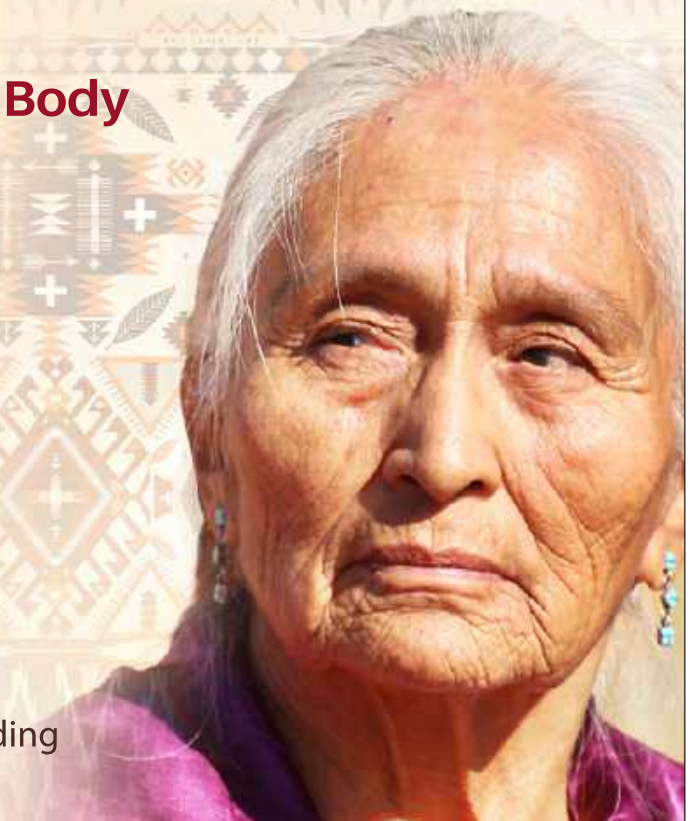
1 in 10

People age 65 and older
has Alzheimer's



1 in 3

American Indians over 65
develops dementia, including
Alzheimer's



EXERCISE

- Muscle mass and strength decline with age
- People who have had diabetes longer or have higher a1c have lower strength per unit of muscle mass than age and Body Mass Index (BMI) matched people without diabetes and people who have better control and diabetes of shorter duration
- EVEN LIGHT ACTIVITY = psychosocial well-being and higher self-rated health

International Diabetes Federation (2013b) Global Guideline for Managing Older People with Type 2 Diabetes. IDF, Brussels. Available at: <http://bit.ly/1izxDlj>

Kirkman, M Sue et al. Diabetes in older adults. *Diabetes Care* 2012 Dec; 35(12): 2650-2664.
<https://doi.org/10.2337/dc12-1801>

BRAIN HEALTH

- Mental health conditions are undiagnosed
- Challenge your brain by obtaining new skills
- Eat for your body
- Lower heart disease risk
- Socialize and help elders not be isolated
- Protect your noggin – wear a helmet!
- Sleep well and treat issues
- No smoking

RISK FACTORS-MODIFIABLE

- Traumatic brain injury in mid-life
- Exposure to air pollution in later life
- Excessive alcohol use (>than 14 drinks a week)
- Less education, hearing loss, hypertension, obesity, smoking, depression, social isolation, lack of physical activity, and diabetes

Livingston G, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission
[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)30367-6/fulltext#seccestitle30](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30367-6/fulltext#seccestitle30)

MEDICATIONS

- Donepezil and Galantamine-prevent acetylcholine breakdown, helps nerve cells communicate
- Common side effects: nausea, vomiting, diarrhea
- Take with food
- Interruption of meds = start back at lowest dose
- Vivid dreams: take in am
- Bradycardia (slow heart rate)

AD2000 Collaborative Group, Lancet 2004;363

MEDICATIONS

- Likely no disease modifying effects – modest cognitive improvement
- Delay progression 6 mo - 1 yr
- Guidelines: “Base the decision to initiate therapy on individualized assessment”
- Insufficient evidence regarding head-to-head comparisons; choose medication based on side effects and dosing
- Be wary of decrease/stop

OTHER MEDICATIONS

- Memantine (Namenda)
 - Commonly used as an anesthesia
 - Glutamate stimulates N-Methyl-D-aspartic acid or N-Methyl-D-aspartate (NMDA) receptor
 - Overstimulation results in neuronal damage
- Pooled estimate from 3 trials (vs. placebo)
 - Statistically significant improvements on Alzheimer’s Disease Assessment Scale (ADAS) – cognitive scale but modest clinical improvement
- Memantine combined with other acetylcholinesterase inhibitors (ACHEI)

Qaseem A, et al. Ann Intern Med, 2008;148

BEER’S CRITERIA

Potentially inappropriate medications

Drug or drug class	Rational
First-generation antihistamines	Highly anticholinergic; greater risk of confusion, dry mouth, and other anticholinergic adverse events
Nitrofurantoin	Pulmonary toxicity may occur; lack of efficacy data in those with a CrCl < 60 mL/min
Alpha-1 blockers	May cause orthostatic hypotension; do not use as an antihypertensive
Alpha agonists (e.g., clonidine, guanabenz, methyldopa)	High risk for central nervous system adverse events
ANTICHOLINERGIC: INHIBITS ACTION OF ACETYLCHOLINE	

ANTIHISTAMINES

- **Agents:** diphenhydramine, chlorpheniramine, brompheniramine
- **Dosing:** multiple times a day (every 4 - 6 hours)
- **Side effects:** Central nervous system depression (sedation, impaired cognition, impaired coordination), CNS excitation (anxiety, hallucinations, stimulation), anticholinergic effects (dryness of mouth, nose and eyes; blurred vision; constipation urinary retention)

BEER'S CRITERIA

Drug or drug class	Rational
Digoxin > 0.125 mg/d	Higher doses do not result in additional benefit and risk of toxicity high especially in those with reduced renal function
Antipsychotics, both first and second generation	Increased risk of stroke and mortality in those with dementia
Barbiturates	High rate of physical dependence; overdose a concern
Benzodiazepines	Older adults more sensitive to effects; increases risk of cognitive impairment, delirium, falls, and fractures
Nonbenzodiazepine hypnotics (e.g., zolpidem)	Adverse events similar to those observed with benzodiazepines
Estrogens	Evidence of carcinogenic potential and lack of cardiovascular or cognitive benefits
Sliding scale insulin	Higher risk of hypoglycemia without improving hyperglycemia
Non-COX selective oral Nonsteroidal anti-inflammatory drugs (NSAIDS)	Increased risk of gastrointestinal bleed and peptic ulcer disease in high-risk groups
Skeletal muscle relaxants	Poorly tolerated because of anticholinergic effects

SOCIAL CAPITAL AND DEMENTIA

- Cognitive reserve, social capital accrued in early and midlife may reduce effects of psychological stress on cognitive functioning in old age
- Fostering structural aspects of social capital in a community is a potential dementia prevention strategy
- Social capital is associated with better health, lower risks for dementia, disability, and mortality

Murayama, H., Miyamae, F., Ura, C., Sakuma, N., Sugiyama, M., Inagaki, H., ... & Awata, S. (2019). Does community social capital buffer the relationship between educational disadvantage and cognitive impairment? A multilevel analysis in Japan. *BMC Public Health*, 19(1), 1-12.

Ihle, A., Oris, M., Sauter, J., Rimmele, U., & Kliegel, M. (2018). Cognitive reserve and social capital accrued in early and midlife moderate the relation of psychological stress to cognitive performance in old age. *Dementia and geriatric cognitive disorders*, 45(3-4), 190-197.

Kuiper JS, Zuidersma M, Oude Voshaar RC, et al. Social relationships and risk of dementia: a systematic review and meta-analysis of longitudinal cohort studies. *Ageing Resr Rev.* 2015;22:39-57.

Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. *PLoS Med.* 2010;7:1-20.

Make sure to tell people they're valued, they have a purpose and responsibility. Engage people and keep them involved - THAT is social capital.

- traditional art programs
- adopt an elder
- language immersion programs led by elders

UNIT 1 KNOWLEDGE CHECK

1. True or False?
The following are all routes to dementia systems: Alzheimer's disease, vascular dementia, frontotemporal dementia, and Parkinson's disease.
 - a. True
 - b. False
2. Pick One:
Which of the following is NOT a risk factor for Alzheimer's disease?
 - a. Diabetes
 - b. Social isolation
 - c. Obesity
 - d. Excessive alcohol use
 - e. More education
3. True or False?
Medications for Alzheimer's disease and related dementias have shown to delay progression 2 - 3 years.
 - a. True
 - b. False

Please find the correct answers for the knowledge check in appendix 3.



Unit 2:

THE ROAD MAP FOR INDIAN COUNTRY

INTRODUCTION

Unit 2 will take approximately 30 minutes to complete

This unit contains information on the Healthy Brain Initiative Road Map for Indian Country (RMIC), including how it was developed, RMIC themes, strategies and practical applications. Within this unit is a slide deck presentation by Heidi Holt, as well as a visioning activity to help imagine what your community would look like if brain health was a focus or priority.

Heidi Holt is a Public Health Advisor in CDC's Alzheimer's Disease and Healthy Aging program where she has responsibility for strategic planning, program development and cross-sector collaboration. Ms. Holt holds a Masters of Public Administration from the University of Southern California, and a Certificate in Gerontology from the University of Georgia and had an integral part in the creation of the Road Map.

Materials needed for Unit 2:

- Self-study:
 - Slide deck (following)
 - Visioning activity worksheet (following)
 - Writing utensil
- Group facilitation:
 - Slide deck (following)
 - Visioning activity facilitator guide ([appendix 4](#))
 - Visioning activity worksheet (following)
 - Writing utensil

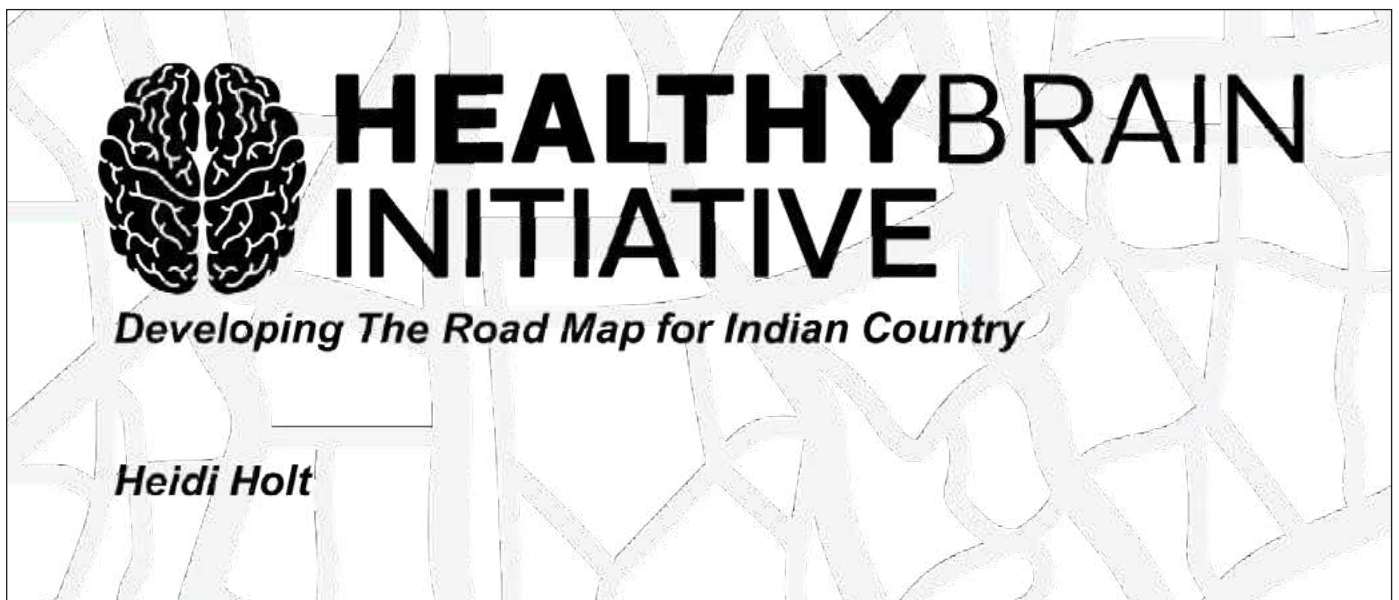
SLIDE DECK



Heidi Holt

CENTERS FOR DISEASE CONTROL AND PREVENTION
ALZHEIMER'S DISEASE AND HEALTHY AGING PROGRAM

hholt@cdc.gov

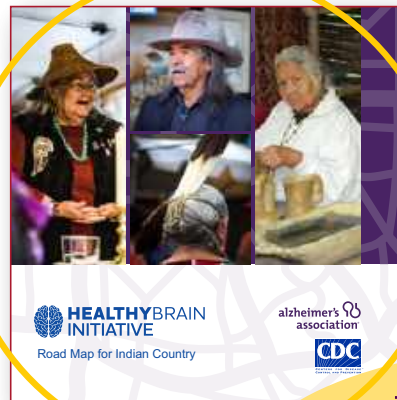
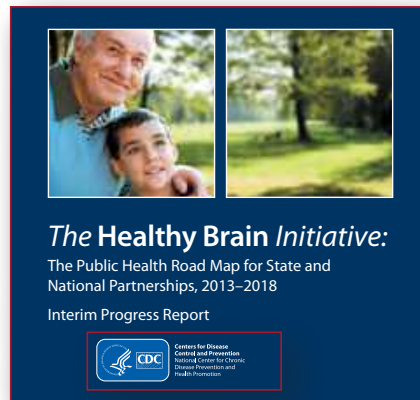
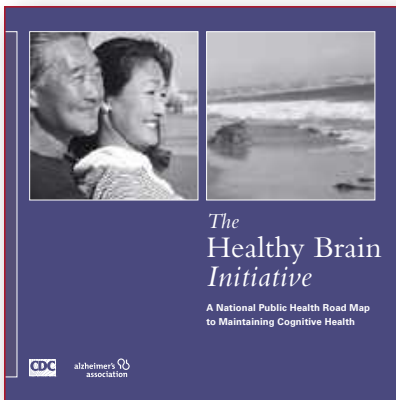


The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers of Disease Control and Prevention.



Public health strategies to promote brain health, address dementia and help support caregivers

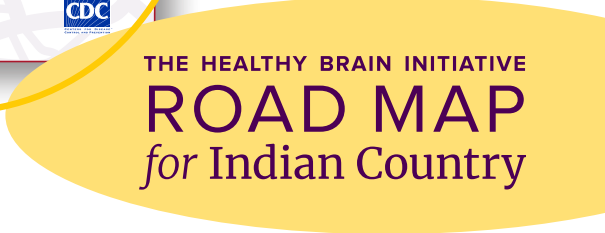
The Healthy Brain Initiative Road Map series. The initiative creates and supports partnerships, collects and reports data, increases awareness of brain health, and supports populations with a high burden of Alzheimer’s disease and related dementias.



www.cdc.gov/aging

ROAD MAP INTENT

- Conversation starter
- Prompt local planning
- Encourage
 - Public health strategies
 - Work across and between generations for the good of all



ADVICE & EXPERTISE & COLLABORATION

- Indian Health Service
- 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
- National Institute on Aging
- And many more.....Thank You!

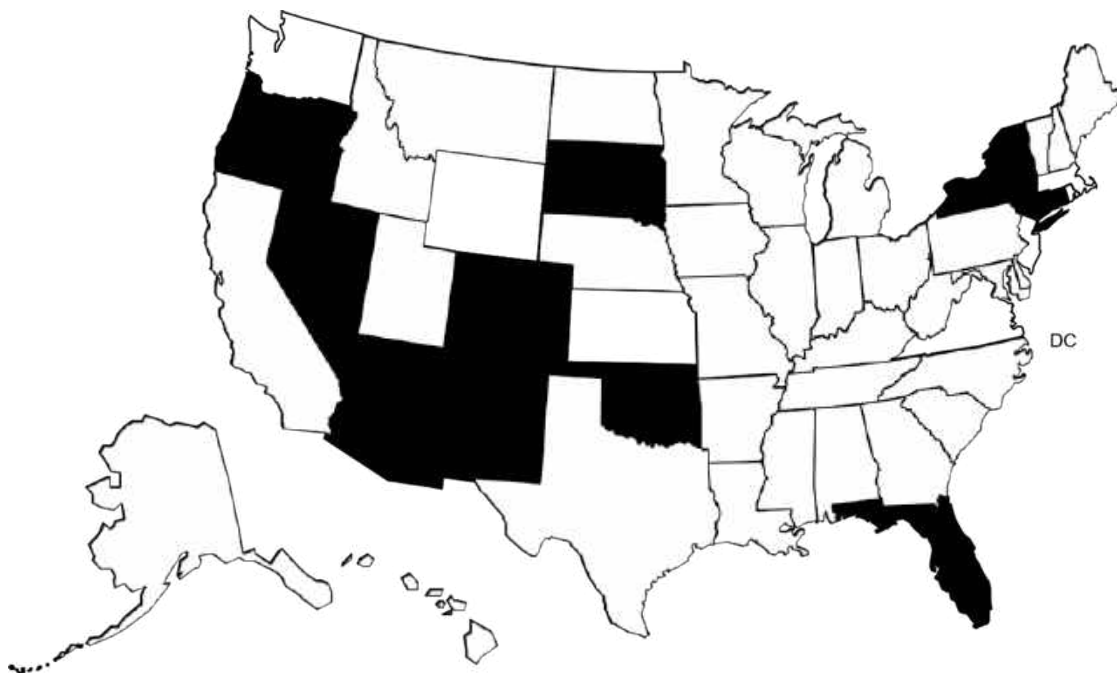
LISTENING AND LEARNING

2 virtual listening sessions

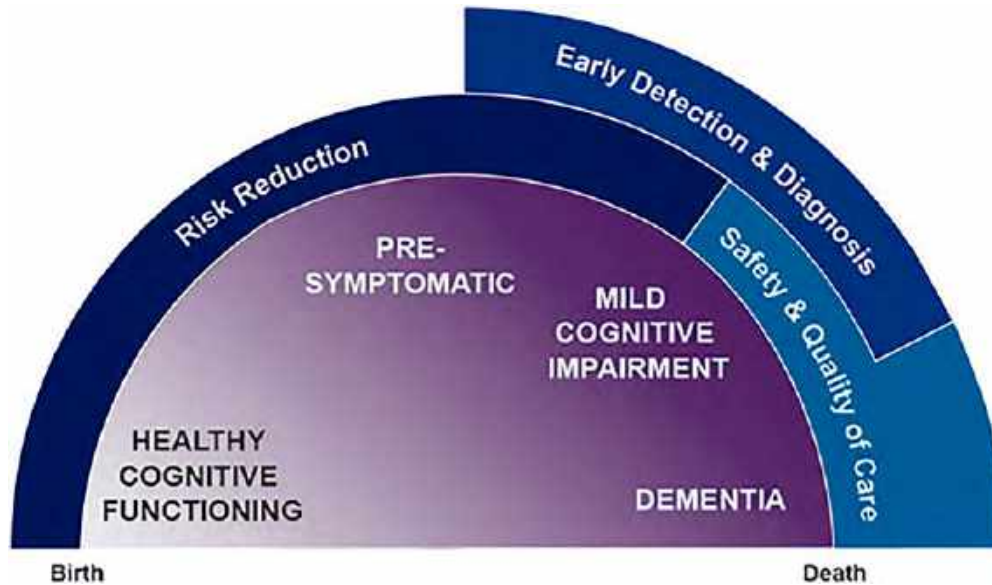
- Tribal Health Directors
 - 12 regions, 500+ invitations
- Tribal Senior Program (Title VI Directors)
 - Invitations through Administration for Community Living

40+ Tribal leaders and experts offered written suggestions and comments partnering with AI/AN Communities

PARTNERING WITH AI/AN COMMUNITIES CHAPTER INNOVATION GROUP



DEMENTIA LIFE-COURSE PERSPECTIVE AND PUBLIC HEALTH ROLES



THEMES

- Knowledge & awareness of dementia varies
- Complex, changing context

Recommendations

- Local leaders know the best ways to reach and serve their members
- Build upon community strengths & existing public health systems

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 AND 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

Refer to page 20-21 of the RMIC for more information

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)

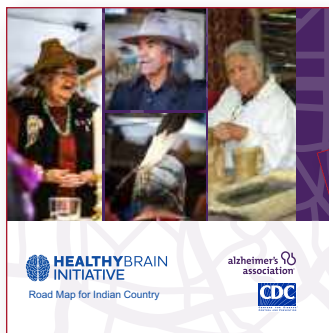
Refer to page 22 of the RMIC for more information

COLLECT & USE DATA

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

Refer to page 20-21 of the RMIC for more information

RESOURCES TO ACCOMPANY ROAD MAP FOR INDIAN COUNTRY



- Executive Summary
- Dissemination Guide
- 10 Warning Signs
- Starting Conversations
- Other Public Health Programs

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

The collage includes several key documents:

- Learn, Plan, Respond to Dementia:** A guide for community members on how to respond to dementia, including information on the prevalence of dementia in AI/AN populations and the impact of dementia on AI/AN communities.
- DISSEMINATION GUIDE:** A guide for community members on how to disseminate information about dementia and caregiving, including information on the Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association.
- 10 Warning Signs of Alzheimer's:** A list of 10 warning signs of Alzheimer's disease, including memory loss that disrupts daily life, changes in planning or judgment, and confusion with time or place.
- Starting Conversations About Alzheimer's:** A guide for community members on how to start conversations about dementia and caregiving, including information on the importance of starting conversations and the role of community members.
- Indian Country Public Health Programs:** A guide for community members on how to identify and engage with public health programs in Indian Country, including information on the role of public health programs and the importance of community engagement.

PODCAST SERIES

- [What About the Caregivers?](#)
- [Health Risks of Loneliness and Social Isolation in Older Adults](#)
- [Healthy Body, Healthier Brain](#)
- [Cuerpo sano, cerebro sano](#)

<https://tools.cdc.gov/medialibrary/index.aspx#/podcastseries/id/302101>

SERIES OF COMMUNICATION MATERIALS

- Poster and flyers for clinics and health fairs
- Radio public service announcements
- Micro-videos for clinics
- Provider guide about heart and brain health
- Newspaper articles for the Indian Country Today Media Network

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



NEW: WISDOM KEEPERS CAMPAIGN

Healthy Heart, Healthy Brain...
Help the wisdom keepers keep their wisdom

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

Make an appointment at your local Urban Indian Organization to talk about how to keep your mind and heart healthy.

1 in 10 people aged 65 and older have Alzheimer's disease.	1 in 3 American Indians over 65 develop dementia, including Alzheimer's disease.	5.7 million Americans have Alzheimer's disease.
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Watch the video and learn more at ncuih.org/wisdomkeeper

CDC

Early Detection Matters.

Learn how to recognize the signs of Alzheimer's and other forms of dementia in loved ones and schedule an appointment with your local Urban Indian Health facility.

Watch the video and learn more at ncuih.org/wisdomkeeper

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CDC

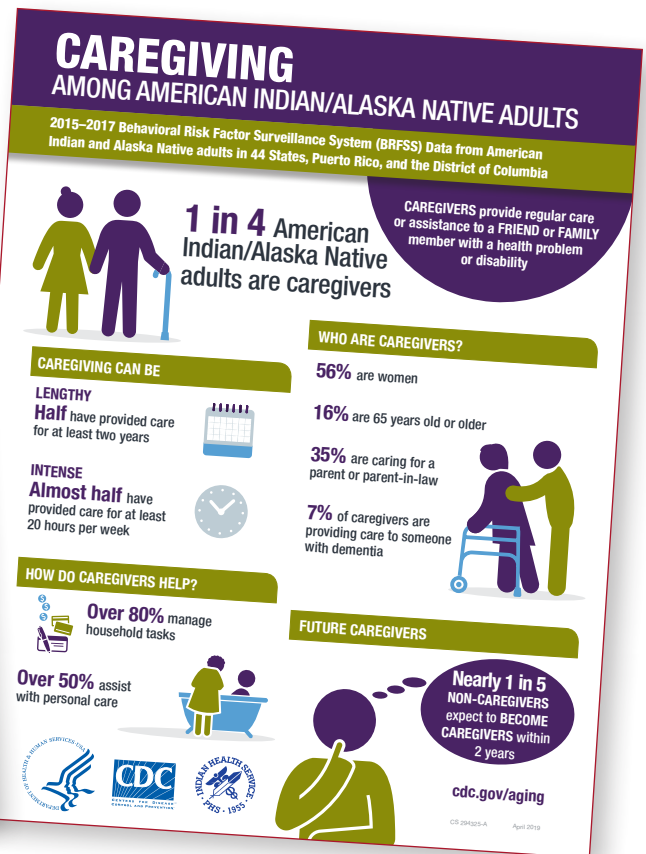
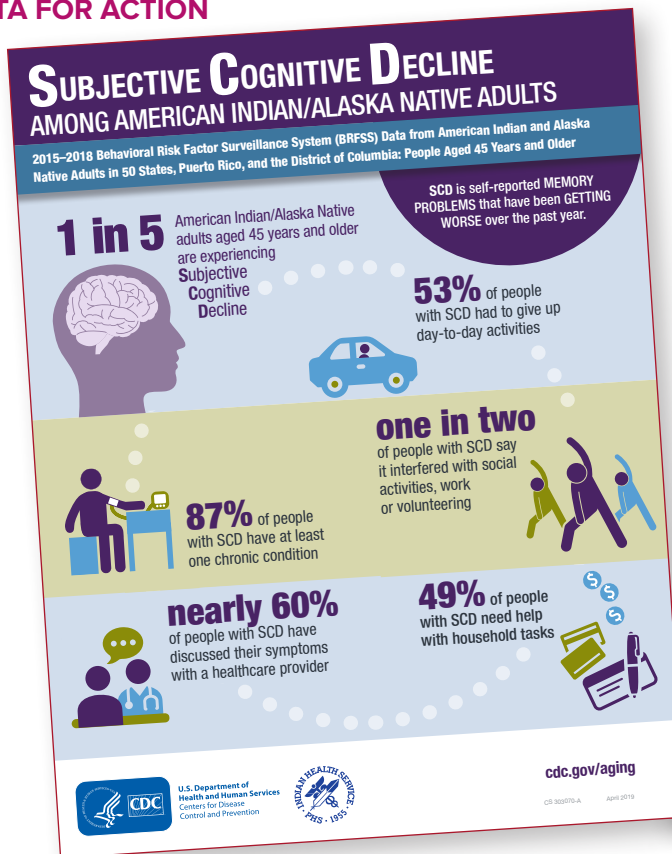
<https://www.cdc.gov/aging/healthybrain/videos/index.html>

NEW: HEALTHY BRAIN VIDEOS FOR WISDOM KEEPERS



<https://www.cdc.gov/aging/healthybrain/videos/index.html>

DATA FOR ACTION



Infographics in English and Spanish: <https://www.cdc.gov/aging/data/infographic/index.html>

CUSTOMIZED NATIONAL AND STATE LEVEL REPORTS



The Alzheimer's Disease and Healthy Aging Data Portal provides easy access to national and state level CDC data on a range of key indicators of health and well-being for older adults, including:

- Caregiving
- Subjective Cognitive Decline
- Screenings and vaccinations
- Mental health

These indicators provide a snapshot of currently available surveillance information, and can be useful for prioritization and evaluation of public health interventions.

Explore Alzheimer's Disease and Healthy Aging Data By Location

Explore Alzheimer's Disease and Healthy Aging Data for all indicators for one location: the U.S., a region, or a state.

Location



Explore Alzheimer's Disease and Healthy Aging Data By Indicator

Explore Alzheimer's Disease and Healthy Aging Data for one indicator for all available locations.

Category

Create Custom Reports and Visualizations

Go to the Alzheimer's Disease and Healthy Aging Data Portal to create a custom report, customize visualizations, download data, and more.

[Alzheimer's Disease and Healthy Aging Data Portal](#)


Alzheimer's Disease and Healthy Aging Data Publications

[State of Aging and Health in America: Data Briefs](#)
[Healthy Brain Initiative Road Map](#)




<https://www.cdc.gov/aging/agingdata/index>.

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[What's this?](#)




Alzheimer's Disease and Healthy Aging

COVID-19: Guidance for Older Adults




Alzheimer's Disease Public Health Curriculum




Healthy Brain Initiative 2023 Road Map

What's New


- Podcasts, Health Risks of Social Isolation and Loneliness Before and During COVID-19
- Social Determinants of Health and Alzheimer's Disease
- Study Shows Baby Boomer Caregivers in Poor Health
- Help for Caregivers




What is Alzheimer's disease?





Caregiving





Healthy Brain Road Maps


 What's New?


 Data and Statistics


 Alzheimer's Disease and Healthy Aging Data Portal

 Resources & Publications

 Healthy Brain Initiative

 Communications Center

 Training for Health Professionals

 Partner Resources

Newsletter Subscription: <https://tools.cdc.gov/campaignproxyservice/subscriptions.aspx>

More information and materials available at: www.cdc.gov/aging



HEALTHYBRAIN INITIATIVE

Advance brain health as a central part of public health practice (Nationally)



BOLD is designed to create a strong public health infrastructure for dementia and dementia caregiving

Component A

The Alzheimer's Association

Component B

International Association for Indigenous Aging
University of Illinois at Chicago
UsAgainstAlzheimer's

BOLD PUBLIC HEALTH CENTERS OF EXCELLENCE

Building Our Largest Dementia Infrastructure (BOLD) — *Public Health Centers of Excellence* to Address Alzheimer's Disease and Related Dementias (CDC-RFA-DP20-2005)

Public Health Center of Excellence in Dementia Caregiving

University of Minnesota

Public Health Center of Excellence in Dementia Risk Reduction

Alzheimer's Association

Public Health Center of Excellence in Early Detection of Dementia

NYU School of Medicine

BOLD PUBLIC HEALTH PROGRAMS

Enhanced (Implementation)

Georgia
Rhode Island
Wisconsin
Minnesota
Virginia

Core Capacity (Planning)

Northwest Portland Area Indian Health Board
Colorado
Iowa
Maine
Nevada
Oklahoma
Hawaii
Los Angeles County
Mississippi
North Carolina
Vermont

UNIT 2 ACTIVITY: VISIONING ACTIVITY

Use the worksheets below to help envision a community where brain health is prioritized. Write down your answers in the space provided. There is no right or wrong answer.

ACTIVITY OBJECTIVE:

- Participants will be able to describe what an "ideal" community might look like if brain health was fully addressed and prioritized

Materials Needed for Unit 2 Activity:

- Self-study:
 - Visioning activity worksheet
 - Writing utensil
- Group facilitation:
 - Visioning activity facilitator guide (appendix 4)
 - Visioning activity worksheet
 - Writing utensil

WORKSHEET #1

Brain Health Visioning Activity

*In a community where **brain health** is prioritized:*

Community Members would...

VISION:



***Caregivers** would...



National Indian
Health Board



*A caregiver is a family member or paid helper who regularly helps someone who needs assistance with daily living, such as a child, someone with an illness or the elderly.

Tribal Leaders would...

VISION:



Data would be used to...

VISION:



National Indian
Health Board



Healthcare Services would...

VISION:



What Else?

VISION:



National Indian
Health Board



UNIT 2 KNOWLEDGE CHECK

1. Pick Many:
Input from which of the following entities were used to inform the Road Map for Indian Country?
 - a. Tribal Leaders
 - b. Tribal Health Directors
 - c. Tribal Title VI Directors
 - d. Tribal Elders
2. Pick Many:
Which of the following are Road Map for Indian Country Strategies?
 - a. Collect and use data
 - b. Strengthen the workforce
 - c. Educate and empower community members
 - d. Develop policies and mobilize partnerships
3. True or False?
Mild cognitive impairment always progresses into dementia.
 - a. True
 - b. False

Please find the correct answers for the knowledge check in appendix 3.



Unit 3:

CULTURAL CONSIDERATIONS IN BRAIN HEALTH FOR INDIAN COUNTRY

INTRODUCTION

Unit 3 will take approximately
35 minutes to complete

This unit contains information on cultural considerations, including the importance of communication and practicing cultural humility, the impact of cultural understanding, sensitivities, appropriateness and humiliation when providing health services to American Indians and Alaska Natives. This slide deck contains a presentation by Dr. Linda Bane Frizzell.

Dr. Frizzell, (Eastern Band of Cherokee Indians/Lakota) has extensive experience and practice as a provider and administrator with Indian health systems. She has a doctorate in Physiology, Education Administration, and Gerontology and a postdoc in epidemiology. She has been honored to be a Tribal technical advisor for health care and services policy and legislation for over 26 years. Dr. Frizzell has extensive experience in working with countless Tribes across the nation to enhance their infrastructures and assist in their quest for self-determination. She is currently a faculty member of the University of Minnesota where she teaches American Indian health and wellness and provides presentations on Tribal public health and wellness.

Materials needed for Cultural Considerations in Brain health for Indian Country:

- Self-study:
 - Slide deck (following)
 - Cultural considerations for Tribal brain health worksheets (following)
 - Writing utensil
- Group facilitation:
 - Slide deck (following)
 - Cultural considerations for Tribal brain health facilitator guide ([appendix 5](#))
 - Cultural considerations for Tribal brain health worksheets (following)
 - Writing utensil

SLIDE DECK

CULTURAL CONSIDERATIONS FOR PROVIDING HEALTH SERVICES WITH AMERICAN INDIANS AND ALASKA NATIVES: HOW IMPORTANT IS COMMUNICATION AND THE PRACTICE OF CULTURAL HUMILITY



Dr. Linda Bane Frizzell, Ph.D., M.S.

UNIVERSITY OF MINNESOTA
SCHOOL OF PUBLIC HEALTH

WHAT IS CULTURE?

- Is it race?
- Is it ethnicity?
- Is it geographical?
- Does it relate to spirituality/religion?
- Does it have familial ties/history?
- Are there different levels of culture?
- Is it possible to be multicultural?
- Can culture be open or closed? Both?
- Is there more than one culture that governs/guides an individual? e.g. “sub-cultures”

WHY IS CULTURE IMPORTANT FOR PATIENT SERVICES?

- How do you communicate with Patients or Clients?
 - Verbal
 - Visual
 - Body language
 - Face to Face
 - Gestures
 - Physical contact (e.g. shaking hands, holding hand...)
 - How do you listen? What importance is “**listening**”?
 - Does **YOUR** culture have any effect on communication?
 - Do you believe that **EVERY** patient/client has their own unique culture?

HOW DO YOU BECOME CULTURALLY SENSITIVE/ATTUNED?

- Cultural sensitivity is a lifelong pursuit
- Cultures are continuously changing - by way of their own acceptable guides to SURVIVE
- Members of cultural groups have a responsibility to be gate keepers, change agents, mentors, and willing to evolve to protect their cultural practices
- Individuals can learn to be culturally sensitive by first being respectful of their own cultures, and be humbled in other cultures (**NOT** condescending)
- It is important to never assume facts (may be myths) or assume to understand the actions of other cultures
- When in doubt ask for advice

GENERAL CULTURAL HUMILITY

- Are there “general” processes/education for health service providers?
 - Importance?
- What are the current expectations of U.S. citizens in regard to respect/considerations of “culturally appropriate” health services?
 - Can this be generalized?
- Suggested “culturally competent” definition:

Culturally competent services can ONLY be determined by the Patient or Client

WHY IS IT IMPORTANT TO HAVE CULTURAL HUMILITY?

- Does culture affect the quality and effectiveness of services?
- Does culture affect understanding of signs and symptoms?
- Are there some questions/topics that are not part of various cultures?
- Are there some questions/topics that cultural customs prohibit from being asked?
- Should there be traditions that culture protects?
- Can one become culturally aware, sensitive, respectful?
- Can one become culturally competent?

WHAT ARE WE TRYING TO DO UNDER THE CULTURAL HUMILITY UMBRELLA?

- Enlighten health service providers?
 - Should health providers also help Patients/Clients to understand how the health services system operates?
Or do they even know?
- Are there “prerequisites for culture humility”?
- Are there tools that can be used, e.g. education, mentors?
- The “keepers” of the culture? Who are they?
- How will you know if you practice cultural humility?

CULTURAL CONSIDERATIONS

- Consider historical issues of “trust” of health services providers
- Consider the individual’s perceptions of “normal aging” (e.g. it is NOT “normal to lose memory”)
- Does the individual’s culture have “stigma” in regard to memory loss? “A” word = terminal; dementia vs “demented”
- What is the individual’s choice of family involvement?
 - What are the cultural expectations?
 - What are the family’s responsibility to care for individual?
 - Does/will the family experience “shame” from others?
- Are there cultural impacts for choices of ethical issues, artificial nutrition, life support, autopsies?



COMMUNICATION CONSIDERATIONS

- Perceptual barriers – we all see the world differently
- Emotional barriers – withholding thoughts and feelings
- Cultural barriers – misunderstandings, group behaviors
- Age barriers, generational, historical
- Language barriers – not everyone is familiar with all languages or jargon (e.g. subs, hoagies, grinders)
- Learned expectations – often referred to as stereotyping
- Learned dependence – high rate of AI/ANs
- Misinterpretations – misjudgment – dangerous and quickly noted by patients

OTHER CULTURAL CONSIDERATIONS

- Consider linguistic, economic and social experiences of the individual:
 - What is the choice of communication (self, or family member, advocate)?
 - Are there barriers to access services (including access to culturally sensitive providers)?
 - Do not place all of the family in a single culture or ethnic group.
 - Respect individual choice of:
 - Physical distance
 - Physical contact
 - Tone of voice
 - Eye contact

METHODS FOR INCREASING CULTURAL HUMILITY

- Grow your Own - empower local residents, to be the foundation of a culturally attuned and grounded professional health service workforce
- Mentoring – offer opportunities for professionals to learn from each other – embrace building “cultural capital”
- Two way mentoring – can help reduce culture shock of moving from a rural or village life to urban areas (e.g. college student pairing with high school students)
- Learning – all levels of life
- Job-based learning (work a sub-culture? – within a culture)
- Determine who are the “keepers” of traditions and solicit advice from them

SO WHAT ABOUT DIRECT SERVICE PROVISION FOR MENTALLY IMPAIRED INDIVIDUAL?

- What is your first step as a health service provider?
- How important is the patient/client history?
- Are there records available to provide history?
- How cognizant is the patient/client?
 - Remembering that individuals generally are aware if they are experiencing memory or cognitive issues
 - Individuals that have the ability to realize they are having memory issues are quite crafty at “hiding” their impairment
- Is the patient/client’s family available for consultation (if the patient/client agrees) for cultural, medical and behavioral health history?
- Understand the high likelihood that AI/ANs will have had a history of health services that were not sensitive to their culture

CULTURAL CONSIDERATIONS FOR AI/ANS WITH MEMORY IMPAIRMENTS

- Consider each person as an individual:
 - Member of a family
 - A dual citizen
 - With tribal affiliation (if willing to share)
 - Choice of spirituality (Western or Traditional or both)
 - Language preference
 - Historical trauma (100% of all AI/ANs have a history)
- Understand that some elders have histories of horrific racial experiences:
 - Genocide (bounty on dead Indians)
 - Forced assimilation (boarding schools, harsh punishments of using Native language, clothing)

OUTCOME POSSIBILITIES OF A SUCCESSFUL HEALTH AND WELLNESS ENCOUNTER

- Health and wellness service providers will:
 - Learn the history about the community you serve
 - Practice and serve with cultural humility
 - Have abilities to respect individuals and with permission, collaborate with families in “holistic” approaches that have been used for centuries by indigenous peoples
 - Do not assume all members of a family have the same cultural beliefs or same values of traditions
 - Provide the highest quality and effective services possible
- These “fundamentals” are a critical basis for improved understanding of cultural diversity and cultural traditions to reduce unknowing cultural oppression, subconscious racism, gender inequities, and forced historical dominant culture practices and policies

UNIT 3 ACTIVITY: CULTURAL CONSIDERATIONS WORKSHEET

This unit contained information on the impact of cultural understanding, sensitivities, appropriateness, and humility when providing health services. Please use the following questions to think about your own community and identify areas worth considering when improving you and your team's cultural competency. Use the space below each question to jot down your notes. Remember, having and showing cultural competency is a lifelong pursuit and evolves alongside the cultures themselves. The key to having cultural competency is to start with no assumptions. By showing empathy and humility when (humbly) approaching a cultural community, you can be most receptive to what you can learn from that culture.

ACTIVITY OBJECTIVE:

- Participants will discuss cultural considerations and strategies for how community voices can be incorporated in brain health services, policies and programming.

Materials needed for Unit 3 Activity:

- Self-study:
 - Cultural considerations worksheets
 - Writing utensil
 - An additional considerations deeper dive (optional) with questions is available in the cultural considerations facilitator guide ([appendix 5](#))
- Group facilitation:
 - Cultural considerations facilitator guide ([appendix 5](#))
 - Cultural considerations worksheets
 - Writing utensil
 - An additional considerations deeper dive (optional) with questions is available in the cultural considerations facilitator guide ([appendix 5](#))

CULTURAL CONSIDERATIONS WORKSHEET

1. What stood out from Dr. Frizzell's presentation? Do any of those considerations ring true in your community?
2. What experiences have your elders or family members had with brain health?
3. How is memory or cognition discussed in your Tribe or community? Are there words, phrases or topics of discussion to be avoided? Are there any traditions that relate to taking care of cognition?
4. Who is best to lead brain health discussions in your community?
5. What are the ways the Tribe(s) and/or community can be involved in brain health programs?
6. How can healthcare staff and program staff be more culturally competent when it comes to brain health in your community?
7. Are there traditions that could help support prevention of cognitive decline or the care of those who may have cognitive impairment?

UNIT 3 KNOWLEDGE CHECK

1. True or False?

Cultural sensitivity is a lifelong pursuit.

- a. True
- b. False

2. Pick Many:

How can you increase cultural humility, according to Dr. Frizzell's presentation? Please select all that apply.

- a. Grow your own (empower local residents to be the foundation of a culturally attuned and grounded professional health service workforce)
- b. Determine who are the "keepers" of traditions and solicit advice from them
- c. Job-based learning
- d. Learning
- e. Mentoring

3. Pick Many:

Dr. Frizzell's presentation included several cultural considerations for American Indians and Alaska Natives with memory impairments, which considerations did she share? Please select all that apply.

- a. Consider each person with choice of spirituality (Western or Traditional or both)
- b. Consider each person as an individual
- c. Consider each person with historical trauma (100% of AI/ANs have a history)
- d. Understand that some elders have histories of horrific racial experiences

Please find the correct answers for the knowledge check in appendix 3.



Unit 4:

PRIORITIZATION OF BRAIN HEALTH IN INDIAN COUNTRY

INTRODUCTION

Unit 4 will take approximately
65 minutes to complete

This unit contains the public health strategies outlined in the Road Map for Indian Country. Please have the Road Map for Indian Country available as a resource.

Materials needed for Prioritization of Brain Health in Indian Country:

- I Self-study:
 - a. Slide deck (following)
 - b. Prioritizing Strategies from the Road Map for Indian Country worksheets (following)
 - c. Road Map for Indian Country (pages 20 – 22)
 - d. Writing utensil
- II Group facilitation:
 - a. Slide deck (following)
 - b. Prioritizing Strategies from the Road Map for Indian Country facilitator guide ([appendix 6](#))
 - c. Prioritizing Strategies from the Road Map for Indian Country worksheets (following)
 - d. Road Map for Indian Country (pages 20 – 22)
 - e. Writing utensil

SLIDE DECK

PRIORITIZATION OF BRAIN HEALTH IN INDIAN COUNTRY



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.)

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

EDUCATE AND EMPOWER COMMUNITY MEMBERS



1. Strategy 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. Strategy 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. Strategy 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. Strategy 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. Strategy 5: Support collection and use of local data on dementia and caregiving in AI/AN communities to plan programs and approaches.
6. Strategy 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. Strategy 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. Strategy 8: Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.

<https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.htm>, page 19

UNIT 4 ACTIVITY: PRIORITIZING STRATEGIES FROM THE ROAD MAP FOR INDIAN COUNTRY ACTIVITY

This unit contained Road Map for Indian Country strategies to support prioritizing in your community. Use the worksheets below to take notes on what prioritizing each Road Map for Indian Country strategy looks like in your community. Think of innovative ways to incorporate these activities into your community. Think of challenges to incorporating these activities into your community. Is it something that can be easily accomplished in your community, why or why not? Use the things to consider questions to guide your thinking.

After thinking through each strategy, assess your community's readiness and capacity to advance brain health through that strategy. You'll be assessing three things:

- How **important** is this strategy for the community/region/state? (**Priority**)
- How **difficult** would it be to implement this strategy, thinking about time, resources, workforce, etc.? (**Difficulty**)
- How does this strategy align with the other activities your community/organization have planned? (**Alignment**)

ACTIVITY OBJECTIVE:

- Participants will be able to learn more about the 8 public health strategies, consider which ones are realistic and feasible for their community brain health initiatives and assess their community's readiness to act on each strategy.

Materials needed for Unit 4 Activity:

- Self-study:
 - Prioritizing and Assessing Strategies from the Road Map for Indian Country worksheets
 - Road Map for Indian Country (pages 20 – 22)
 - Writing utensil
- Group facilitation:
 - Prioritizing and Assessing Strategies from the Road Map for Indian Country facilitator guide ([appendix 6](#))
 - Prioritizing Strategies from the Road Map for Indian Country worksheets
 - Road Map for Indian Country (pages 20 – 22)
 - Writing utensil



EXAMPLE - Prioritizing and Assessing Strategies from the Road Map for Indian Country

Tribe X has decided they want to increase support for dementia screening, education, and caregiving services over the next five years. These goals are included in their recent 5 year community health plan.

Their clinic currently offers dementia screening as part of annual visits, but follow up shows limited utilization of referrals for neurology and supportive services. When asked, patients and their families have shared that the programs feel overbearing and do not understand the role elders play in the community.

Assess Strategy #8 for Community X

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

Things to consider (take notes in the space provided):

1. What support from healthcare and aging service professionals do families and caregivers of older adults with dementia need?
 - Understand how dementia impacts the healthy and daily living of older adults with dementia and how to care for their changing needs
 - Potential health risks dementia may cause
 - Cultural-appropriate tools and resources

2. What education materials would healthcare and aging service professionals need?
 - How to be a culturally competent healthcare provider
 - Orientation to the norms of the community

3. What resources would you need to implement this strategy in your community?
 - Funding
 - Staff training
 - Materials
 - Training materials
 - Time
 - Time to develop trainings and orientations
 - People
 - Tribal leaders
 - Board of health/healthcare board
 - Elders
 - Families / caregivers
 - Clinicians

Priority <i>How important is this strategy for the community/Tribe?</i>	Low 1 point	Medium 2 points	High 3 points
Difficulty <i>How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?</i>	Low 3 points	Medium 2 points	High 1 point
Alignment <i>How does this strategy align with the other activities your community/organization have planned?</i>	Low 1 point	Medium 2 points	High 3 points
<i>Strategy 8 Total Points*:</i>			8 points

EDUCATE AND EMPOWER

Strategy 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.

Things to consider (take notes in the space provided):

1. Who needs to be educated on this in your community?

2. What facilitators currently exist in your community to achieve this?

3. What barriers currently exist in your community that might pose a challenge?

4. What resources would you need to implement this strategy in your community?
 - Funding:
 - Materials:
 - Time:
 - People:

ASSESSING STRATEGY 1:

Instructions: Circle the appropriate response based on the priority, difficulty, and alignment for your community. Add the points up to determine your community's readiness to act on this strategy. You'll input the score into a table at the end of this activity and refer to them in Unit 5's activity.

Priority How important is this strategy for the community/Tribe?	Low 1 point	Medium 2 points	High 3 points
Difficulty How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?	Low 3 points	Medium 2 points	High 1 point
Alignment How does this strategy align with the other activities your community/organization have planned?	Low 1 point	Medium 2 points	High 3 points
Strategy 1 Total Points*:			

*Minimum = 3 points Maximum = 9 points

Strategy 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.

Things to consider (take notes in the space provided):

1. Who do you think needs encouragement to practice protective behaviors?
2. What is the best way to provide this encouragement? For example, community group meetings, posters in shared spaces, radio messages, etc.
3. What resources would you need to implement this strategy in your community?
 - Funding:
 - Materials:
 - Time:
 - People:

ASSESSING STRATEGY 2:

Instructions: Circle the appropriate response based on the priority, difficulty, and alignment for your community. Add the points up to determine your community’s readiness to act on this strategy. You’ll input the score into a table at the end of this activity and refer to them in Unit 5’s activity.

Priority How important is this strategy for the community/Tribe?	Low 1 point	Medium 2 points	High 3 points
Difficulty How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?	Low 3 points	Medium 2 points	High 1 point
Alignment How does this strategy align with the other activities your community/organization have planned?	Low 1 point	Medium 2 points	High 3 points
Strategy 2 Total Points*:			

*Minimum = 3 points Maximum = 9 points

Strategy 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.

Things to consider (take notes in the space provided):

1. What information about brain health and dementia do older adults and their caregivers need?

2. What are good ways to get information to older adults and their caregivers?

3. What resources would you need to implement this strategy in your community?
 - Funding:
 - Materials:
 - Time:
 - People:

ASSESSING STRATEGY 3:

Instructions: Circle the appropriate response based on the priority, difficulty, and alignment for your community. Add the points up to determine your community's readiness to act on this strategy. You'll input the score into a table at the end of this activity and refer to them in Unit 5's activity.

Priority How important is this strategy for the community/Tribe?	Low 1 point	Medium 2 points	High 3 points
Difficulty How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?	Low 3 points	Medium 2 points	High 1 point
Alignment How does this strategy align with the other activities your community/organization have planned?	Low 1 point	Medium 2 points	High 3 points
Strategy 3 Total Points*:			

*Minimum = 3 points Maximum = 9 points

Strategy 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.

Things to consider (take notes in the space provided):

1. What do Tribal leaders need to know about brain health and dementia?
2. What are some ways to engage Tribal leaders in health issues, and especially brain health?
3. What resources would you need to implement this strategy in your community?
 - Funding:
 - Materials:
 - Time:
 - People:

ASSESSING STRATEGY 4:

Instructions: Circle the appropriate response based on the priority, difficulty, and alignment for your community. Add the points up to determine your community's readiness to act on this strategy. You'll input the score into a table at the end of this activity and refer to them in Unit 5's activity.

Priority How important is this strategy for the community/Tribe?	Low 1 point	Medium 2 points	High 3 points
Difficulty How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?	Low 3 points	Medium 2 points	High 1 point
Alignment How does this strategy align with the other activities your community/organization have planned?	Low 1 point	Medium 2 points	High 3 points
Strategy 4 Total Points*:			

*Minimum = 3 points Maximum = 9 points



COLLECT AND USE DATA

Strategy 5:

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

Things to consider (take notes in the space provided):

1. What data is already being collected on dementia and caregiving?

2. How can local data on dementia and/or caregiving be collected?

3. Who plans programs for your elders? How could they benefit from local data?

4. What resources would you need to implement this strategy in your community?
 - Funding:
 - Materials:
 - Time:
 - People:

ASSESSING STRATEGY 5:

Instructions: Circle the appropriate response based on the priority, difficulty, and alignment for your community. Add the points up to determine your community's readiness to act on this strategy. You'll input the score into a table at the end of this activity and refer to them in Unit 5's activity.

Priority How important is this strategy for the community/Tribe?	Low 1 point	Medium 2 points	High 3 points
Difficulty How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?	Low 3 points	Medium 2 points	High 1 point
Alignment How does this strategy align with the other activities your community/organization have planned?	Low 1 point	Medium 2 points	High 3 points
Strategy 5 Total Points*:			

*Minimum = 3 points Maximum = 9 points

Strategy 6:

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

Things to consider (take notes in the space provided):

1. What quality measures for cognitive assessments and delivery of care to AI/ANs with dementia exist?

2. How can healthcare systems incorporate quality measures for cognitive assessment and care delivery to AI/ANs with dementia?

3. What resources would you need to implement this strategy in your community?
 - Funding:
 - Materials:
 - Time:
 - People:

ASSESSING STRATEGY 6:

Instructions: Circle the appropriate response based on the priority, difficulty, and alignment for your community. Add the points up to determine your community's readiness to act on this strategy. You'll input the score into a table at the end of this activity and refer to them in Unit 5's activity.

Priority How important is this strategy for the community/Tribe?	Low 1 point	Medium 2 points	High 3 points
Difficulty How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?	Low 3 points	Medium 2 points	High 1 point
Alignment How does this strategy align with the other activities your community/organization have planned?	Low 1 point	Medium 2 points	High 3 points
Strategy 6 Total Points*:			

*Minimum = 3 points Maximum = 9 points

STRENGTHEN THE WORKFORCE

Strategy 7:

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

Things to consider (take notes in the space provided):

1. What is the status of brain health and dementia knowledge among healthcare and aging professionals in your community?

2. Are there existing trainings and resources that could be easily accessed? If no, what would you need to access trainings and resources?

3. What resources would you need to implement this strategy in your community?
 - Funding:
 - Materials:
 - Time:
 - People:

ASSESSING STRATEGY 7:

Instructions: Circle the appropriate response based on the priority, difficulty, and alignment for your community. Add the points up to determine your community's readiness to act on this strategy. You'll input the score into a table at the end of this activity and refer to them in Unit 5's activity.

Priority How important is this strategy for the community/Tribe?	Low 1 point	Medium 2 points	High 3 points
Difficulty How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?	Low 3 points	Medium 2 points	High 1 point
Alignment How does this strategy align with the other activities your community/organization have planned?	Low 1 point	Medium 2 points	High 3 points
Strategy 7 Total Points*:			

*Minimum = 3 points Maximum = 9 points

Strategy 8:

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

Things to consider (take notes in the space provided):

1. What support from healthcare and aging service professionals do families and caregivers of older adults with dementia need?
2. What education materials would healthcare and aging service professionals need?
3. What resources would you need to implement this strategy in your community?
 - Funding:
 - Materials:
 - Time:
 - People:

ASSESSING STRATEGY 8:

Instructions: Circle the appropriate response based on the priority, difficulty, and alignment for your community. Add the points up to determine your community's readiness to act on this strategy. You'll input the score into a table at the end of this activity and refer to them in Unit 5's activity.

Priority How important is this strategy for the community/Tribe?	Low 1 point	Medium 2 points	High 3 points
Difficulty How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?	Low 3 points	Medium 2 points	High 1 point
Alignment How does this strategy align with the other activities your community/organization have planned?	Low 1 point	Medium 2 points	High 3 points
Strategy 8 Total Points*:			

*Minimum = 3 points Maximum = 9 points

Total Points from All Strategies – Fill out the table below to identify the highest scores. You'll refer back to this table to develop your action plan in Unit 5.

Strategy	Total Points from Assessment minimum = 3 points maximum = 9 points
Strategy #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.	
Strategy #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.	
Strategy #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.	
Strategy #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.	
Strategy #5: Support collection and use of local data on dementia and caregiving in AI/AN communities to plan programs and approaches.	
Strategy #6: Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to AI/ANs with dementia.	
Strategy #7: Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia.	
Strategy #8: Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.	

UNIT 4 KNOWLEDGE CHECK

1. Match:

Place the following activities in the appropriate box next to each Road Map for Indian Country strategy:

- Educate and empower
- Collect and use data
- Strengthen the workforce

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.	
Support collection and use of local data on dementia and caregiving in AI/AN communities to plan programs and approaches.	
Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.	

2. Pick Many:

Which of the following should you consider when planning for action, according to the presentation? Please select all that apply.

- a. The difficulty to implement.
- b. Alignment with other services.
- c. The importance of community.

Please find the correct answers for the knowledge check in appendix 3.



Unit 5

PLANNING FOR ACTION – INITIAL STEPS

INTRODUCTION

Unit 5 will take approximately 20 minutes to complete

This unit contains information for how to map out a detailed action plan for addressing the Road Map for Indian Country strategies in your community. Please have the Road Map for Indian Country available as a resource.

Materials needed for Planning for Action – Initial Steps

1. Self-study:
 - a. Slide deck (following)
 - b. Planning for Action – Initial Steps worksheets (following)
 - c. Road Map for Indian Country
 - d. Writing utensil
2. Group facilitation:
 - a. Slide deck (following)
 - b. Planning for Action – Initial Steps facilitator guide (appendix 7)
 - c. Planning for Action – Initial Steps worksheets (following)
 - d. Road Map for Indian Country
 - e. Writing utensil

SLIDE DECK

PLANNING FOR ACTION – INITIAL STEPS

WHAT IS AN ACTION PLAN?

An action plan is an organized description of the way your group will use selected strategies to meet its objectives. An action plan consists of a number of concrete steps or changes that will help your community achieve its vision.

Things to consider in your Action Plan:

- How will you measure success of this action?
- What inputs will you need (funding, materials, personnel) to achieve these actions?
- What are potential barriers to achieving this action?
- Who on your staff will be involved?
- Who are your partners and stakeholders that will be involved?
- What are concrete next steps you can take to achieve this action?

Each action step or change to be sought should include the following information:

- **What** actions or changes will occur?
- **Who** will carry out these changes?
- **By when** they will take place, and for how long?
- **What resources** (i.e., money, staff) are needed to carry out these changes?
- **Communication** (who should know what?)

What are the criteria for a good action plan?

The action plan for your initiative should meet several criteria.

Is the action plan:

- **Complete?** Does it list all the action steps or changes to be sought in all relevant parts of the community (e.g., schools, business, government, faith community)?
- **Clear?** Is it apparent who will do what by when?
- **Current?** Does the action plan reflect the current work? Does it anticipate newly emerging opportunities and barriers?

PLANNING FOR ACTION – CONSIDERATIONS FOR SELECTING A STRATEGY

- How **important** is this strategy for the community/region/state? (**Priority**)
- How **difficult** would it be to implement this strategy, thinking about time, resources, workforce, etc.? (**Difficulty**)
- How does this strategy align with the other activities your community/organization have planned? (**Alignment**)
- How will **success be measured**?
- What **inputs** are needed?
- What are some **potential barriers**?
- What are the **roles and responsibilities** of:
 - Staff?
 - Partners and stakeholders?
- What are the **next steps** in being successful?



UNIT 5 ACTIVITY: PLANNING FOR ACTION – INITIAL STEPS

This unit contained information and considerations for how to map out a detailed action plan for addressing the Road Map for Indian Country strategies. Use the worksheets, below to apply the Road Map for Indian Country strategies to brain health programming in your community. Refer to page 52 to select the three strategies with the highest point totals based on priority, difficulty and alignment to develop your action plan. An action plan is an organized description of the way your group will use its strategies to meet its objectives. An action plan consists of a number of concrete steps or changes that will help your community achieve its vision.

Things to consider in your Action Plan:

- How will you measure success of this action?
- What inputs will you need (funding, materials, personnel) to achieve these actions?
- What are potential barriers to achieving this action?
- Who on your staff will be involved?
- Who are your partners and stakeholders that will be involved?
- What are concrete next steps you can take to achieve this action?

Additionally, ask yourself, is the action plan:

- **Complete?** Does it list all the action steps or changes to be sought in all relevant parts of the community (e.g., schools, business, government, faith community)?
- **Clear?** Is it apparent who will do what by when?
- **Current?** Does the action plan reflect the current work? Does it anticipate newly emerging opportunities and barriers?

ACTIVITY OBJECTIVES:

- Participants will be able to map out a detailed action plan for at least one RMIC strategy using a template.
- Participants will set realistic goals, actionable steps, a timetable, identify contacts and resources needed.

Materials needed for Unit 5 Activity

- Self-study:
 - Planning for Action – Initial Steps worksheets
 - Road Map for Indian Country
 - Writing utensil
- Group facilitation:
 - Planning for Action – Initial Steps facilitator guide ([appendix 7](#))
 - Planning for Action – Initial Steps worksheets
 - Road Map for Indian Country
 - Writing utensil



EXAMPLE – Planning for Action

Tribe X has decided they want to increase support for dementia screening, education, and caregiving services over the next five years. These goals are included in their recent 5 year community health plan.

Their clinic currently offers dementia screening as part of annual visits, but follow up shows limited utilization of referrals for neurology and supportive services. When asked, patients and their families have shared that the programs feel overbearing and do not understand the role elders play in the community.

Example from Unit 4 – Prioritizing and Assessing Strategies from the Road Map for Indian Country

Tribe X has decided they want to increase support for dementia screening, education, and caregiving services over the next five years. These goals are included in their recent 5 year community health plan.

Their clinic currently offers dementia screening as part of annual visits, but follow up shows limited utilization of referrals for neurology and supportive services. When asked, patients and their families have shared that the programs feel overbearing and do not understand the role elders play in the community.

Assess Strategy #8 for Community X

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

Things to consider (take notes in the space provided):

1. What support from healthcare and aging service professionals do families and caregivers of older adults with dementia need?
 - Understand how dementia impacts the healthy and daily living of older adults with dementia and how to care for their changing needs
 - Potential health risks dementia may cause
 - Cultural-appropriate tools and resources
2. What education materials would healthcare and aging service professionals need?
 - How to be a culturally competent healthcare provider
 - Orientation to the norms of the community

3. What resources would you need to implement this strategy in your community?

- Funding
 - Staff training
- Materials
 - Training materials
- Time
 - Time to develop trainings and orientations
- People
 - Tribal leaders
 - Board of health/healthcare board
 - Elders
 - Families / caregivers
 - Clinicians

Priority How important is this strategy for the community/Tribe?	Low 1 point	Medium 2 points	High 3 points
Difficulty How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?	Low 3 points	Medium 2 points	High 1 point
Alignment How does this strategy align with the other activities your community/organization have planned?	Low 1 point	Medium 2 points	High 3 points
Strategy 8 Total Points*:			8 points

EXAMPLE – Planning for Action

After thinking through the “things to consider” and assessing the community’s readiness (from Unit 4 activity), Community X Health Director has chosen Strategy #8 as one of the top priorities.

ACTION PLAN

Action 1: Strategy #8: Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.

Measure of Success: Increase in reported patient and caregiver satisfaction with referral and supportive services.

Inputs needed: Funding (for trainings and staff); leadership support; provider trainings; patient satisfaction questionnaires...

Potential barriers: Staff time, funding

Who on staff will be responsible: Elder care programs coordinators (2)

Who are your partners and stakeholders: Tribal leaders; healthcare board; elders; families; referral clinicians

What are some next steps you will take to achieve this action? Convene group of Elders and families to better understand how services can be more culturally-tailored.



DEVELOP AN ACTION PLAN TEMPLATE

BRAIN HEALTH FOR TRIBAL NATIONS ACTION PLAN TEMPLATE
Action 1 (priority action from Unit 4 activity):
Measure(s) of Success:
Inputs Needed:
Potential Barriers:
Who on your staff will be responsible?
Who are your partners and stakeholders?
What are some next steps you will take to achieve this action?
Action 2: (priority action from Unit 4 activity):
Measure(s) of Success:
Inputs Needed:
Potential Barriers:
Who on your staff will be responsible?
Who are your partners and stakeholders?
What are some next steps you will take to achieve this action?
Action 3: (priority action from Unit 4 activity):
Measure(s) of Success:
Inputs Needed:
Potential Barriers:
Who on your staff will be responsible?
Who are your partners and stakeholders?
What are some next steps you plan to take to achieve this action?

UNIT 5 KNOWLEDGE CHECK

1. True or False?

A good action plan should meet the following criteria:

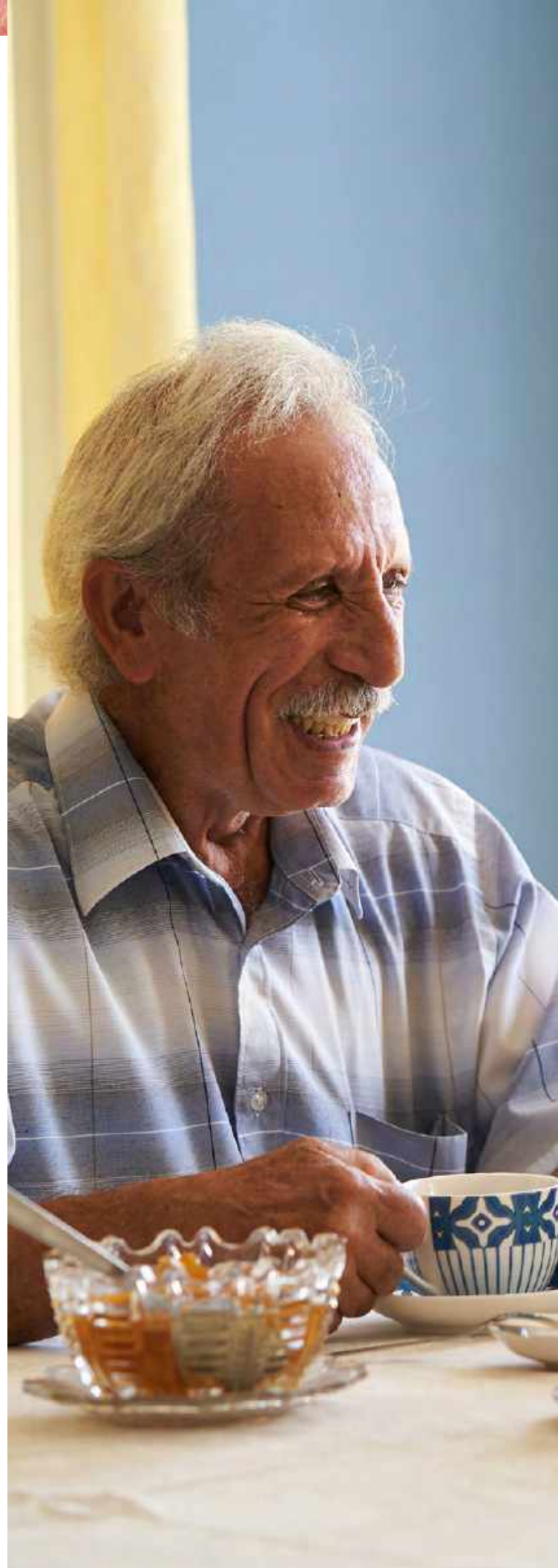
- It lists all of the action steps or changes to be sought in all relevant parts of the community.
- It is apparent who will do what by when.
- It reflects the current work and anticipates emerging opportunities and barriers.
 - a. True
 - b. False

2. True or False?

It is not necessary to consider potential barriers when selecting a strategy for your community.

- a. True
- b. False

Please find the correct answers for the knowledge check in appendix 3.





Closing

Congratulations on completing the Brain Health Action Institute for Tribal Nations workbook. You are now well on your way to being a brain health champion in your community! With a better understanding of brain health and having completed the action plan template, you now have actionable steps to improve brain health in your community.

If you would like to receive a Certificate of Completion please contact NIHB at szdunek@nihb.org.

If you are completing this along with the online module, you can print your certificate there.

Resources



ADDITIONAL RESOURCES SPECIFIC TO BRAIN HEALTH IN INDIAN COUNTRY:

RESOURCES REFERENCED IN THIS WORKBOOK:

- National Indian Health Board
(<https://nihb.org/brain-health/resources/>)
 - Talking Points
 - Brain Health Action Institute for Tribal Nations Online Module
- Centers for Disease Control and Prevention
(<https://www.cdc.gov/aging>)
 - Road Map for Indian Country (<https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>)

ADDITIONAL RESOURCES:

- National Indian Health Board
(<https://nihb.org/brain-health/>)
- Centers for Disease Control and Prevention
(<https://www.cdc.gov/aging>)
- Alzheimer’s Association (<https://www.alz.org/professionals/public-health/road-map/tribal-roadmap>)
- International Association for Indigenous Aging
(<http://iasquared.org/wordpress2/>)
- National Council of Urban Indian Health
(<https://www.ncuih.org/wisdomkeeper>)
- National Indian Council on Aging
(<https://www.nicoa.org/>)

Appendices



APPENDIX 1:

2-DAY BRAIN HEALTH ACTION INSTITUTE SAMPLE AGENDA

BRAIN HEALTH ACTION INSTITUTE AGENDA

Goal: Feel a commitment to and excitement for moving forward with actions that can be taken in your own community.

DAY 1: 12:00 PM - 4:15 PM

Day 1 Objectives:

- Clearly understand the impact of dementia on Indian Country
- Explore visions of what communities that prioritize brain health might look like
- Learn about the tool for a public health approach, the Road Map for Indian Country
- Consider how culture may affect how we talk about and act on brain health issues

TIME	ACTIVITY
12:00 - 12:45pm	Welcome, Prayer, Introductions and Expectations for the Day
12:45 - 1:30pm	What is Brain Health in Indian Country? Objectives: The attendee will be able to describe: <ol style="list-style-type: none">1. The current scientific understanding of Alzheimer’s disease and other dementia syndromes.2. Actions they can take to promote brain health and prevent or delay onset of Alzheimer’s disease and related dementias.3. Current understanding of effective treatments for Alzheimer’s disease and related dementias.
1:30 - 2:00pm	Road Map for Indian Country Objectives: The attendee will be able to describe: <ol style="list-style-type: none">1. How the Road Map for Indian Country was developed.2. How Native communities were consulted during the development of the Road Map for Indian Country.3. The intent and content of the Road Map for Indian Country, including the 8 public health actions.
2:00 - 2:15pm	Break

TIME	ACTIVITY
2:15 - 2:45pm	<p>Visioning Activity (Breakout Session)</p> <p>Objectives: The attendee will be able to describe:</p> <ol style="list-style-type: none"> 1. What an “ideal” community might look like if brain health was fully addressed and prioritized, <ul style="list-style-type: none"> • Community members would... • Caregivers would... • Tribal Leaders would... • Data would be used to... • The health system workforce would...
2:45 - 3:00pm	<p>Sharing out from Visioning Activity</p> <p>Attendees will share back select vision ideas with the wider group.</p>
3:00 - 3:30pm	<p>Cultural Considerations for Providing Health Services with American Indians and Alaska Natives: How Important is Communication and the Practice of Cultural Humility</p> <p>Objectives: The attendee will be able to describe:</p> <ol style="list-style-type: none"> 1. The impact of cultural understanding, sensitivities, appropriateness and humility when providing health services. 2. How commonly used phrases or words may be inappropriate with some cultures and how misinterpretation and misjudgments can be counterproductive or dangerous.
3:30 - 3:45pm	<p>Cultural Considerations (Breakout Session)</p> <p>Objective: The attendee will be able to:</p> <ol style="list-style-type: none"> 1. Discuss cultural considerations and strategies for how community voices can be incorporated in brain health services, policies and programming.
3:45 - 4:00pm	<p>Sharing out from Cultural Considerations Breakout Session</p> <p>Attendees will share back their discussion on their culture and what might need to be considered in brain health programs.</p>
4:00 - 4:15pm	<p>Reflection and Summary of Day 1 and Complete Evaluation</p> <p>Attendees will reflect on the day, including areas of strength and opportunities for improvement. Before closing out the day attendees are asked to complete the evaluation.</p>

BRAIN HEALTH ACTION INSTITUTE AGENDA

Goal: Feel a commitment to and excitement for moving forward with actions that can be taken in your own community.

DAY 2: 12:00 PM - 3:45 PM

Day 2 Objectives:

- Prioritize and planning for actions in your own settings
- Individualized TA

Time	Activity
12:00 - 12:15pm	Recap of Day 1 and Expectations of Day 2
12:15 - 1:30pm	<p>Prioritizing Road Map for Indian Country Strategies (Breakout Session)</p> <p>Objectives: The attendee will:</p> <ol style="list-style-type: none"> 1. Develop a deeper understanding of the Road Map for Indian Country and the 8 public health actions. 2. Identify realistic and feasible actions for their community based on factors such as resources available, political will, opportunities for overlap with other priorities, etc. 3. Select 1-3 actions to prioritize in their community (via poll).
1:30 - 1:55pm	<p>Sharing Our from Prioritizing Road Map for Indian Country Strategies Breakout Session</p> <p>Attendees will share highlights of priorities and discuss reasons for their choices.</p>
1:55 - 2:15pm	Break
2:15 - 2:50pm	<p>Planning for Action - Initial Steps (Breakout Session)</p> <p>Objective: Attendees will be able to</p> <ol style="list-style-type: none"> 1. Identify realistic goals, actionable steps, a timeline, identity contacts and resources needed.
2:50 - 3:15pm	<p>Recap Resources, Discuss Next Steps, and Complete Evaluation</p> <p>Attendees will review available resources and how they will accomplish their next steps to improve brain health in their community. Before adjourning attendees are asked to complete an evaluation.</p>
3:15pm	Adjourn
3:15 - 3:45pm	<p>Individualized Technical Assistance for Work Plans (optional)</p> <p>Facilitators are available to answer questions and provide support individually.</p>

APPENDIX 2:

2-DAY BRAIN HEALTH ACTION INSTITUTE SAMPLE EVALUATION

DAY 1 EVALUATION

QUESTION 1: Please answer the following questions about Day 1's CONTENT

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
The Action Institute's objectives were clearly stated.					
The Action Institute's objectives were met.					
The information discussed was relevant.					
There was sufficient time for participants to share their insights.					
I am better able to describe what brain health is and the implications for Indian Country than before attending this Action Institute					
I am better able to describe the components of the Road Map for Indian Country than before attending this Action Institute.					
I found the visioning activity helpful for understanding what brain health could look like in my community.					
I better understand the cultural considerations for brain health programs and policy in Indian Country than before attending the Action Institute.					

QUESTION 2: Please answer the following questions about Day 1's FORMAT

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
The sessions were well-organized.					
The presenter(s) were knowledgeable on the content.					
The presenter(s) communicated information clearly.					
The presenter(s) were responsive to my questions.					
The presenter(s) were respectful of my cultural beliefs.					
The presenter(s) displayed strong facilitation skills.					
The Action Institute platform was adequate.					
Presentation methods were effective.					

QUESTION 3: Please use the space below to share any comments about specific presenters:

QUESTION 4: Please answer the following questions about Day 1's BREAKOUT SESSIONS:

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
The format of the breakout sessions was easy to understand.					
There was sufficient time in the breakout sessions for participants to share their insights.					
The breakout sessions helped me learn more about brain health.					
The breakout sessions helped me develop concrete steps to take for brain health in my community.					

QUESTION 5: Please rate your overall satisfaction with this Action Institute:

Extremely Dissatisfied	Somewhat Dissatisfied	Neither Satisfied nor Dissatisfied	Somewhat Satisfied	Extremely Satisfied

QUESTION 6: What else would like to have discussed in this session?

QUESTION 7: What things were done well in this session?

QUESTION 8: What things could be improved?

QUESTION 9: If you have any additional comments, please provide them here:

DAY 2 EVALUATION

QUESTION 1: Please answer the following questions about Day 2's CONTENT

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
The Action Institute's objectives were clearly stated.					
The Action Institute's objectives were met.					
The information discussed was relevant.					
There was sufficient time for participants to share their insights.					
I am better able to describe what brain health is and the implications for Indian Country than before attending this Action Institute					
I am better able to describe the components of the Road Map for Indian Country than before attending this Action Institute.					
I found the visioning activity helpful for understanding what brain health could look like in my community.					
I better understand the cultural considerations for brain health programs and policy in Indian Country than before attending the Action Institute.					

QUESTION 2: Please answer the following questions about Day 2's FORMAT

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
The sessions were well-organized.					
The presenter(s) were knowledgeable on the content.					
The presenter(s) communicated information clearly.					
The presenter(s) were responsive to my questions.					
The presenter(s) were respectful of my cultural beliefs.					
The presenter(s) displayed strong facilitation skills.					
The Action Institute platform was adequate.					
Presentation methods were effective.					

QUESTION 3: Please use the space below to share any comments about specific presenters:

QUESTION 4: Please answer the following questions about Day 2's BREAKOUT SESSIONS:

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
The format of the breakout sessions was easy to understand.					
There was sufficient time in the breakout sessions for participants to share their insights.					
The breakout sessions helped me learn more about brain health.					
The breakout sessions helped me develop concrete steps to take for brain health in my community.					

QUESTION 5: Please rate your overall satisfaction with this Action Institute:

Extremely Dissatisfied	Somewhat Dissatisfied	Neither Satisfied nor Dissatisfied	Somewhat Satisfied	Extremely Satisfied



QUESTION 6: Which of the strategies would you like more information about? (Select all that apply)

Strategy #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.
Strategy #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.
Strategy #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.
Strategy #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 caregiver and communities, and the role of public health approaches in addressing this priority problem.
Strategy #5: Support collection and use of local data on dementia and caregiving in AI/AN communities to plan programs and approaches.
Strategy #6: Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to AI/ANs with dementia.
Strategy #7: Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia.
Strategy #8: Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.

QUESTION 7: What else would like to have discussed in this session?

QUESTION 8: What things were done will in this session?

QUESTION 9: What things could be improved?

QUESTION 10: If you have any additional comments, please provide them here:

APPENDIX 3:

KNOWLEDGE CHECK ANSWERS

UNIT 1:

WHAT IS BRAIN HEALTH IN INDIAN COUNTRY?

1. True or False?

The following are all routes to dementia systems: Alzheimer's disease, vascular dementia, frontotemporal dementia, and Parkinson's disease.

- True

2. Pick One:

Which of the following is NOT a risk factor for Alzheimer's disease?

- More education

3. True or False?

Medications for Alzheimer's disease and related dementias have shown to delay progression 2 - 3 years.

- False

UNIT 2:

ROAD MAP FOR INDIAN COUNTRY

1. Pick Many:

The following Tribal entities received an invitation to join the virtual listening sessions to inform the Road Map for Indian Country.

- Tribal Leaders
- Tribal Health Directors
- Tribal Title VI Directors
- Indian Country Experts

2. Pick Many:

Which of the following are Road Map for Indian Country Strategies?

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

3. True or False?

Mild cognitive impairment always progresses into dementia.

- False

UNIT 3:

CULTURAL CONSIDERATIONS IN BRAIN HEALTH FOR INDIAN COUNTRY

1. True or False?

Cultural sensitivity is a lifelong pursuit.

- True

2. Pick Many:

How can you increase cultural humility, according to Dr. Frizzell's presentation? Please select all that apply.

- Grow your own (empower local residents to be the foundation of a culturally attuned and grounded professional health service workforce)
- Mentoring
- Learning
- Job-based learning
- Determine who are the "keepers" of traditions and solicit advice from them

3. Pick Many:

Dr. Frizzell's presentation included several cultural considerations for American Indians and Alaska Natives with memory impairments, which considerations did she share? Please select all that apply.

- Consider each person as an individual
- Consider each person with choice of spirituality (Western or Traditional or both)
- Consider each person with historical trauma (100% of AI/ANs have a history)
- Understand that some elders have histories of horrific racial experiences

UNIT 4: PRIORITIZATION OF BRAIN HEALTH IN INDIAN COUNTRY

1. Match:

Place each activity into the appropriate Road Map for Indian Country strategy:

- Educate and empower
- Collect and use data
- Strengthen the workforce

Scenario	Strategy
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.	Educate and empower
Support collection and use of local data on dementia and caregiving in AI/AN communities to plan programs and approaches.	Collect and use data
Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.	Strengthen the workforce

2. Pick Many:

Which of the following should you consider when planning for action, according to the presentation? Please select all that apply.

- The difficulty to implement.
- Alignment with other services.
- The importance of community.

UNIT 5: PLANNING FOR ACTION – INITIAL STEPS

1. True or False?

A good action plan should meet the following criteria:

- It lists all of the action steps or changes to be sought in all relevant parts of the community.
- It is apparent who will do what by when.
- It reflects the current work and anticipates emerging opportunities and barriers.
- True

2. True or False?

It is not necessary to consider potential barriers when selecting a strategy for your community.

- False

APPENDIX 4:

VISIONING ACTIVITY FOR TRIBAL BRAIN HEALTH FACILITATOR GUIDE

During this session, participants will spend time imagining what their communities would look like if brain health was a focus or prioritized. The breakout will not be recorded but facilitators will take notes and share out some thoughts when we return to the larger group.

SET UP:

Divide the group into an appropriate number of smaller groups based on the size of the larger group and the number of facilitators you have. At minimum, each group should include two participants and one facilitator.

DURATION:

45 minutes total

- Activity Breakout Session (30 minutes)
 - 5 minutes for instructions and set up
 - 25 minutes for small group breakout session
- Sharing from Activity Breakout Session (15 minutes)
 - 15 minutes for sharing with the larger group (divide 15 by the total number of smaller groups to determine how much time each group will have to share)

ACTIVITY OBJECTIVE:

- Participants will be able to describe what an “ideal” community might look like if brain health was fully addressed and prioritized.

MATERIALS:

- Visioning Activity worksheet
- Writing utensil

INSTRUCTIONS:

1. Introduce yourself to the group!
2. Set the stage for visioning. Explain that there are no right or wrong answers for this activity. Ask them to relax and get comfortable, maybe eliminate other distractions such as cell phones. They can close their eyes if they want.
3. Explain that you will read a sentence and they are to think about finishing that sentence, using their imagination. They should use their visioning worksheet to jot down their thoughts. It may be helpful to ask them to think about how they will know if brain health is prioritized.
4. Explain that after they’ve completed the activity individually, they’ll be asked to share their thoughts with the breakout group. The larger group will come back together to share, as well.
5. Utilizing the visioning activity worksheet, state each sentence and ask them to complete the sentence on their worksheet. Allow 2 minutes to jot down their thoughts for each sentence. (5 sentences so ~10 minutes).
6. Go through each sentence and invite participants to share what they wrote down. Spend another 2-3 minutes on each sentence.

FACILITATOR TIPS:

- We encourage facilitators to be mindful of best practices for supporting meaningful conversation with Tribal participants. Specifically:
 - Tribal Leaders and Elders are typically invited to speak first, out of respect for their roles in the community.
 - Try to balance allowing each participant enough time to share, and encouraging all members of the group to speak.
 - Not everyone may choose to speak during discussions. Ask another participant in the circle to share instead.
 - Leave space for silence in the conversations.

APPENDIX 5:

CULTURAL CONSIDERATIONS FOR TRIBAL BRAIN HEALTH FACILITATOR GUIDE

During this activity participants discuss their culture and what might need to be considered in brain health programs. They will also discuss strategies for including voices from their community.

SET UP:

Participants will complete the worksheet individually and share back to the larger group. Only one facilitator is needed for this activity.

DURATION: 30 MINUTES TOTAL

- 1-2 minutes for participants to think about each question
- 1-2 minutes for participants to share with the larger group

ACTIVITY OBJECTIVE:

- Participants will discuss cultural considerations and strategies for how community voices can be incorporated in brain health services, policies and programming.

MATERIALS:

- Cultural Considerations worksheet
- Writing utensil
- An additional considerations deeper dive (optional) with questions is available at the end of this facilitator guide.

INSTRUCTIONS:

1. Using the worksheet questions and optional additional considerations deeper dive discussion questions (below), ask participants to think about their own community's culture and what might need to be considered in brain health programs.
2. Ask them to consider all perspectives, such as elders, caregivers, community members and leadership.
3. Allow 1-2 minutes for participants to think through the question and jot down their responses.
4. After each question, ask 1-3 participants to share their thoughts with the larger group.
5. Optional: explain that this session will not be recorded but you'll be taking notes during it to capture what was discussed.

ADDITIONAL CONSIDERATIONS DEEPER DIVE:

1. Distrust in the healthcare field

Distrust in the healthcare field may be why some American Indians and Alaska Natives do not seek medical treatment. Is there a possibility that your own services are not reaching Tribal members for this reason? If so, what steps can be taken to increase outreach and trust-building to your community? Are there opportunities for Tribal members with the cultural knowledge to join health service roles (e.g. pipeline programs)?

2. Cultural humility in the workplace

There is no definition for cultural competency except for what is determined by the patient/client. Are there qualitative ways to measure your success in practicing cultural humility with your patients/clients, for example, whether the patient/client returns to your services? How often are discussions surrounding cultural consideration or humility held with your team? Are Tribal members with the cultural knowledge able to participate

in these discussions? How can you ensure Tribal member with the cultural knowledge are able to participate in these discussions?

3. Appropriate terminology

You should consider your community and whether or not the terms “Alzheimer’s” and “dementia” may stigmatize those with dementia-related disorders. What are some alternative terms that can be used within your community? Are these terms deficient-based language or can they be reworded?

4. Tribal / Community history and norms

You should consider your community and whether or not the terms “Alzheimer’s” and “dementia” may stigmatize those with dementia-related disorders. What are some alternative terms that can be used within your community? Are these terms deficient-based language or can they be reworded? What information is available to new workforce members who may not be familiar with the local Tribe(s)’s culture? Is there a Tribal orientation available to new employees? Is the orientation mandatory? Has the orientation been reviewed and/or approved by Tribal members? Beyond what is considered “traditional”, are there any subcultures that could be defined in your community (e.g. rodeo fans, artists, etc.)? Have differences between these subcultures been taken into consideration when building your cultural competency? How can differences between these subcultures be taken into consideration? Are there cultural norms within your Tribal community that should be kept in mind when directly interacting with a patient or client (e.g., avoiding eye contact, having both parties sitting or standing, etc.)? What topics or words are considered taboo or frowned upon when brought up in conversation or by outsiders? What is the role of showing emotion or humor when speaking to members of a culture?

5. Language

Does the concept of memory-loss in older adults or dementia exist within your Tribal community? Is there already a word in the local language that can capture this concept or does one need to be introduced? Should a translated word be introduced? Is there someone available who can serve as an interpreter or translator for Tribal members who prefer or can only speak their native language? Why might this be important for Tribal members experiencing dementia-related symptoms?

FACILITATOR TIPS:

- We encourage facilitators to be mindful of best practices for supporting meaningful conversation with Tribal participants. Specifically:
- Tribal Leaders and Elders are typically invited to speak first, out of respect for their roles in the community.
- Try to balance allowing each participant enough time to share, and encouraging all members of the group to speak.
- Not everyone may choose to speak during discussions. Ask another participant in the circle to share instead.
- Leave space for silence in the conversations.

APPENDIX 6:

PRIORITIZING STRATEGIES FROM THE ROAD MAP FOR INDIAN COUNTRY FACILITATOR GUIDE

During this session participants will rotate between five tables to discuss Road Map for Indian Country strategies and how they might incorporate them into their community. Participants are encouraged to think through challenges and ease of accomplishing the activities in their community. After thinking through each strategy, participants will assess their community's readiness and capacity to advance brain health by taking into consideration priority, difficulty, and alignment with existing programming. The facilitator of the strategy will take note of how each strategy was scored and determine the final score by calculating the average score of each strategy.

SET UP:

1. Divide the larger group into five smaller groups. The groups will rotate to each table. You will need one facilitator per group table.
2. A walkthrough of a prioritizing for action case scenario — Prioritizing Strategies from the Road Map for Indian Country slide deck (page 42)

DURATION:

- Activity Breakout Session (75 minutes)
 - 15 minutes for each table (total of 75 minutes for breakout session)
- Sharing from Activity Breakout Session (15 minutes)
 - 15 minutes for sharing with the larger group

ACTIVITY OBJECTIVE:

- Participants will be able to learn more about the 8 public health strategies, consider which ones are realistic and feasible for their community brain health initiatives and assess their community's readiness to act on each strategy.

MATERIALS:

- Prioritizing Strategies from the Road Map in Indian Country Worksheet
- Road Map for Indian Country, pages 20 - 22
- Writing utensil

INSTRUCTIONS:

1. Once in smaller groups, each facilitator will present information and lead discussion on the 1-2 Road Map for Indian Country strategies.
 - a. Introduce which strategy this round is discussing (it will be the same one every time, but new to each participant group). Some folks may have 2 related strategies to discuss.
 - b. Each strategy is covered in the RMIC, and we anticipate most of your 15 minutes will be discussion-based. No need for PowerPoints or visual aids unless they are helpful to your process.
2. Instruct participants to use the Prioritizing Road Map for Indian Country worksheet and take their own notes during the group discussion.
3. Read each strategy and ask participants to consider the planning ahead questions as they think of innovative ways to incorporate these activities into their community. Ask participants:
 - a. Are there challenges to incorporating these activities into their community.
 - b. Is it something that can be easily accomplished in their community, why or why not?

4. After discussing each strategy, ask the group to assess their community's capacity and readiness to take action on the strategy based on:
 - **Priority:** How important is this strategy for the community/region/state?
 - **Difficulty:** How difficult would it be to implement this strategy, thinking about time, resources, workforce, etc.?
 - **Alignment:** How does this strategy align with the other activities your community/organization have planned?
5. If you are responsible for leading the discussion of two strategies switch to the second strategy after 7 minutes.
6. Explain that the breakout will not be recorded but notes will be taken and thoughts may be shared out with the larger group.
7. Please take notes (or designate a note taker) to capture unique ideas from participants, common challenges you hear, or anything else that strikes you as important.
8. Encourage participants to use the Road Map for Indian Country or draw on their own resources to start conversations and explore what each strategy looks like in their community.
9. If you have extra time, dig deeper into how participants might start incorporating the strategies into their brain health planning.
10. After all groups have assessed their community's readiness of priority, difficulty, and alignment calculate the group average. This information will be used in the Unit 5 activity.

FACILITATOR TIPS:

- We encourage facilitators to be mindful of best practices for supporting meaningful conversation with Tribal participants. Specifically:
- Tribal Leaders and Elders are typically invited to speak first, out of respect for their roles in the community.
- Try to balance allowing each participant enough time to share, and encouraging all members of the group to speak.
- Not everyone may choose to speak during discussions. Ask another participant in the circle to share instead.
- Leave space for silence in the conversations.



SET UP PREP:

TABLE	STRATEGY	FACILITATOR	NOTE TAKER
1	<p>Strategy #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.</p> <p>Strategy #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.</p>		
2	<p>Strategy #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.</p>		
3	<p>Strategy #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.</p>		
4	<p>Strategy #5: Support collection and use of local data on dementia and caregiving in AI/AN communities to plan programs and approaches.</p> <p>Strategy #6: Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to AI/ANs with dementia.</p>		
5	<p>Strategy #7: Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia.</p> <p>Strategy #8: Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.</p>		



STRATEGY SCORING:

STRATEGY	TOTAL POINTS FROM ASSESSMENT average minimum = 3 points average maximum = 9 points																									
<p>Strategy #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.</p>	<table border="1"> <tr><td>Group 1</td><td></td></tr> <tr><td>Group 2</td><td></td></tr> <tr><td>Group 3</td><td></td></tr> <tr><td>Group 4</td><td></td></tr> <tr><td>Group 5</td><td></td></tr> <tr><td>Average</td><td></td></tr> </table>	Group 1		Group 2		Group 3		Group 4		Group 5		Average		<table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>												
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APPENDIX 7:

PLANNING FOR ACTION – INITIAL STEPS ACTIVITY FACILITATOR GUIDE

During this activity participants are asked to apply the Road Map for Indian Country strategies to brain health programming in their community. Participants will create an action plan based on strategies that would suit their community's readiness and capacity to advance brain health, which were identified in Unit 4's activity.

SET UP:

This activity is completed as a large group and is split into two sections:

1. A walkthrough of a planning case scenario Planning for Action – Initial steps slide deck (page 58)
2. A discussion of how select strategies chosen by the participants could be realized in their communities.

DURATION:

35 minutes total

ACTIVITY OBJECTIVES:

- Participants will be able to map out a detailed action plan for at least one RMIC strategy using a template.
- Participants will set realistic goals, actionable steps, a timetable, identify contacts and resources needed.

MATERIALS:

- Planning for Action – Initial Steps worksheets
- Writing utensil
- Road Map for Indian Country

INSTRUCTIONS:

1. Review how the group assessed each strategy based on priority, difficulty, and alignment from the Unit 4 activity.
2. Identify the top three actions that you'll create an action plan for.
3. Use the worksheet to discuss what elements should be included in the action plan.
4. As a group develop an action plan with three actions based on your assessment from the Unit 4 activity.
5. After completing each action, ask participants if their action plan is:
 - **Complete?** Does it list all the action steps or changes to be sought in all relevant parts of the community (e.g., schools, business, government, faith community)?
 - **Clear?** Is it apparent who will do what by when?
 - **Current?** Does the action plan reflect the current work? Does it anticipate newly emerging opportunities and barriers?





National Indian
Health Board



Healthy Heart, Healthy Brain...

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

Everyone slows down as they get older, both in body and mind. But big changes with forgetfulness, thinking, or how you solve problems that make it hard to get through the day don't happen to everyone. These changes could be a sign of early dementia or Alzheimer's disease.



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
develops dementia, including
Alzheimer's

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

Key steps you can take for a healthy mind, heart, and body:



- ◆ **Call your doctor** today for an appointment to talk about how to keep your mind and heart healthy.
- ◆ **Schedule** "wellness" checkups and health screenings every year. Blood pressure and diabetes screenings are usually free with Medicare Part B or through the Indian Health Service.
- ◆ **Get a little exercise** every day.
- ◆ **Eat more fresh fruits and vegetables** and foods low in salt and sugar.
- ◆ **Stop smoking** and chewing tobacco.
- ◆ **Get help** managing high blood pressure, diabetes, high blood cholesterol, and depression or anxiety.
- ◆ **Protect your head.** Falls are the number one cause of head injury in older adults.
- ◆ **If you have trouble** with memory or forgetfulness that makes it hard to get through the day, see your doctor right away.

You can do things today to protect your mind and help try to prevent or slow dementia and Alzheimer's disease.

Turn over for your checklist to help keep the river of life flowing freely.



Keep Your River Flowing ...

Your heart is like the start of a free-flowing river. Veins and arteries that take blood away from and to the heart are like many connected small streams that flow all through the body, including the brain, feeding it with oxygen and energy.

You have to work to keep the streams flowing through your body from becoming clogged and the heart from being hurt.

Working with Your Doctor

- ◆ **Make an appointment** for health screening tests and “wellness” checkups every year. They are usually free with Medicare Part B or through the Indian Health Service.
- ◆ **Have your blood pressure checked** regularly and know your numbers. A blood pressure of less than 120/80 mmHg is normal.
- ◆ **Ask your doctor** to go over how to measure and track your own blood pressure results and find out where you can go in your community to check your blood pressure yourself.
- ◆ **Have your cholesterol checked** regularly and know your numbers. Talk to your doctor about what you can do if your cholesterol is high.
- ◆ **If you do not have diabetes**, have your blood sugar level checked regularly. Blood sugar should be less than 100 mg/dl.
- ◆ **If you do have diabetes**, have your blood sugar and A1C levels checked regularly, and work with your doctor to get them to normal levels. Your A1C should be less than 5.7%.
- ◆ **Talk with your doctor** about your medicines and vitamins to make sure they do not cause problems with your memory, sleep, or brain function.

Working on Your Own

- ◆ **Be active** or walk every day. Try to get 1 ½ - 2 hours of exercise each week.
- ◆ **Eat more fruits and vegetables** and less salt and sugar.
- ◆ **Take your medicine** for blood pressure and diabetes even if you feel good.
- ◆ **If you smoke** or chew tobacco, stop. Talk to your doctor if you need help quitting.
- ◆ **If you are overweight**, try to lose weight with exercise and a healthy diet. Losing even a few pounds can make a difference. Talk to your doctor for help.
- ◆ **Read food labels** to see how much salt (sodium) or fat is in your food. If you don't know how to read food labels, ask your doctor for help.
- ◆ **Limit alcoholic drinks**. No more than one drink per day for women and no more than two for men. Talk to your doctor if you need help.
- ◆ **Get at least seven hours of sleep** each night. Talk to your doctor if you have trouble sleeping.
- ◆ **Keep your mind active**. Go out and visit with people in your community, take classes, go to your senior center, play cards, and visit with others.



SUBJECTIVE COGNITIVE DECLINE AMONG AMERICAN INDIAN/ALASKA NATIVE ADULTS

2015–2018 Behavioral Risk Factor Surveillance System (BRFSS) Data from American Indian and Alaska Native Adults in 50 States, Puerto Rico, and the District of Columbia: People Aged 45 Years and Older

1 in 5

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.

53% of people with SCD had to give up day-to-day activities



87% 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



nearly 60% of people with SCD have discussed their symptoms with a healthcare provider

49% of people with SCD need help with household tasks



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention



cdc.gov/aging

CAREGIVING

AMONG AMERICAN INDIAN/ALASKA NATIVE ADULTS

2015–2018 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 3

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

Over Half have provided care for at least two years



INTENSE

Nearly 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?

60% are women

16% are 65 years old or older

32% are caring for a parent or parent-in-law



FUTURE CAREGIVERS

Nearly 1 in 6 NON-CAREGIVERS expect to **BECOME CAREGIVERS** within 2 years



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention



cdc.gov/aging

10 Warning Signs of Alzheimer's



**HEALTHYBRAIN
INITIATIVE**

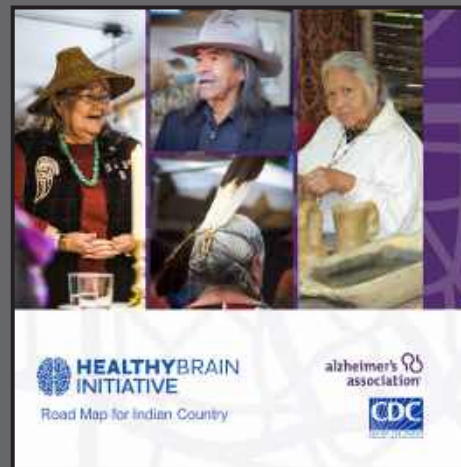
Road Map for Indian Country

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.



alzheimer's
association



cdc.gov/aging

alz.org/publichealth/indiancountry

If you notice any of the 10 Warning Signs of Alzheimer's in yourself or someone you know, don't ignore them. Please consult your physician.

#1 Memory changes that disrupt daily life

One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. For example:



Typical age-related changes: Sometimes forgetting names or appointments, but remembering them later.

#2 Challenges in planning or solving problems

Some people may have difficulty concentrating and take much longer to do things than they did before.



Some people may experience changes in their ability to develop and follow a plan or work with numbers.

They may have trouble following a familiar recipe or keeping track of monthly bills.

Typical age-related changes: Making occasional errors when balancing a checkbook.

#3 Difficulty completing familiar tasks

People with Alzheimer's often find it hard to complete daily tasks such as:



Typical age-related changes: Occasionally needing help to use the settings on a microwave or record a television show.

#4 Confusion with time or place

People with Alzheimer's can lose track of dates, seasons and the passage of time.

They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.



Typical age-related changes: Getting confused about the day of the week but figuring it out later.

#5 Trouble understanding visual images and spatial relationships



Some people may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not realize they are the person in the mirror.

Typical age-related changes: Vision changes related to cataracts.

#6 New problems with words in speaking or writing

People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name.

Typical age-related changes: Sometimes having trouble finding the right word.



#7 Misplacing things and losing the ability to retrace steps

A person with Alzheimer's disease may put things in unusual places.

They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.



Typical age-related changes: Misplacing things from time to time.

#8 Decreased or poor judgment

People with Alzheimer's may demonstrate unusual changes in judgment or decision making.

For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers.



They may pay less attention to grooming or keeping themselves clean.

Typical age-related changes: Making a bad decision once in a while.

#9 Withdrawal from work or social activities

A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may also avoid being social because of the changes they have experienced.



Typical age-related changes: Sometimes feeling weary of work, family and social obligations.

#10 Changes in mood and personality

The mood and personalities of people with Alzheimer's can change.

They may be easily upset in places where they are out of their comfort zone.

They can become confused, suspicious, depressed, fearful or anxious.



Typical age-related changes: Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

Warning Signs of Alzheimer's and Related Dementias

HEALTHY BEHAVIORS THAT MAY PROTECT AGAINST COGNITIVE DECLINE

- Eat a healthy diet
- Exercise the body, mind and spirit
- Stay socially engaged
- Take care of your heart and manage blood sugar levels
- Limit tobacco to ceremonial use
- Try to get enough sleep and maintain good sleep hygiene

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.

Talk to your healthcare provider if you or your loved one experiences one or more of these warning signs.



WHAT IS Brain Health?

Definitions

What is Brain Health?

Brain health refers to your thinking, understanding, and memory abilities. It also can refer to the things you do to keep your brain healthy and active, like staying physically active and following a healthy diet.

What is Cognitive Decline?

Cognitive Decline refers to a person's increased confusion or memory loss. It is not a diagnosis but a description of what someone is experiencing.

What is Dementia? Alzheimer's Disease?

Dementia is a general term for the impaired ability to remember, think, or make decisions that interferes with doing everyday activities. Alzheimer's disease is a form of dementia. It can progress from mild memory loss to being unable to carry a conversation, live independently, or be aware of your environment.

What is Mild Cognitive Impairment?

Mild cognitive impairment (MCI) is a diagnosis and refers to cognitive changes that are serious enough to be noticed by the person affected, family members, and friends, but do not affect the individual's ability to carry out everyday activities. MCI may or may not lead to dementia.

NON-TYPICAL AGING

Cognitive impairment can take many forms. You may frequently not be able to recall a family member's name, find something you've put down, or remember details of your life. These changes are caused by damage to your brain cells. You may also experience issues with making decisions, planning, or motor function. Cognitive impairment, including Alzheimer's and related dementia, may not affect everyone as they age.

VS.

TYPICAL AGING

As you or a loved one age you may notice some changes in your memory, thoughts, or reasoning. You may forget things once in a while, or take some time to remember a detail. A key difference between typical aging and dementia is memory or thinking problems that disrupt your daily life and ability to complete daily activities, such as preparing meals or paying bills.



WHAT IS DEMENTIA?

Indigenous Perspectives
and Cultural Understandings



Health Care Providers Understandings of Dementia

“Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgement and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person’s ability to function at work, in relationships or in everyday activities.”

The Alzheimer’s Society of Canada.

Indigenous Understandings of Age-Related Dementia

There is some evidence that suggests age-related dementias have only recently become more common in Indigenous populations. As people live longer they are more likely to experience dementia.

Just as Indigenous communities in Canada are different, Indigenous peoples, communities and cultures hold different understandings of dementia, memory loss, forgetfulness and confusion related to aging. These understandings may be very different from those held by doctors, nurses and support workers.

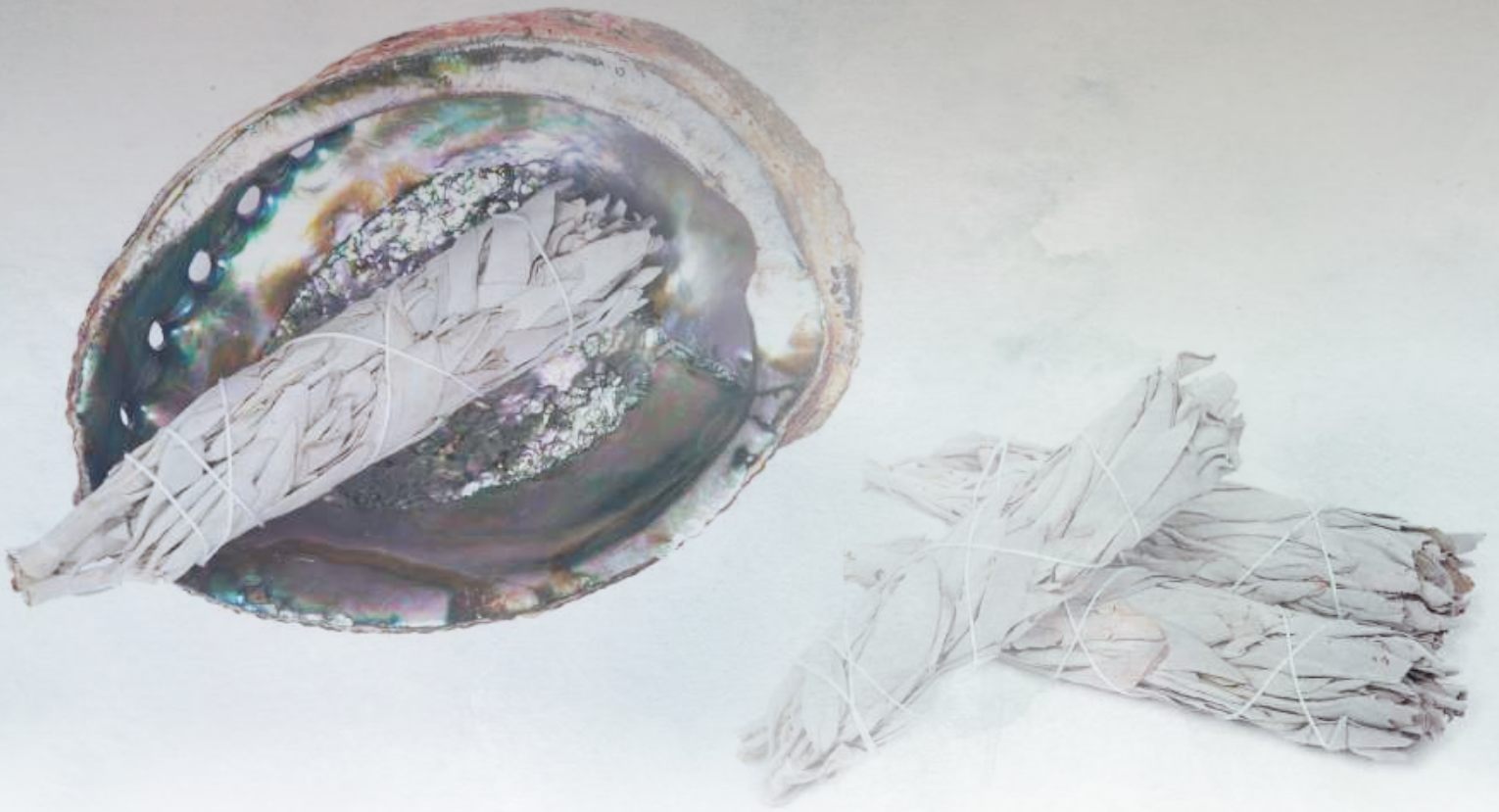
Some descriptions of dementia that are common are that:

- “It’s normal”
- “It’s natural”
- “It’s part of the circle of life” or “coming full circle”

Dementia may also be described as a “second childhood” and a time when one is “closer to the Creator.” A person’s spiritual beliefs often influence how dementia is viewed.

Historical changes in diet, changes to the land or environment, disconnection from culture, as well as trauma, intergenerational trauma, stress, and unresolved grief are significant factors that cause people and communities to sometimes be out of balance and may partially explain a rise in the number of elderly with dementia.





Talking about Dementia

Dementia may or may not be an accepted term for all people. It may be more appropriate to speak of forgetfulness or thoughts being mixed up.

There is no word that has been identified to mean dementia in Aboriginal languages in Canada. Instead, Indigenous languages have words that describe the symptoms or state of mind. For example, words and phrases such as:

- “forgetful”
- “confused”
- “thoughts mixed up”
- “something wrong with my head”
- “mind changes”
- “going back to childhood”

The words people use to describe the symptoms often indicate the severity or stage of the illness which can be helpful for health care workers, physicians and specialists in their assessments and care planning.

Health care worker interactions with Indigenous people concerning dementia should include an early conversation with the patient and family to explore their understandings of the symptoms being experienced and the acceptability of words such as dementia or Alzheimer’s disease.

Views held by families and individuals can be respected by adjusting your language use and approach to care.

WHAT TO EXPECT AFTER A DIAGNOSIS OF DEMENTIA:

An Indigenous Persons' Guide



For people with a diagnosis of dementia...

A diagnosis of dementia can be scary. Sometimes people diagnosed with dementia do not accept it at first. Many older people believe that changes to the mind come naturally with age and their journey through life. While some memory changes can be expected as you age, dementia as a disease will change your memory and concentration more quickly. For this reason, it is important to start talking about it now with your loved ones and others who will support you.

We have created this Indigenous Person's guide to help you understand your diagnosis and the path ahead. Indigenous peoples who have had dementia in their own families made these suggestions:

- Learn about the different types of dementia – they may have different symptoms
- Find resources that tell you about the progression of dementia and make sure you know what to expect at each stage. Dementia can act slow or fast in different cases. Make sure you are planning ahead
- Think of the people who will help support you when you need it, such as family, friends, community members or health care workers
- Think about who you will ask to make decisions for you when you need them to. It is best to think about these legal issues when you are first diagnosed
- Find community supports such as the local health centre programs or staff, home and community care programs or your local Alzheimer's Society
- If you are still driving you will need to think about how you will eventually stop and work with the local programs, friends and family to find other ways to get around
- Pay attention to your physical health by eating well, being active and taking care of other illnesses you might have like diabetes or high blood pressure
- Stay connected with people and be social

- Set up regular appointments with your health care providers to check in on the dementia and any new care needs that arise – for example, you may need more home care or medical equipment in your home
- Consider taking family members to your medical appointments and information sessions so they can learn how best to help you
- Consider wearing a medical I.D. bracelet
- Keep track of what tasks are frustrating or upsetting and ask for support to complete them
- Keep calendars, journals or lists. Sticky notes on mirrors and refrigerators can help
- Formal medical care is not the only way to deal with dementia. Other techniques Indigenous people use include prayer, ceremony, church, meditation, yoga, visiting with youth, art-therapy, story-telling, speaking the language and humour
- Connect with a doctor you trust and visit regularly and tell them about any changes to your memory or health

“One of the things that I’ve found is try not to get frustrated. I’ve laughed but also I’ve gotten angry when I’m by myself and trying to figure out something. There was times of frustration because I couldn’t think why can’t I do this thing, but I had to overcome that with laughter or you know.” (Person diagnosed with Dementia from Moose Cree).



For caregivers...

There is much to consider following a diagnosis of dementia. Your role as a support person or caregiver is very important. Caregiving can be challenging but many Indigenous caregivers stories also show that they have found the role rewarding in many ways. Some found it a way to reconnect with loved one and as an opportunity to learn about them and their life in a new way. Caring for a loved one with dementia is demanding on your mind, emotions, body and spiritual self. Some Indigenous caregivers find that they lose sleep, worry often, become frustrated with their loved one and find it tough to balance work, caregiving and their own lives.

“I’m doing a lot of working from home right now which is hard; another challenge is that I don’t have any down time.” (Caregiver from Sudbury)

At the same time, many caregivers find that dementia gave them the opportunity to become closer to their loved one.

“It brought us, both of us closer since she had to rely on me too. It just brought us closer as a mother and daughter. And then having someone to depend on me and needing me helped to change my attitude. I learned to enjoy the simple things like she would, we would go outside and just look at the trees, at colours of the trees of the leaves, we would go outside and look at the birds sitting on the wires.” (Caregiver from Six Nations)



Here are some tips from other Indigenous caregivers about your new role and how to stay well:

- Draw on your values to help you through the hard times
- Be active in the care plan. Meet often with family, friends and health care workers to keep everyone involved and informed
- Talk to your loved one about what they need and what they are experiencing. Are they frustrated? Why? How can you help? Would they like to speak in their language or listen to music? Get to know what brings them joy
- Attend as many appointments and information sessions with your loved one as you can. Be informed about your loved one's care plan and speak up for their needs as well as yours
- Let neighbours and community members know about your loved one's memory challenges. They can be a great source of support and an extra set of eyes when needed
- Check in regularly with your loved one and ask friends and family to drop by too. A visitor's logbook kept by the door is a good idea
- If your loved one seems disinterested in visiting, favourite activities or taking care of themselves, address it right away. They may be experiencing depression, loneliness or their dementia may have worsened. Connect with your health care provider if you need to



- You may learn about parts of your loved one's past that you never knew about. This could be good or painful, depending on the memories that surface. If they are painful, comfort your loved one and care for yourself as best you can. Consider what in their routine or environment could have pushed that memory to the surface and change it if you can
- Keep copies of your contact information in your loved one's coats, shoes and wallet
- Connect with other caregivers, family members and community organizations for support and information
- Find ways to learn about dementia supports, treatments and the types and stages of the illness. Knowing what is coming and what choices will need to be made is important



- Take care of your own wellness. Visit your own health care providers regularly and find time to take care of your spiritual, emotional, physical and mental wellness
- Ask your providers about access to respite (someone who can care for your loved one for a short period) – you need a break too
- Take joy in the moments you have with your loved one – the time you spend, the stories that are shared, the humour and the love

“There are moments when... you got to take a break for yourself and let somebody else take your place ... you can't do it 24/7.” (Caregiver, Sudbury).



TALKING POINTS for Brain Health Champions

For Sharing with Elders

Why is it important to share with Elders about Brain Health?

- ▶ Elders are respected members of the community, who hold valuable stories, traditional knowledge, and cultural values.
- ▶ Elders often express deep concern about the health and wellbeing of the Tribe. Sharing about brain health is one way to support elders, families, and your community.
- ▶ The Healthy Brain Initiative Road Map for Indian Country is a resource for the Tribe or community to respond to brain health challenges. It can also help you learn more about how to engage others to take action for the community's brain health.
- ▶ Invite elders to speak and participate in community meetings or talking circles on brain health.

TALKING POINT 1

Brain health is important to understand as we grow older. Caring for our mental and brain health will help us continue to serve as guides and teachers for the next generations.

TALKING POINT 2

Changes in brain health can happen slowly over time. What experiences have you had or changes have you noticed in your own brain health? Brain health refers to your thinking, understanding, and memory abilities. It also can refer to the things you do to keep your brain healthy and active, like staying physically active and following a healthy diet.

- Explain early warning signs, what is typical aging and what may be cause for concern, like increased difficulty in remembering or thinking (signs of cognitive decline).
- Do not attempt to diagnose but encourage elders to talk with their healthcare provider about any symptoms.
- Feel free to use the warning signs listed on page 3.

TALKING POINT 3

Starting conversations about brain health can feel awkward. Try explaining your motivation for wanting to share strategies for brain health. To start, consider why brain health is important to you. What has been your experience with your own or a loved one's brain health?

TALKING POINT 5

Ask the best way to talk about brain health with other elders and how brain health is viewed. Are there any words or phrases to use or avoid when talking about memory?

TALKING POINT 6

People can continue to live a healthy and balanced life with cognitive decline. There are many tools, like the Road Map for Indian Country, that can help elders and communities find the best ways to support brain health. What are the ways that your Tribe and community can address brain health? How can people with cognitive impairment best be supported in their communities?

TALKING POINT 4

Some people with health conditions like diabetes, high blood pressure, commercial tobacco use, or mid-life obesity may be at risk for cognitive decline.

- However, these health conditions can be treated or prevented.
- See page 3 for healthy behaviors that may protect against cognitive decline.

TALKING POINTS for Brain Health Champions

For Sharing with Families and Caregivers



Why is it important to talk to Families and Caregivers about Brain Health?

- ▶ Taking care of elders is an important responsibility. By supporting and caring for their health and wellbeing, you respect their wisdom and insights.
- ▶ Your elders are important members of your family and community. Changes in brain health, including cognitive decline, can happen slowly over time. Knowing the signs of cognitive decline and dementia can help you notice if there may be concerns for your elder's brain health.
- ▶ Acknowledge that you and some elders may not feel comfortable discussing the subject. Follow your own customs in asking for help if needed. Having these conversations shows that you value elder health and the health of your community.
- ▶ You can support brain health by encouraging family members and caregivers to share their challenges with healthcare providers and decision-makers such as Tribal leaders and administrators. These groups may not be aware of the needs and gaps in services for those affected by declining brain health.

TALKING POINT 1

Brain health is extremely important as we age, not only for our minds but our bodies and spirits. Changes in brain health can happen slowly over time. What changes have you noticed in your elder's brain health?

TALKING POINT 2

Developing Alzheimer's, dementia, or memory loss is not a "normal" part of aging. Know the 10 warning signs of Alzheimer's and related dementias. See the warning signs on page 3. Signs of memory loss may mean you and your elder should talk to a healthcare professional.

TALKING POINT 3

Some people with health conditions like diabetes, high blood pressure, commercial tobacco use, or mid-life obesity may be at risk for cognitive decline. However, these health conditions can be treated or prevented. See back of this page for healthy behaviors that may protect against difficulties remembering, thinking, or processing.

TALKING POINT 4

Challenges to brain health are expected to increase significantly in the next few decades. This will increase the number of caregivers and the need for healthcare and services for elders.

TALKING POINTS for Brain Health Champions

For Sharing with
Healthcare Providers and Public
Health Professionals

Why is it important to share with Healthcare Providers and Public Health Professionals about Brain Health?

- ▶ Healthcare providers are usually trusted by patients and respected by the community. They hold a special role to help their patients achieve health and wellness. Their voice can also play an important role in making changes in the health system to address brain health challenges for individuals and caregivers.
- ▶ Many AI/AN leaders, experts, and practitioners helped shape the Healthy Brain Initiative and the Road Map for Indian Country by providing insights, guidance, and examples from their own work.
 - » The Road Map contains useful information for planning, implementing and monitoring dementia programs in Indian Country.
 - » This includes resources for starting a conversation about how Alzheimer's and related dementias affect all generations and key background information about dementia.

TALKING POINT 1

Dementias, including Alzheimer's disease is underdiagnosed in Indian Country. Only one in three (31%) AI/ANs aged 65 and older who experience memory loss have talked with their healthcare provider about it. Less than half of people with dementia in all populations nationwide have been diagnosed.

TALKING POINT 2

Supporting a balanced life strengthens brain health! Certain chronic conditions and behaviors may increase the risk of dementia. Supporting your patients to manage their diabetes or heart disease and promoting healthy behaviors like stopping commercial tobacco use can reduce their risks of dementia and other complications.

TALKING POINT 3

Challenges to brain health are expected to increase significantly in the next few decades. In 2015-2017, one in six AI/ANs aged 45 and older reported subjective cognitive decline (SCD), which are self-reported difficulties in thinking or remembering. Nearly two-thirds (63%) of those with SCD had to give up some day-to-day activities because of these cognitive problems.

TALKING POINT 4

The Road Map for Indian Country outlines a public health approach to addressing cognitive decline and dementia, including Alzheimer's. Eight strategies focus on three core outcomes:

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

National Indian
Health Board



TALKING POINTS for Brain Health Champions

For Sharing with
Tribal Leaders and/or
Governing Bodies

Why is it important to share with Tribal Leaders and Governing Bodies about Brain Health?

- ▶ Tribal leaders hold an essential role in supporting the health and wellbeing of Tribal members.
- ▶ Tribal leaders can influence attitudes of community members and can affect health systems change.
- ▶ Leadership is needed for a public health approach to be successful.
- ▶ By focusing on prevention and support, Tribal leaders can help to promote good brain health.

TALKING POINT 1

Brain health is an often-overlooked health topic.

- Difficulties with memory and thinking may impact elders, who are a vital part of the community and keepers of traditions.
- **Dementia, including Alzheimer's, is underdiagnosed in Indian Country. Only one in three (31%) AI/ANs aged 65 and older who experience memory loss have talked with their healthcare provider about it.** Less than half of people with dementia in all populations nationwide have been diagnosed.

TALKING POINT 2

Brain health challenges will continue to grow. The burden of Alzheimer's and related dementias is expected to increase over five times between 2014 and 2060. This will increase the number of caregivers and the need for healthcare and services for elders.

TALKING POINT 3

An excellent resource exists: The Road Map for Indian Country. Native leaders, experts and practitioners helped shape the Road Map by providing insights, guidance and examples from their own work. It was produced in 2019 by the Alzheimer's Association and Centers for Disease Control and as part of the Healthy Brain Initiative.

- This document contains useful information for planning, implementing and monitoring dementia programs in Indian Country.
- This includes resources for starting a conversation about how Alzheimer's and related dementias affect all generations and key background information about dementia.

TALKING POINT 4

The Road Map for Indian Country outlines a public health approach to addressing cognitive decline and dementia, including Alzheimer's. Eight strategies focus on three core outcomes:

- **Educate and empower the community.** For example, increasing awareness of brain health and early warning signs through outreach and education campaigns
- **Collect and use data.** For example, ensuring your healthcare operations collect quality measures related to dementia
- **Strengthen the workforce.** For example, advocating for brain health training for healthcare providers and public health professionals.

National Indian
Health Board



Healthy Heart, Healthy Brain...



Talking to American Indian and Alaska Native Patients About Brain Health

Guidance for Primary Care Providers – Key Brain Health Promotion Facts

- ◆ 1 out of 3 American Indians who live to 65 will develop dementia.
- ◆ Native elders with heart disease, high blood pressure, diabetes, or depression have a higher risk for Alzheimer’s disease or dementia.
- ◆ Evidence for the following three interventions for healthy brain promotion are encouraging: blood pressure management, increased physical activity, and cognitive training.
- ◆ Evidence-based behavior change interventions: cognitive-behavioral therapy, motivational interviewing, mindfulness/mind-body, positive psychology, and management of mental health conditions. Consider referrals for behavior modification.
- ◆ Observe and evaluate cognition in all older adults at every visit. Perform cognitive screening when indicated by observation, patient or family concern.
- ◆ Alzheimer’s Association offers a cognitive assessment toolkit with brief screenings tools to quickly assess for impairment and aid with referral and management. To learn more, visit: <https://www.alz.org/professionals/healthcare-professionals/cognitive-assessment>.

Explaining the Heart-Brain Connection to Your Patients

*We now know that reducing high blood pressure, which helps preserve heart health and prevents strokes, is the best thing you can do to try to prevent dementia and Alzheimer’s. **Your heart and brain are connected by “rivers” in your body.** The brain is the command center and the heart works as a pump to send energy through the rivers to the brain to keep us going. There are things you can do to ensure that the rivers are healthy, open and flowing and to keep body and mind healthy.*



Health Factor or Behavior

Blood Pressure

American College of Cardiology/American Heart Association Guidelines (2017)

Normal <120 systolic AND <80 diastolic

Elevated >120-129 systolic AND <80 diastolic

Patient Messaging

The only way to know your blood pressure is to have your blood pressure checked.

Understanding your blood pressure numbers is key to controlling high blood pressure.

It should be less than 120/80 mmHg.

Take your blood pressure medication (if prescribed) even if you feel good.

Have your blood pressure checked regularly.

We can teach you how to check your blood pressure at home.

Potential Interventions

- ◆ Medication
- ◆ Reduce sodium in diet
- ◆ Daily physical activity
- ◆ Quit smoking
- ◆ Referral for medical nutrition therapy
- ◆ Routine screening
- ◆ Plan for patient self-monitoring

Review sample triage protocol for emergency, urgent and non-urgent management of high blood pressure <http://www.astho.org/Healthy-Aging/>

Fasting Blood (plasma) Glucose

American Diabetes Association

Blood glucose level

Normal less than 100 mg/dl

Prediabetes 100 mg/dl to 125 mg/dl

Diabetes 126 mg/dl or higher

A1C (%) or eAG (mg/dL)

Normal < than 5.7%

Prediabetes 5.7% to 6.4%

Diabetes 6.5% or higher

The only way to know your blood glucose level is to have your blood tested.

Understanding your blood sugar numbers and your A1C levels are key to controlling your diabetes.

Normal blood sugar is less than 100 and a normal A1C is less than 5.7%.

Take your diabetes medication (if prescribed) even if you feel good.

Have your blood sugar and A1C levels checked regularly.

Living with diabetes can make you feel stressed or sad. Talk to me (or your diabetes educator) if you start to feel overwhelmed.

- ◆ Medication
- ◆ Referral for diabetes self-management education (DSME); Medicare covered benefit up to 10 hours
- ◆ Referral for medical nutrition therapy
- ◆ Referral for weight loss, physical activity, diabetes distress counseling
- ◆ Annual screening

Review Standards of Medicare Care in Diabetes – 2019: Abridge for Primary Care Providers <http://clinical.diabetesjournals.org/content/36/1/14>



Health Factor or Behavior

Cholesterol

American Heart Association

HDL (good cholesterol)

LDL (bad cholesterol)
 *Ranges no longer used
HDL & LDL are evaluated in context of other risk factors

Triglycerides: high triglyceride level combined with low HDL cholesterol or high LDL cholesterol is linked with fatty buildups in artery walls.

Patient Messaging

The only way to know your cholesterol is to have it checked through a blood test.

You should have your cholesterol checked regularly and know your numbers.

Take your cholesterol medication (if prescribed) even if you feel good.

Potential Interventions

- ◆ Medication
- ◆ Heart-healthy diet
- ◆ Daily physical activity
- ◆ Smoking cessation intervention if relevant
- ◆ Weight loss
- ◆ Referral for medical nutrition therapy, weight loss, physical activity counseling
- ◆ Routine screening

Medication Adherence

Adherence is an important health factor for the management of hypertension, high cholesterol, and diabetes. Suggest adherence vs. compliance.

Effective two-way communication with healthcare providers doubles the odds of patients taking medication properly.

Consider working with local pharmacists to assist with counseling and monitoring.

Medication may be prescribed by your health care provider to help control your blood pressure, cholesterol or diabetes numbers.

It is important to go to a pharmacy to have the prescription filled and to take the medication as directed by your health care provider.

If you have trouble paying for your prescriptions or the medicine makes you feel bad, talk to your doctor about your concerns. Don't just stop taking them.

Your pharmacist can talk to you about your medications and if needed contact us if you are having side effects or problems taking them.

SIMPLE method for medication adherence:

- ◆ **Simplify** the regimen: promote adherence tools; match to daily routine
- ◆ **Impart** knowledge: write it down for them; reinforce verbally
- ◆ **Modify** patients' beliefs and behavior: provide positive reinforcement; understand fears
- ◆ **Provide** communication and trust: let patients speak freely; use plain language; ask for input
- ◆ **Leave** the bias: ask questions about attitudes, beliefs, and cultural norms
- ◆ **Evaluate** adherence: ASK; use medication adherence scale

Review more on SIMPLE method https://millionhearts.hhs.gov/files/TipSheet_HCP_MedAdherence.pdf



Health Factor or Behavior

Smoking

Ceremonial tobacco used infrequently is not likely to have the same negative health effects as commercial tobacco use.

Patient Messaging

Never smoke or if you do smoke, stop now.

Ceremonial tobacco use may be okay if it is not done regularly.

We can talk about steps we can take together to help you quit.

Cigarette smoking harms nearly every organ of the body, causes many diseases, and reduces the health of smokers in general.

Quitting smoking lowers your risk for smoking-related diseases and can add years to your life.

Potential Interventions

- ◆ Brief physician counseling (up to 8 counseling sessions may be covered by Medicare Part B at no cost to the patient)
- ◆ Medication (nicotine replacement or Bupropion)
- ◆ Referral to quit line/ telephone counseling

5A Model for smoking cessation:

- ◆ **Ask:** every patient at every visit about tobacco use
- ◆ **Advise:** about the benefits of smoking cessation
- ◆ **Assess:** patient's readiness to quit; introduce harm reduction strategies
- ◆ **Assist:** patients with a quit plan. Combination of counseling and medications is most successful.
- ◆ **Arrange:** follow-up visits starting at 1 week

Review more on the 5A Model or Ask-Advise-Refer programs <https://dcp.psc.gov/OSG/pharmacy/sharedresources/tctp.aspx>





Health Factor or Behavior

Physical Activity

American Heart Association

Adults should also do muscle-strengthening activities on 2 or more days per week.

Weight/ Body Mass Index (BMI)

US Department of Health and Human Services

*BMI range: 18.5-24.9 kg/m² (use BMI calculator)

Weight loss of 5-10 percent of initial weight will lower risk of disease.

Frail elders or those with low muscle mass should NOT try to lose weight

Patient Messaging

Be physically active every day.

Try to get 1 ½ - 2 hours of exercise EVERY week.

Try three 10-minute walks each day instead of 30 minutes of exercise at a time.

You should also work on keeping up or building muscle strength. Simple things like wall push-ups (demonstrate) or chair squats can be done at home while watching TV.

Maintain your ideal body weight.

You can work to lose weight by changing how you eat and getting more physical activity.

If you lose just 10% of your weight, it will make a big difference in your risk factors.

We can help you with steps to lose weight and be more active.

Potential Interventions

Recommended exercise guidelines (modify as necessary for chronic conditions):

- ◆ Adults should do 2 hours and 30 minutes a week of moderate-intensity, or 1 hour and 15 minutes (75 minutes) a week of vigorous-intensity aerobic activity, or equivalent combination of moderate- and vigorous-intensity aerobic physical activity.
- ◆ Aerobic activity should be performed in episodes of at least 10 minutes, spread throughout the week.

- ◆ Referral to registered dietitian
- ◆ Referral to structured weight loss program
- ◆ Follow-up for management of weight reduction program by primary care

3 steps to talk about weight management:

- ◆ Set an effective tone: ask permission, non-judgmental
- ◆ Assess motivation/ readiness: "On a scale of 1 -10, how ready are you to lose weight?"
- ◆ Build a partnership with the patient: set 2-3 realistic goals together

Review more discussion tips <https://www.nhlbi.nih.gov/files/docs/resources/heart/steps.pdf>



Health Factor or Behavior

Heart-Healthy Diet

American Heart Association

Food choices:

5 fruits/vegetables a day, low-fat dairy & lean meats, avoid processed food and meats, and sugary beverages

Sodium:

1 tsp salt = 2300 mg of sodium, ideal is 1500 mg/day, but no more than 2300 mg/day (most eat 3400 mg/day)

Food labels:

140 mg or less/serving is “low sodium”

Patient Messaging

Traditional foodways may be an opportunity to improve dietary habits; “tell me about what you eat each day.”

Read food labels for sodium content and know what the serving size is.

Eat plenty of vegetables and fruits, and whole grains.

Switch to fat-free or low-fat foods and meat and eat more fish, poultry, beans, and nuts.

Cut down on foods that are high in saturated fat, such as fatty meats, dairy products, and tropical oils such as coconut, palm kernel, and palm oils; sugar-sweetened beverages and sweets.

We can help you learn to read labels and make healthier food choices.

Potential Interventions

- ◆ Referral to registered dietitian
- ◆ Follow-up appointments for physician office counseling on diet
- ◆ Refer to community resources and programs on health and nutrition

Alcohol Use

American Heart Association

No more than 2 drinks/day (men)

No more than 1 drink/day (women)

Consider cultural significance of alcohol and drug use in and availability of services. Targeted referrals enhance physical health as well.

Don’t drink more than one alcoholic drink per day if you’re a woman and two if you’re a man.

Drinking a lot at one time or drinking many days of the week can have a direct impact on how your brain functions. You can have trouble concentrating, have memory loss, have trouble focusing your attention and more.

We can help you if you feel like you have a problem with alcohol or drug use.

“To help us understand how we can help you, I would like to spend a few minutes asking you some questions that we ask everyone. How many times in the past year have you:”

- ◆ (for men) had 5 or more drinks (beer, wine, or hard liquor) in a day?
- ◆ (for women or anyone over 65) had 4 or more drinks in a day?
- ◆ used recreational or prescription drugs to get high?

If response to either question is yes, implement CAGE questionnaire https://www.integration.samhsa.gov/A_Discussion_Guide_for_Primary_Health_Care_Providers.pdf



Health Factor or Behavior

Sleep

American Academy of Sleep Medicine and Sleep Research

Typical adults need 7 hours of sleep/night

Less than 7 hours is linked to greater risk of obesity and diabetes

Patient Messaging

Get 7 hours of sleep per night.

Not getting enough sleep can cause or make it harder to control other health problems like diabetes or weight problems.

If you are having trouble sleeping, we can help you if we talk about it.

Potential Interventions

- ◆ Referral for sleep study
- ◆ Review of medications that can interfere with sleep

Implement the **Pittsburg Sleep Quality Index to assess degree of sleep interference** <http://sleep.pitt.edu/research/instruments.html>

Falls

Falls with resultant moderate or severe head injuries can injure the brain and increase the risk of certain types of dementia or Alzheimer’s.

Utilize the Centers CDC’s **STEADI algorithm for fall risk screening, assessment and intervention to assess fall risk** <https://www.cdc.gov/steadi/pdf/STEADI-Algorithm-508.pdf>

Falling and hitting your head can injure your brain and increase the chance of dementia or Alzheimer’s.

Reduce the chance of falling by doing simple strength and balance exercises at home three times per week.

To help reduce the chance of you falling at home:

Get rid of small rugs, floor mats, and things you can trip over at home.

Put grab bars in your bath tub or shower.

Move slower when getting up.

Use a cane or walker if you are unsteady.

Add more lights around the house and use a night light when sleeping.

- ◆ Conduct falls assessment
- ◆ For home-bound or frail adults, consider home occupational therapy assessment

Selected STEADI interventions:

Low risk:

- ◆ Patient education
- ◆ Vitamin D+/- calcium
- ◆ Refer for strength and balance exercise (community or fall prevention program)

Moderate risk:

- ◆ Low risk interventions + refer to PT to improve gait, strength and balance

High risk:

- ◆ Low risk + moderate interventions +
- ◆ Conduct multifactorial risk assessment
- ◆ Manage and monitor hypotension
- ◆ Manage medications
- ◆ Address foot problems
- ◆ Optimize vision
- ◆ Optimize home safety



Health Factor or Behavior

Cognitive Activities

NASEM recommends cognitive training as an intervention to aid in prevention of cognitive impairment. In older adults with normal cognition, training in reasoning and speed improves performance in these areas and select IADL function for up to 10 years.

Patient Messaging

It's important to keep your mind active. Your mind is a like a muscle and if you don't use it, you lose it.

Work to keep your mind busy: take classes, do cross word puzzles, read, go to your senior center, play cards, or visit with friends and family

The local senior center has several programs for older adults you should consider. **[Provide contact information for referral]**

Potential Interventions

- ◆ Recommend community programs/ services designed to provide individual and group interventions aimed at promoting cognitive training-like activities, e.g., senior center, Title VI agencies, congregate meal sites.
- ◆ Consider referral for cognitive training if indicated.
- ◆ Consider referrals for transportation services if needed.

Social Isolation

Social isolation increases risk of depression, abuse, falls, substance abuse, heart disease, dementia, and contributes to other health issues. It can also lead to increased health care utilization.

It's important to that you maintain connections with people in the community. Being isolated from people can cause problems with your health.

It gets harder to go out as you get older and sometimes driving is harder, but you should still try to go out and visit in the community as much as you can.

Good places to meet and talk with people are church if that is something you like to do, the local senior center, and visiting with family and friends.

The local senior center has several programs for older adults you should consider. **[Provide contact information for referral]**

- ◆ Recommend community programs/services designed to provide individual and group interventions aimed at reducing social isolation, e.g., senior center, Title VI agencies, congregate meal sites.
- ◆ Consider referrals for transportation services if needed.

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Learn. Plan. Respond to Dementia.



**HEALTHYBRAIN
INITIATIVE**

Road Map for Indian Country

The population of older American Indians and Alaska Natives (AI/ANs) is growing — and quickly. Between 2014–2060, the number of AI/ANs aged 65 and older living with dementia is projected to grow over five times. These longer lives give more time for older generations to share knowledge and traditions with the next. But greater age brings increased risk for Alzheimer’s and other dementias — when memory and thinking problems interfere with daily life and activities.

The impact of dementia is felt by multiple generations. People living with this chronic condition gradually need more help caring for themselves including help managing medications, bathing and feeding, paying bills and cleaning, or help going to appointments or social events. Family members, from the young to the old, play a vital role in providing this care to relatives with dementia which can grow more intense over time. But there are ways to lessen this impact. More education about dementia and increased support throughout the community can help both people with dementia and caregivers stay as healthy as possible. And, traditional wellness practices and public health efforts that control high blood pressure and diabetes are ways to reduce the risk of dementia across generations.

What can tribal leaders and tribal health and aging professionals do to promote wellness among elders, including those affected by dementia? How can they support family care and prepare their communities for the future?

The Healthy Brain Initiative’s (HBI) **Road Map for Indian Country** is a guide for AI/AN leaders to learn about dementia and start discussions throughout their communities. The guide suggests eight strategies that embrace community strengths, including traditional practices, resilience, and existing services. The strategies can be tailored to unique priorities of each community. Educational materials from the Alzheimer’s Association, the Centers for Disease Control and Prevention, and others can make it easy to get started.

Discover how to strengthen the well-being of older adults and families dealing with dementia and to protect future generations. Get the Road Map and find helpful tools at:

- cdc.gov/aging
- alz.org/publichealth/indiancountry

The impact of Alzheimer’s will only continue to grow. AI/AN leaders can use the *Road Map for Indian Country* to learn about Alzheimer’s, find out what some AI/AN communities are doing, plan their response, and start taking action throughout their own community.

SELECT FACTS

- The number of older American Indians and Alaska Natives (AI/ANs) is increasing. An estimated 569,000 AI/ANs are aged 65 or older. This number is expected to triple over the next three decades.
- The number of AI/ANs living with dementia is also expected to increase. Between 2014–2060, the number of AI/ANs aged 65 and older living with dementia is projected to grow over five times.
- In 2015–2017, one in six AI/ANs aged 45 and older reported subjective cognitive decline (SCD), which are self-reported difficulties in thinking or remembering. Nearly two-thirds (63%) of those with SCD had to give up some day-to-day activities because of these cognitive problems.
- With dementia, it’s not just the person with cognitive challenges dealing with the condition. Family members and friends feel the impact too.

WHAT IS DEMENTIA?

Dementia is a chronic condition that affects a person’s brain. People with dementia have a variety of cognitive problems with memory, thinking, communication, and carrying out everyday tasks. Dementia gets worse over time, and people gradually lose their ability to take care of themselves. It can be difficult to provide care for people with dementia, especially when they need many hours of care over multiple years.

Alzheimer’s is the leading cause of dementia. Alzheimer’s is a disease that damages and destroys brain cells over time. Vascular dementia is the second most common cause of dementia. Vascular dementia is caused by conditions or lifestyle behaviors, such as smoking cigarettes or not being active, that weaken or block blood flow to the brain.



PUBLIC HEALTH ACTIONS TO CARE FOR AN AGING POPULATION

The Healthy Brain Initiative's *Road Map for Indian Country* is tailored for leaders of American Indian and 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.

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.

RESOURCES TO SUPPORT IMPLEMENTATION

The Alzheimer's Association has an online resource library ([alz.org/publichealth](https://www.alz.org/publichealth)) with background information, case studies, data, and tools that could be adapted to implement Road Map strategies.

The CDC Healthy Aging Data Portal ([cdc.gov/aging](https://www.cdc.gov/aging)) provides data on key indicators of health and well-being, screenings and vaccinations, and cognitive and mental health among older AI/AN populations.

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/healthy-heart-healthy-brain](https://www.astho.org/healthy-aging/healthy-heart-healthy-brain)

DEVELOPING THE HBI ROAD MAP FOR INDIAN COUNTRY

The Healthy Brain Initiative's (HBI) *Road Map for Indian Country* was shaped by many experts and leaders throughout Indian Country who provided guidance, reviewed documents, and shared their experience addressing dementia and helping caregivers. These AI/AN leaders recognized Alzheimer's and other dementias as a serious and growing problem. They wanted to learn more about dementia and ways to promote wellness across generations and prepare for the future. This expert input helped shape the *Road Map for Indian Country* into a guide that AI/AN communities could tailor and generate their own solutions based on the community's priorities and unique heritage.



[cdc.gov/aging](https://www.cdc.gov/aging)
[alz.org/publichealth](https://www.alz.org/publichealth)

Starting Conversations About Alzheimer's



**HEALTHYBRAIN
INITIATIVE**

Road Map for Indian Country

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 American Indian/Alaska Native (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 if Alzheimer's disrupts the sharing of cultural traditions and heritage.

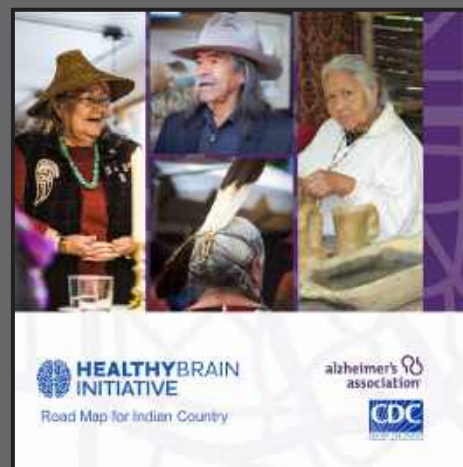
An initial community gathering to discuss dementia could begin with an invocation drawing on the community's traditions, such as a prayer or performance of a tribal song. The person leading the discussion may then acknowledge Elders and thank hosts for the space and refreshments. After sharing a personal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

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?

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.



alzheimer's 
association®



cdc.gov/aging

alz.org/publichealth/indiancountry

A Planning Guide for the Healthy Brain Initiative Road Map for Indian Country

>> PURPOSE OF THE PLANNING GUIDE

Designed for public health professionals who work with American Indian/Alaska Native (AI/AN) communities, this planning guide will help you select Healthy Brain Initiative (HBI) [Road Map for Indian Country](#) (Road Map) strategies and get started with implementation. The guide's six quick steps will direct you to a path for success that best meets your specific needs. Easy-to-use worksheets and resources will help you prioritize, plan, and promote Road Map strategies within AI/AN communities.

>> WHAT IS DEMENTIA? HOW DOES IT RELATE TO ALZHEIMER'S DISEASE?

Dementia is the loss of cognitive functioning that is severe enough to interfere 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.

Alzheimer's disease is 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.

10 Warning Signs of Alzheimer's¹

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.

Page 1 - Purpose and What is Dementia?

Page 2 - The Role of Public Health

Page 3 - Road Map for Indian Country Strategies

Page 4 - Know.Plan.Go.™ for Road Map Success

Page 5 - Six Steps to Planning Your Public Health Response to Dementia

Page 7 - Table 1: Suggestions for Implementing Road Map Strategies

Page 14 - Worksheet: Action Planning

Page 15 - Table 2: Potential Data Sources

Page 17 - Checklist: Engaging Partners and Stakeholders

Page 18 - Worksheet: Stakeholder Analysis Matrix

>> THE ROLE OF PUBLIC HEALTH

The public health field seeks to achieve lasting positive change in the health of entire communities. The values underlying a public health approach — promoting wellness and providing care in the community for people who need it — are mirrored in long-standing cultural values and in the spirit of AI/AN traditions. 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.

A public health approach to addressing all forms of dementia — including Alzheimer's — starts with understanding that these conditions should be viewed as part of a continuum of cognitive health and function that spans an entire lifetime (see Figure 1 – The Development of Dementia across the Life Course for People Who Are At-Risk).

While the causes of dementia are largely unknown, there is growing evidence that it may develop as a result of multiple risk factors over the course of a person's life. While some risk factors — such as age, family history, and risk genes — cannot be changed, other risk factors can be addressed to help change the path of dementia and keep people healthier longer.²

These include:

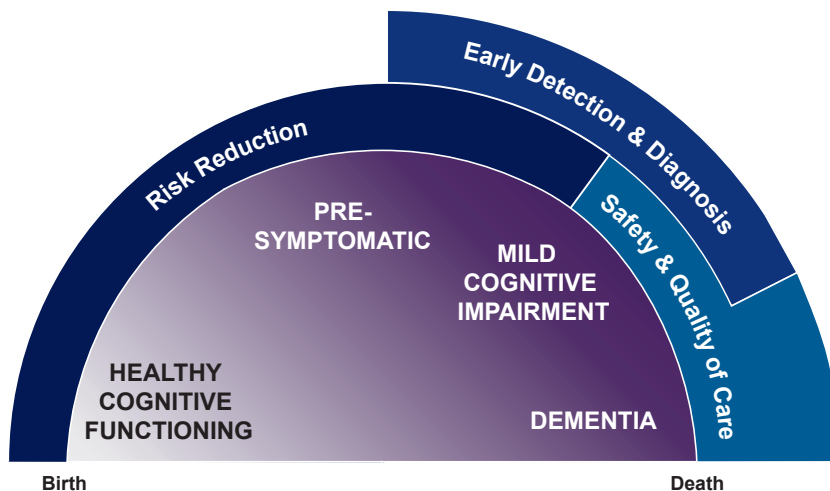
- Diabetes
- High blood pressure
- Smoking
- Mid-life obesity
- Traumatic brain injuries

In addition to avoiding the risk factors that may lead to dementia, there are protective factors that can improve overall physical health and promote healthy aging.

Protective factors include:

- Eating a healthy diet (three sisters soup)
- Exercise the body (walk, traditional dance)
- Exercise the mind (beading, drumming)
- Stay socially engaged and active (elder talking circles)
- Limit tobacco to ceremonial use
- Avoid secondhand smoke

Figure 1. The Development of Dementia across the Life Course for People Who Are At-Risk



How Is Public Health Different from Healthcare?

Public health aims to reduce poor health outcomes from occurring within a community as a whole, while healthcare is patient-focused: diagnosing and treating individuals. To make meaningful improvements across Indian Country, communication and collaboration across these sectors is needed. Other sectors can be invited, such as businesses that serve your community, local aging or human services programs, behavioral health services, transportation, housing services, and parks and recreation, among others.

This illustration shows the life course for people who will eventually develop dementia, including Alzheimer's. 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



>> ROAD MAP FOR INDIAN COUNTRY STRATEGIES

The following are the eight strategies that can inform and shape the public health response to Alzheimer's and all dementia in AI/AN communities. Tribal and Urban Indian/Urban leaders are encouraged to discuss these strategies with their community and involve members in planning and implementing these community-wide approaches.

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.
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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.



>> FIGURE 2. KNOW. PLAN. GO.™ FOR ROAD MAP SUCCESS



- » Familiarize yourself and others with the Road Map and its strategies
- » Understand how the Road Map can be used to integrate and align with existing plans and initiatives
- » Know the Road Map is a credible source to support and prioritize strategies
- » Gather key staff and stakeholders to identify which Road Map strategies best meet these priority needs and are most feasible to implement
- » Be familiar with basic knowledge about Alzheimer's and all dementia, mild cognitive impairment, and warning signs
- » Identify other entities working in the healthy aging space in your community



- » Assess individual, community, and system needs around cognitive health
- » Use resources below to prioritize which strategies to do first and create a plan to implement each
- » Map out a series of proactive communications to promote the importance and urgency of your strategies
- » Identify and incorporate strategies within existing plans and initiatives where possible
- » Plan for communication strategies for different audiences (public health and healthcare workforce, Tribal and community leaders, community members)



- » Engage key staff, stakeholders, and partners to help in implementing strategies
- » Learn about success stories, case examples, and best practices from other departments of health or I/T/Us (Indian Health Service/Tribal Health/Urban Indian Health Providers)
- » Measure achievement of your strategies and share progress to maintain support and mobilize others
- » Seek additional support from the CDC and the Alzheimer's Association, International Association for Indigenous Aging, National Council of Urban Indian Health, National Indian Council on Aging, Inc., and National Indian Health Board
- » Review the Road Map resources on alz.org/publichealth; cdc.gov/aging; ncuih.org/wisdomkeeper; iasquared.org; and nihb.org/brain-health/



- » Create calls to action to inform and motivate a prioritized list of others to be a part of the movement
- » Incorporate updates on progress into standing agenda items, key leadership presentations, newsletters, and other messaging
- » Use the case studies and resources provided in the Road Map to encourage others to take action
- » Strive for policy, system, or environmental (PSE) changes to elevate cognitive health and Alzheimer's as priority public health issues
- » Maintain your relationships — stay in touch with those you have engaged with and provide regular updates
- » Keep track of positive changes so you can tell your community's story
- » Ensure sustainability through securing funds from the organizational budget or other sources

>> SIX STEPS TO PLANNING YOUR PUBLIC HEALTH RESPONSE TO DEMENTIA, INCLUDING ALZHEIMER'S

Make an impact in addressing Alzheimer's and all dementia using the *Road Map for Indian Country* with six steps to guide your planning. The Know.Plan.Go.™ Mobilization Model³ (see Figure 2 on page 4) captures these steps in a quick-reference format so you can turn strategy into action that reaches a broad audience.

Step 1: Prioritize potential actions within your area of focus (Know)

Use the HBI *Road Map for Indian Country* as a tool to guide decisions about where to prioritize your efforts to promote cognitive health, expand early detection and diagnosis, improve safety and quality of care for people living with dementia, and attend to caregivers' health and well-being.

The key is to begin, whether you first raise awareness of the HBI *Road Map for Indian Country* with colleagues and leaders, or you create a plan around an easier Road Map action. Initial momentum gives you a base on which to keep building where you have capacity and interest.

Start by reviewing the HBI *Road Map for Indian Country* and its agenda of eight strategies as well as the compelling data presented (find a quick list of all eight strategies on page 3). Educate your staff and other health professionals about dementia. Then, use the Aligning Action Examples (page 6) to identify Road Map strategies that are achievable, that align with existing areas of focus and priorities (Step 2), and fit with available resources and capacity.

Step 2: Integrate and align strategies into your existing plans (Know, Plan)

You do not have to start from scratch. Many Road Map strategies can be integrated into existing plans and initiatives such as community health improvement plans or programs for chronic disease, health promotion, and public safety. Do a scan of current initiatives and strategic plans within your Tribe and by other groups or organizations that you commonly work with. Find places where you can align Road Map strategies with existing initiatives or goals and add the information to your worksheet. See Table 1 for examples (pages 7–11).

Not finding an obvious alignment? Gather a few colleagues for a conversation about using Road Map strategies to create a plan to address all forms of dementia. Together you could conduct a brief environmental scan or needs assessment to uncover priorities or opportunities in your community that relate to cognitive health. Table 2 has potential data sources on pages 15–16.

Step 3: Orchestrate across the I/T/U public health system (Plan)

Whether you serve at a Tribe or an Urban Indian Organization (UIO), your work interfaces with other parts of the health system. It takes us all working together — across community systems — to improve outcomes for all people living with dementia and their caregivers.

Consider how your priority Road Map strategies can be integrated across the entire public health system or community. How might strategies in the Road Map complement the strategic plans and key initiatives that exist? Integration into other areas of health, where appropriate, enables you to leverage resources and build partnerships for sustainable initiatives. Reach out to discuss the possibility of integrating Road Map strategies into those plans or as part of their existing initiatives.

Step 4: Mobilize for action (Know, Go)

Successful public health occurs through collaborative partnerships, planning, and networking to garner support, assistance, best practices, and training. Organize a network of mobilizers, a community coalition, or task force charged with building and taking the action plan to the next level. Consider traditional and nontraditional partners so that engagement is inclusive across all audiences you wish to serve. Suggestions for potential partners are in Engaging Partners and Stakeholders (page 17). Completing a Stakeholder Analysis Matrix worksheet (page 18) may help you prioritize partners to engage now in the planning stage and others to mobilize at a later stage. With these partners, use the Action Planning worksheet (page 14) as a template for determining activities and resources needed to achieve the Road Map action. If you will pursue multiple Road Map strategies, replicate the worksheet template.

As with all plans, identify some measurable goals. Assign accountable people, partners, and measure success. Identify champions to promote the importance and urgency of acting now on the plan.

Step 5: Ask for additional technical support and assistance (Plan, Go)

A plan is only as good as its implementation, and implementation takes forethought, execution, and accountability. Ask for guidance from the Alzheimer’s Association or the Alzheimer’s Disease and Healthy Aging Program at the Centers for Disease Control and Prevention (CDC). They can provide insights into the recommended strategies and suggest other ideas that might work best for your community’s needs. At alz.org/publichealth/IndianCountry and cdc.gov/aging, you can find Road Map resources, emerging implementation practices, and success stories. Additional resources can be found at ncuih.org/wisdomkeeper, iasquared.org/, and nihb.org/brain-health/.

Step 6: Tell the compelling public health story of Alzheimer’s and refer others to the HBI Road Map for Indian Country (Grow)

The goal of the *Road Map for Indian Country* is to enable the public health community and its partners to anticipate and respond to the growing impact of Alzheimer’s and all dementia on every facet of society. Use the compelling data from the Road Map to create your own talking points about why and how you support healthy aging in your work.

As you capture data and anecdotes about your successes, proactively tell the story about how these strategies translate into meaningful outcomes across the lifespan, across other chronic diseases, and support health and safety more broadly. Communicate about your successes to build momentum that can lead to changes to policies, systems, and environments over the long term. Plan forward for sustainability and don’t reinvent the wheel.

>> ALIGNING ACTION EXAMPLES

Incorporating healthy aging practices into your existing wellness, health, or other community programs doesn’t have to be a cumbersome endeavor. Below are examples of how you can do this with varying levels of funding, time, or effort.

Table 1 groups the eight strategies in the Road Map strategies by the type of community-wide approach (see page 7):

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

Table 1 presents the suggested practices in terms of level of potential difficulty or as a “life-course” approach.

Low Difficulty: These are suggested practices that utilize existing staff and resources to gain a better understanding of Alzheimer’s and all dementia and use simple solutions to get information out into the community.

Moderate Difficulty: These are suggested practices to include healthy aging in existing programs that much of Indian Country already has. Blending in cognitive health and dementia may take effort to update an existing workplan or budget.

Greater Difficulty: If you’re ready to invest in healthy aging for your community, these are suggested practices that may take more funding, time, or effort than the previous two levels.

Life Course: Because the continuum of cognitive health and function spans an entire lifetime, suggested practices address risk factors for different generations.

Technical Support and Assistance

To discuss your priorities or request input on your plan, you can contact:

Molly French
Alzheimer’s Association
mfrench@alz.org

Lisa Garbarino
Centers for Disease Control and Prevention
lgt1@cdc.gov

>> TABLE 1: SUGGESTIONS FOR IMPLEMENTING ROAD MAP STRATEGIES BY LEVEL OF DIFFICULTY OR AS A LIFE COURSE APPROACH

Educate and Empower Community Members Strategies		Greater Difficulty		Life Course
Benefit(s) for Each Strategy		Moderate Difficulty	Low Difficulty	
<p>1. Work with community members to understand brain health, early warning signs of dementia, and benefits of early detection for persons living with dementia and their caregivers.</p>				
<p>Helping Tribal members take steps to promote brain health, reduce stigmas and myths about dementia, and seek early diagnosis of dementia requires clear and consistent messages delivered by trusted sources.</p> <p>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.</p>	<ul style="list-style-type: none"> Disseminate health education materials from reliable partner organizations such as NCUHI in various locations throughout the health center and other high traffic areas Reach out to your Title VI team to identify resources available to your community Add resources to your webpage (see list of resources on page 13) 	<ul style="list-style-type: none"> Engage with other Tribes and Native organizations at the local, regional, and national level in educational efforts Provide education on brain health at existing community events such as pow wows and health fairs Utilize media outlets for public service announcements Include information on Alzheimer’s and other forms of dementia at all clinic visits Host talking circles with your community to understand their knowledge of brain health and work together to identify ways to address any knowledge gaps Conduct educational sessions within existing elder groups and cultural groups that may engage with elders (e.g. drum circles, warrior societies, beading or quilting groups) 	<ul style="list-style-type: none"> Integrate brain health education into new or existing curricula; provide in-person or virtual trainings, classes, support groups Create public awareness campaigns on the importance of early detection and ways individuals can reduce their risk of cognitive decline Plan education initiatives — consider training of staff, community health representatives (CHRs), local influential people Train other non-health professionals (educators, childcare educators, business owners, gym or fitness center staff) to recognize the warning signs of dementia and create a referral network 	<ul style="list-style-type: none"> Disseminate health education materials about risk and protective factors of dementia at family planning appointments, during diabetes prevention classes, tobacco cessation events, and traditional practices or ceremonies

Educate and Empower Community Members Strategies			
Benefit(s) for Each Strategy	Low Difficulty	Moderate Difficulty	Greater Difficulty
Life Course			
<p>2. Encourage community members to use effective interventions, best practices, and traditional wellness practices to protect brain health, address cognitive impairment, and support persons living with dementia and their caregivers.</p> <p>Well-designed programs have been shown to benefit persons living 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 living with dementia who live alone.</p> <p>Other support services for older adults could include:</p> <ul style="list-style-type: none"> • 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 • Long-term care for those whose families live far away 	<ul style="list-style-type: none"> • Promote healthy aging during traditional wellness events, calling attention to the benefits to cognition that these activities provide • Provide information on support services in your community (transportation, legal and financial assistance, training for community members working with older adults, peer support groups) • Add resources to your webpage (see list of resources on page 13) • Adapt community events to encourage participation by people living with dementia and their caregivers (such as having a quiet space, adapting event roles so they can readily participate if they choose) 	<ul style="list-style-type: none"> • Provide a space for caregivers to network, provide support to each other and discuss their best practices • Modify existing programs or interventions, such as the Special Diabetes Program for Indians, to include information on healthy aging and Alzheimer's • Identify champions among the community to help spread the message on healthy aging. This can be a Tribal or community leader, a traditional healer, or youth 	<ul style="list-style-type: none"> • Create a healthy aging campaign in your community • Develop an app or other message delivery mechanisms to share tips and ways to live a healthy cognitive life
<ul style="list-style-type: none"> • Educate I/T/U health staff on risk and protective factors and give them the tools they need to inform patients on how their behaviors/lifestyle could impact them later in life 			

Educate and Empower Community Members Strategies			
Benefit(s) for Each Strategy	Low Difficulty	Moderate Difficulty	Greater Difficulty
<p>3. Provide information and tools to help older adults living with dementia and their caregivers anticipate and respond to challenges that typically arise during the course of dementia.</p> <p>The challenges facing people living 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 may have difficulty 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 living with dementia and their caregivers. These can include education on how to use behavioral cues and other strategies to reduce injuries, help manage medication, and keep chronic conditions in check to minimize unnecessary hospitalizations.</p>	<ul style="list-style-type: none"> • Provide resources on the course of dementia and living with the condition, their family members and professional care providers • Provide resources on recognizing the signs of dementia to family members and caregivers (visit Wisdom Keeper for videos, a social media toolkit and more) 	<ul style="list-style-type: none"> • Facilitate support groups for caregivers and family members • Educate caregivers and family members on how to use behavioral cues and other strategies to reduce injuries, help manage medications, and keep chronic conditions in check 	<ul style="list-style-type: none"> • Educate local businesses who interact with elders about the signs of dementia and how to help if needed • Provide one-on-one training for caregivers and family members • Create a toolkit for family members that helps guide them on how to assist with basic self-care and everyday living activities as well as how to help with more complex activities like financial management, personal health, and driving
			<ul style="list-style-type: none"> • Engage with social service programs, elder meals programs, hearing programs, etc. • Engage with tribal housing programs to support home modifications for those in need • Engage with tribal long-term care facilities or elder housing to ensure that they are able to meet the needs of those living with dementia

Educate and Empower Community Members Strategies

Benefit(s) for Each Strategy

Low Difficulty

Moderate Difficulty

Greater Difficulty

Life Course

4. Promote engagement among tribal and community 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.

<p>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 the public and private sectors, will have a strong base to examine potential policies and leverage resources for implementation.</p>	<ul style="list-style-type: none"> • Present information on the state of aging in your community during Tribal council and/or boards of health/directors meetings 	<ul style="list-style-type: none"> • Invite Tribal and community leaders to community awareness events and talking circles 	<ul style="list-style-type: none"> • Host a healthy aging action institute with Tribal/community leaders, staff, community members, and stakeholders • Pass tribal and/or board resolutions to expand for healthy aging • Ensure healthy aging is included in your strategic plan, community health assessment, and community health improvement plan 	<ul style="list-style-type: none"> • Ensure Tribal leaders are aware of the opportunities to embed information and awareness raising across various programs and social services • Facilitate community awareness meetings/talking circles with various entities that offer touch points for subpopulations, such as pregnant women and caregivers
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Collect and Use Data Strategies

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

<p>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.</p>	<ul style="list-style-type: none"> • Contact your Tribal Epidemiology Center to identify available support; data may be available from your state government Indian health or minority health office • Include questions on dementia, cognitive health, and healthy aging into existing intake assessments/surveys • Identify existing data sources at the state or local level (see data sources on page 15) 	<ul style="list-style-type: none"> • Assess elders during annual wellness visits and other medical appointments • Incorporate questions on dementia and caregiving in existing community health assessments or other surveys 	<ul style="list-style-type: none"> • Initiate a survey specifically on dementia and caregiving • Collect data on the risk and protective factors of dementia • Enact data sharing agreements with other healthcare entities • Advocate for the inclusion of AI/AN-specific data in state and national surveillance and monitoring activities 	<ul style="list-style-type: none"> • Ensure data collection efforts can also capture information on younger generations to assess risk and protective factors as a way to inform future public health programming
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Collect and Use Data Strategies			
Benefit(s) for Each Strategy	Low Difficulty	Moderate Difficulty	Greater Difficulty
			Life Course
<p>6. Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to A/ANs with dementia.</p> <p>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 County and can help monitor progress in delivering quality care.</p>	<ul style="list-style-type: none"> Assess the quality of existing data (clinical, community health assessment, etc.) and identify opportunities for improvement Ensure your quality improvement (QI) individual/team is aware of the need to assess quality measures that address cognitive assessments and the delivery of care 	<ul style="list-style-type: none"> Implement quality improvement on cognitive health Incorporate healthy aging measures in quality improvement plans, strategic plans 	<ul style="list-style-type: none"> Begin a healthy aging quality improvement initiative Incorporate dementia assessments in clinical measures, such as the Government Performance and Results Act (GPRA) and in cross-sectoral collaborations (including data sharing agreements)
			<ul style="list-style-type: none"> Adopt quality measures and examine the risk and protective factors in your community

Strengthen the Workforce Strategies				
Benefit(s) for Each Strategy	Low Difficulty	Moderate Difficulty	Greater Difficulty	
			Life Course	
<p>7. Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia.</p> <p>Healthcare and aging professionals in I/T/U services need not only training on cognitive 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 cognitive 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.</p>	<ul style="list-style-type: none"> Disseminate materials and educational information to the workforce Ensure all health and public health staff have access to credible materials for their own education as well as to disseminate to community members 	<ul style="list-style-type: none"> Coordinate healthy aging trainings for all staff Require trainings be taken by all staff Integrate healthy aging and caregiving support into existing health promotion and chronic disease efforts (Special Diabetes Program for Indians, tobacco cessation) 	<ul style="list-style-type: none"> Dedicate staff to become subject matter experts on dementia and caregiving to serve as in-home resources Create fellowship programs for staff to become subject matter experts on dementias and/or their dementia care certification Create a policy that requires at least one staff member be certified in dementia care 	<ul style="list-style-type: none"> Ensure staff understand the life-course approach to dementia and are able to educate their patients

Strengthen the Workforce Strategies			
Benefit(s) for Each Strategy	Low Difficulty	Moderate Difficulty	Greater Difficulty
8. Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.	<p>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 compelling and easy-to-use materials about how to enhance their own health while caring for older adults.</p>	<ul style="list-style-type: none"> • Provide a space for staff to share and learn new ways to support families and caregivers 	<ul style="list-style-type: none"> • Develop and implement a robust case-management/referral follow-up process
	<ul style="list-style-type: none"> • Provide staff with resources on supporting families and caregivers • Disseminate easy-to-use information about enhancing their own health for caregivers 		<ul style="list-style-type: none"> • Ensure staff understand the life-course approach to dementia and are able to educate families and caregivers

>> ASSETS AND RESOURCES

Assets and resources that can be mobilized and utilized to address needs and issues related to Alzheimer’s and other dementias (e.g., support groups, area agencies on aging, volunteer networks, clinical services, hospitals, adult day care services, home care services, or community resources) are available.

- [The Healthy Brain Initiative Road Map for Indian Country](#)
- Alzheimer’s Association 24/7 helpline: 800.272.3900
- [Alzheimer’s Association](#) (alz.org)
- [Wisdom Keeper from the National Council of Urban Indian Health](#)
- [International Association for Indigenous Aging](#)
- [CDC Alzheimer’s Disease and Healthy Aging Program](#)
- [Brain Health Resources from the National Indian Health Board](#)
- [National Indian Health Board’s Public Health in Indian Country Capacity Scan](#) for local training data
- [Tribal Epidemiology Centers](#)
- Network analyses or surveys of local Alzheimer’s Association chapters and partners
- [The Indian Health Service](#)

>> ACTION PLANNING WORKSHEET

Once you have identified and prioritized your Road Map strategies, use this worksheet to determine what activities and resources will be needed to achieve the action. Create one worksheet for each Road Map action.

Activities to accomplish this action	By when?	Staff to work on this activity	Partners and Stakeholders (coalitions, organizations, govt. agencies, healthcare systems)	Funding Sources Available	Potential Barriers	Measure of Success/ Outcomes

>> TABLE 2: POTENTIAL DATA SOURCES

The following references can be used to gather citations, data points, and information to support pursuing specific Road Map strategies.

Category and Description	Examples and Links
<p>PREVALENCE AND DISPARITIES Number of persons and percentage of population with Alzheimer’s and other dementias or subjective cognitive decline by key demographic indicators (as available) such as: age, gender, race, ethnicity, marital status, sexual orientation, income, educational attainment, home ownership, employment status, disability status, veteran status</p>	<p>Behavioral Risk Factor Surveillance System (BRFSS)</p> <ul style="list-style-type: none"> • CDC infographics for AI/AN adults regarding subjective cognitive decline and caregiving • Background information on BRFSS Cognitive Decline and Caregiving Modules • CDC Healthy Aging Data Portal <p>Other</p> <ul style="list-style-type: none"> • Tribal Epidemiology Centers • State Alzheimer’s disease registry data or data portals (e.g., Georgia Department of Public Health Alzheimer’s Disease and Related Dementia State Registry) • Alzheimer’s Association Alzheimer’s Disease Facts and Figures
<p>MORTALITY Number of deaths due to Alzheimer’s and other dementias, by key demographic indicators (as available)</p>	<ul style="list-style-type: none"> • Tribal enrollment and death certificate data • Tribal Epidemiology Centers • State registries or data portals, such as death certificate records • CDC WONDER • Alzheimer’s Association Alzheimer’s Disease Facts and Figures
<p>CAREGIVING</p> <ul style="list-style-type: none"> • Number of family and other unpaid caregivers • Hours of care provided • Economic value of unpaid care • Impact of caregiving on caregivers • Unmet needs, such as for information, psychosocial support, or respite 	<p>Behavioral Risk Factor Surveillance System (BRFSS)</p> <ul style="list-style-type: none"> • CDC infographics for AI/AN adults regarding subjective cognitive decline and caregiving • Background information on BRFSS Cognitive Decline and Caregiving Modules • CDC Healthy Aging Data Portal <p>Other</p> <ul style="list-style-type: none"> • Tribal Epidemiology Centers • Service needs from state or regional information, referral/ assistance networks, such as 211 call systems, or Aging and Disability Resource Centers (ADRCs)** • National Information and Referral Support Center has background information • Alzheimer’s Association chapters may have local data about requests for assistance or care consultations • Alzheimer’s Association Alzheimer’s Disease Facts and Figures • Qualitative data from focus groups or stakeholder input sessions (example from South Dakota)

Category and Description	Examples and Links
<p>MODIFIABLE RISK FACTORS</p> <ul style="list-style-type: none"> • Number of persons and percentage of population who smoke, have diabetes, are obese, have hypertension, are physically inactive, or eat an unhealthy diet • Health status of caregivers 	<ul style="list-style-type: none"> • Tribal/Community Health Assessments • Tribal Epidemiology Centers • CDC Healthy Aging Data Portal BRFSS data on subjective cognitive decline and caregiving for AI/AN communities • Caregiver surveys • CDC's PLACES project provides county-, place-, census-tract-, and Zip Code Tabulation Area-level estimates for chronic disease risk factors, health outcomes, and clinical preventive service use • CDC and National Association of Chronic Disease Directors Coronary Heart Disease, Myocardial Infarction and Stroke data brief
<p>COSTS</p> <ul style="list-style-type: none"> • Use and costs of healthcare, long-term care, and hospice care for people with Alzheimer's and other dementias • Use and costs of community services, such as transportation, meal delivery, home healthcare, or case management • Financial impact of Alzheimer's and other dementias on families, including annual costs and effect on family income 	<ul style="list-style-type: none"> • Indian Health Service • Tribal Epidemiology Centers • Alzheimer's Association Alzheimer's Disease Facts and Figures • State Emergency Department Databases (SEDD) • Hospital, vital records, home and community-based services, nursing home, health plans, all-payers claims databases, and similar Medicare and Medicaid data* • Silver Alert data • Community service providers • Information and referral/assistance network records

*The BRFSS Cognitive Decline module measures the prevalence of “subjective cognitive decline” (SCD) — a non-medical term that identifies the percentage of individuals who self-report they are having increasing memory problems. A growing number of studies have shown that SCD is associated with an increased risk of future dementia; these data indicate potential future problem and burden of dementia.

**Access to such data varies and may not be universally available due to inconsistencies in data collection and management. Consider consulting the state aging department to learn more about state/regional data sets.

>> ENGAGING PARTNERS AND STAKEHOLDERS

Who do you need to engage for support in implementing your selected Road Map strategies? Partners would be organizations or persons who would likely be involved or provide other support, such as funding, a venue, radio show, or supplies. Stakeholders would be organizations, groups of people, or influential persons who may be affected by Alzheimer's and dementia, but may not be directly involved. Examples of stakeholders might be families caring for older relatives and businesses.

Government

- Tribal leadership
- Governor/mayors/county supervisors
- State or local public health officer
- Chronic disease director
- State epidemiology/surveillance branch
- Division of aging services (state and county level)
- State and local policymakers, legislators, state/regional planning commissions
- Public safety (police, fire, transportation)

Healthcare

- Indian Health Service
- Area Indian Health Boards
- Tribal Epidemiology Centers
- Substance use and misuse programs
- Diabetes prevention programs
- Wellness centers
- National Native health and public health organizations (NCUIH, NIHB, IA²)
- State hospital association
- State provider associations (primary care, specialty care, pharmacy)
- Rural and urban health associations, clinics or health systems
- Federally Qualified Health Centers (FQHCs)
- Physician practices (primary care, family practice, geriatrics, internal medicine, neurology)
- Other healthcare service providers (EMS, physical therapy, home health, hospice, pharmacy, community health workers)

Aging Service Providers and Organizations

- Elder programs
- State and local chapters of the Alzheimer's Association
- Area Agency on Aging (AAA) and Aging and Disability Resource Centers (ADRC)
- Nursing home and assisted living communities at local level as well as state associations
- AARP chapters
- Local foundations and non-profits serving seniors and caregivers
- Senior centers

Other Entities

- Tribal colleges
- Tribal enterprises (e.g., casinos)
- State public health association
- Healthy living coalitions/livable communities
- American Heart Association and American Diabetes Association
- Area Health Education Centers (AHEC)
- Schools of public health/Public health institutes
- Large employers (help in reaching caregiver population)
- Academic institutions
- Geriatric Workforce Enhancement Programs (GWEP)
- YMCA or community wellness center
- Religious organizations/faith community
- State or local dementia-friendly coalitions
- Organizations serving populations at higher risk for dementia (Hispanic, African American)

>> STAKEHOLDER ANALYSIS MATRIX

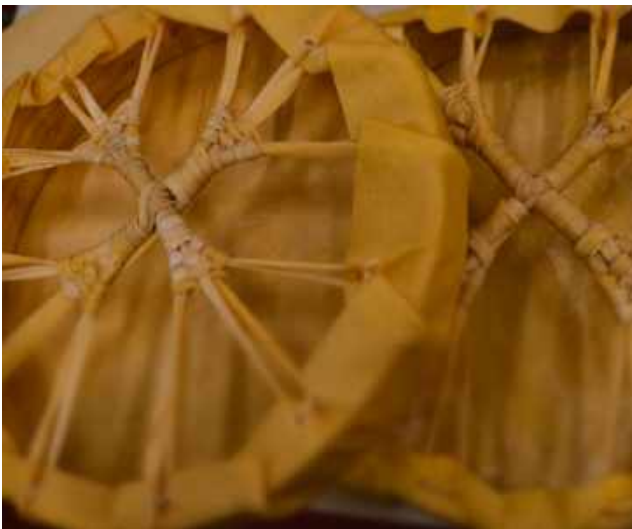
Use this template to identify stakeholders for activities related to Road Map strategies, including their level of influence, which issues are important to them, and how they will be engaged.

Stakeholder Name and Affiliation	Contact Person <i>Email, Phone</i>	Impact How much does the activity impact them? <i>(Low, Medium, High)</i>	Influence How much influence do they have over the activity? <i>(Low, Medium, High)</i>	What is important to them?	How could they contribute to the activity?	How could they hinder the activity?	Strategy for engaging the stakeholder

Stakeholder Name and Affiliation	Contact Person <i>Email, Phone</i>	<i>Impact</i> How much does the activity impact them? <i>(Low, Medium, High)</i>	<i>Influence</i> How much influence do they have over the activity? <i>(Low, Medium, High)</i>	What is important to them?	How could they contribute to the activity?	How could they hinder the activity?	Strategy for engaging the stakeholder

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>> ENDNOTES

1. Learn more at: <https://www.alz.org/media/Documents/10-warning-signs-road-map-for-indian-country.pdf>
2. Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, *Road Map for Indian Country*. Chicago, IL: Alzheimer's Association; 2019
3. Blais LM, Beatty C, Solomon M. (2015). *Know. Plan. Go.™ Strategic Planning*. [Process]. Atlanta, GA: Emory Centers for Training and Technical Assistance, Emory University.

Indian Country Public Health Programs



**HEALTHYBRAIN
INITIATIVE**

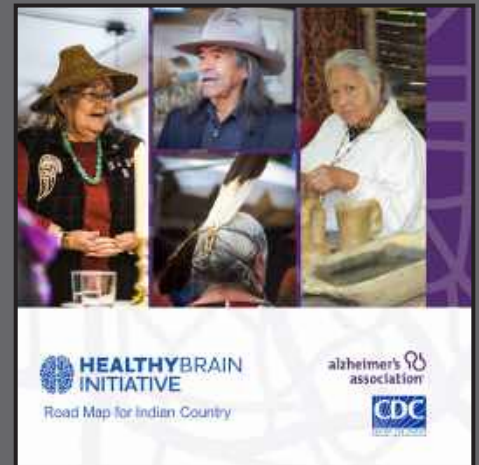
Road Map for Indian Country

Several public health efforts are aimed at improving the health and well-being of American Indian/Alaska Native (AI/AN) communities. These programs and resources help address chronic conditions and improve the public health response throughout Indian Country. AI/AN leaders can use these efforts to 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.
- >> 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. 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 regions.
- >> **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.
- >> 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 communitywide distribution as well as videos that can be shown in clinic settings, and a guide for healthcare providers with culturally-appropriate messaging.

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.



alzheimer's
association



cdc.gov/aging

alz.org/publichealth/indiancountry



**SUPPORTING
AMERICAN INDIANS
AND ALASKA NATIVES
WHO LIVE WITH
DEMENTIA**

**POLICY TIPS AND RESOURCES
FOR YOUR TRIBAL EMERGENCY
AND DISASTER RESPONSE**

SEPTEMBER 2021

National Indian
Health Board



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NIHB would like to thank the following individuals for their expertise in reviewing versions of this document:

Blythe S. Winchester, MD, MPH, CMD, AGSF

(Eastern Band of Cherokee Indians)

Director of Geriatrics Services, Cherokee
Indian Hospital

Chief Clinical Consultant, Geriatrics and Palliative
Care, Indian Health Service

Aneva Turtle Hagberg, BS

(Eastern Band of Cherokee Indians)

Health Operations Director, Public Health and Human Services
Eastern Band of Cherokee Indians

Chelsea C. White IV, MD, NRP, FAEMS, FACEP

Director, UNM Center for Rural and Tribal EMS
University of New Mexico Department of
Emergency Medicine

Tribal emergency management reviewer

(Anonymous)

INTRODUCTION

Emergency situations take many different forms, from natural disasters and extreme weather events, such as fires and floods, to terrorist events, epidemics and global pandemics. Each emergency poses unique challenges and necessitates unique responses. As sovereign entities, Tribal Nations are poised to direct emergency responses that best serve their citizens.

In general, populations with physical, cognitive and even economic limitations may be especially vulnerable during both acute and prolonged emergencies and may be at higher health and safety risks. People who live with dementia, Alzheimer's disease or other brain health challenges may have difficulty understanding and following directions during emergency situations, where communications are critical. They may also get overwhelmed and experience stress which can contribute to health and safety risks for themselves and responders. This resource serves as a quick reference for Tribal leaders and planners to consider how they can best support or accommodate people living with Alzheimer's Disease or another dementia during an emergency. The aim is to raise awareness of how American Indian and Alaska Native (AI/AN) people who live with dementia experience the world and offer possible strategies for policies to accommodate their needs.

The following definitions help explain brain health and Western medical terms for cognitive (thinking and reasoning) changes that AI/ANs may experience (**FIGURE 1**):

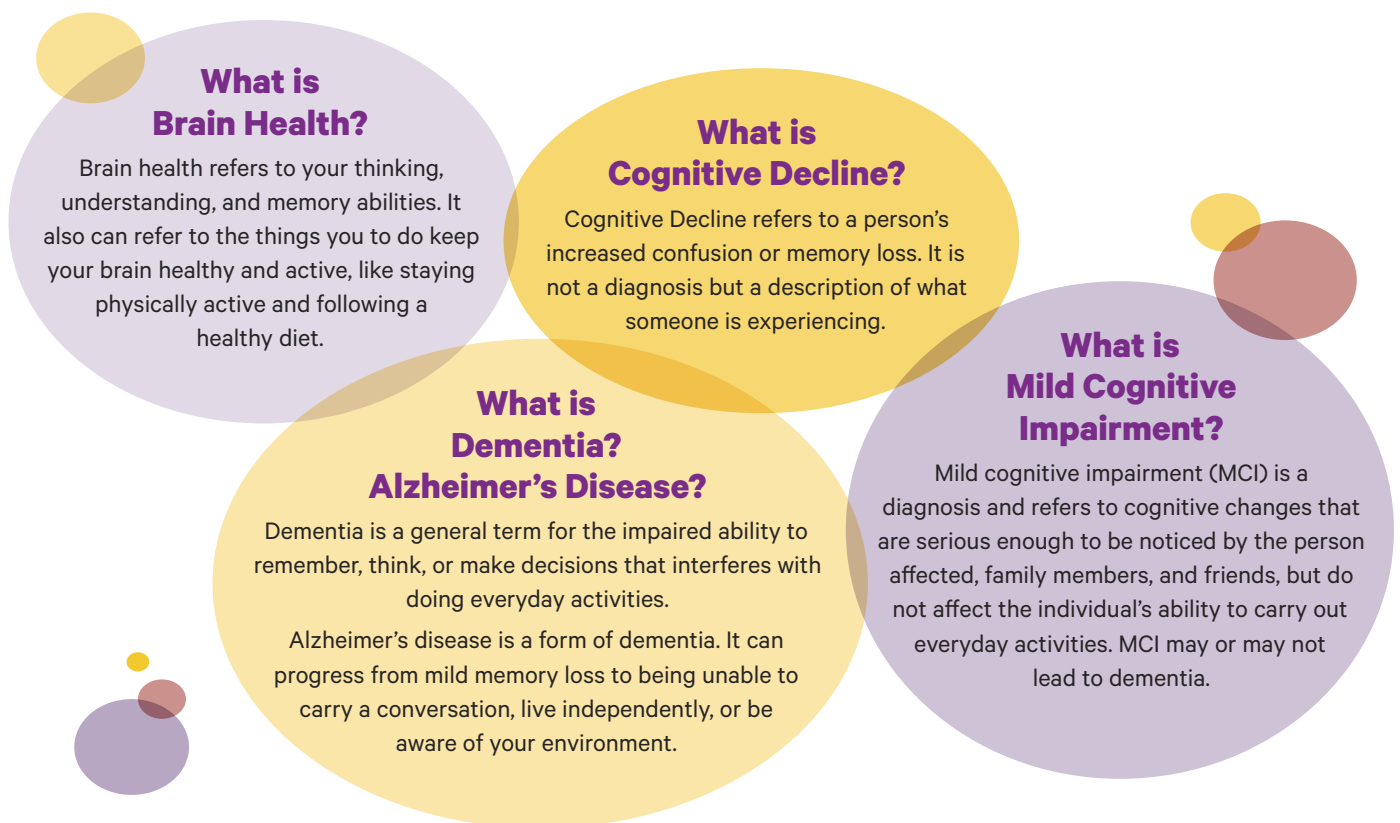


FIGURE 1 DEFINITIONS

Many individuals living with dementia reside in community settings, such as in their own homes or in homes with family members. This is especially true in Tribal communities where multi-generational households are common. In the case of progressive dementias, such as Alzheimer's disease, a person may need ongoing support to help them with daily living, navigating the health system and for safety and protection (FIGURE 2). As cognition changes, reliance upon family caregivers increases and caregivers become essential for all aspects of health and safety. This is particularly relevant in emergency situations where risks are higher.

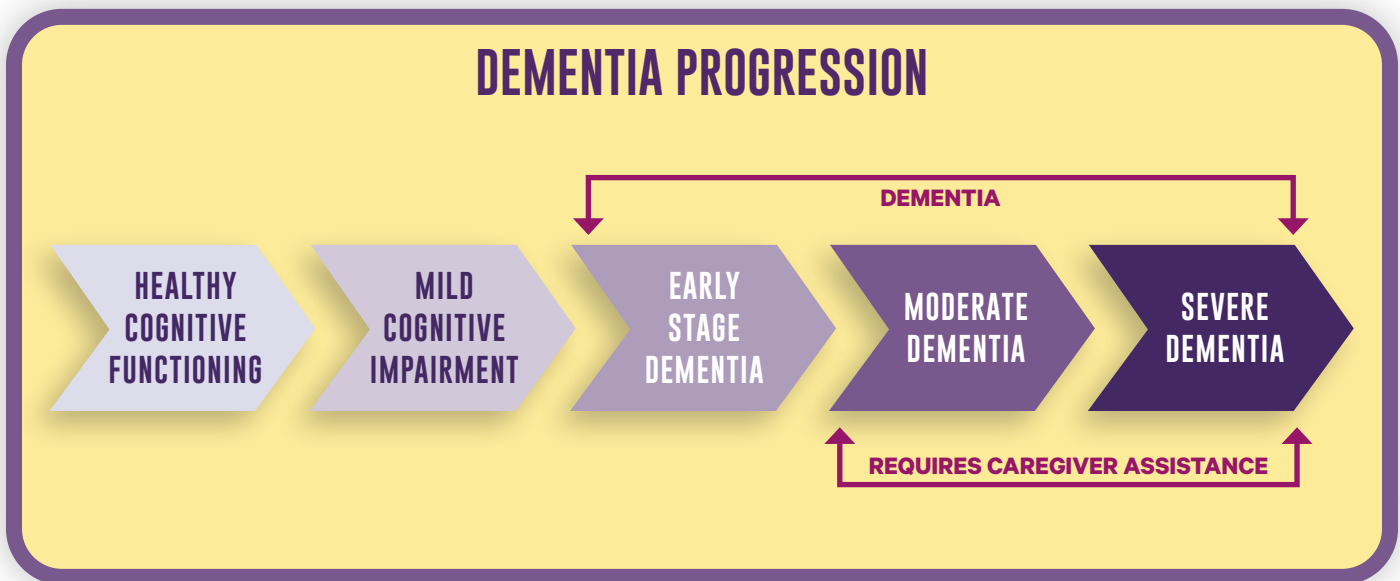


FIGURE 2 DEMENTIA PROGRESSION

Providing care for a loved one can be demanding. The health, mental, social and economic effects on family caregivers are often so significant that caregiving is considered a public health priority as well. Policies supporting Native people living with dementia must incorporate their caregivers too for the best outcomes.





Why Policy?

Emergencies and disasters may pose serious risks to the safety and well-being of AI/ANs living with dementia, particularly in rural Tribal communities where it may be more difficult to reach those at risk. Clear and concise policies and procedures can mitigate the risks for people with dementia and their caregivers.

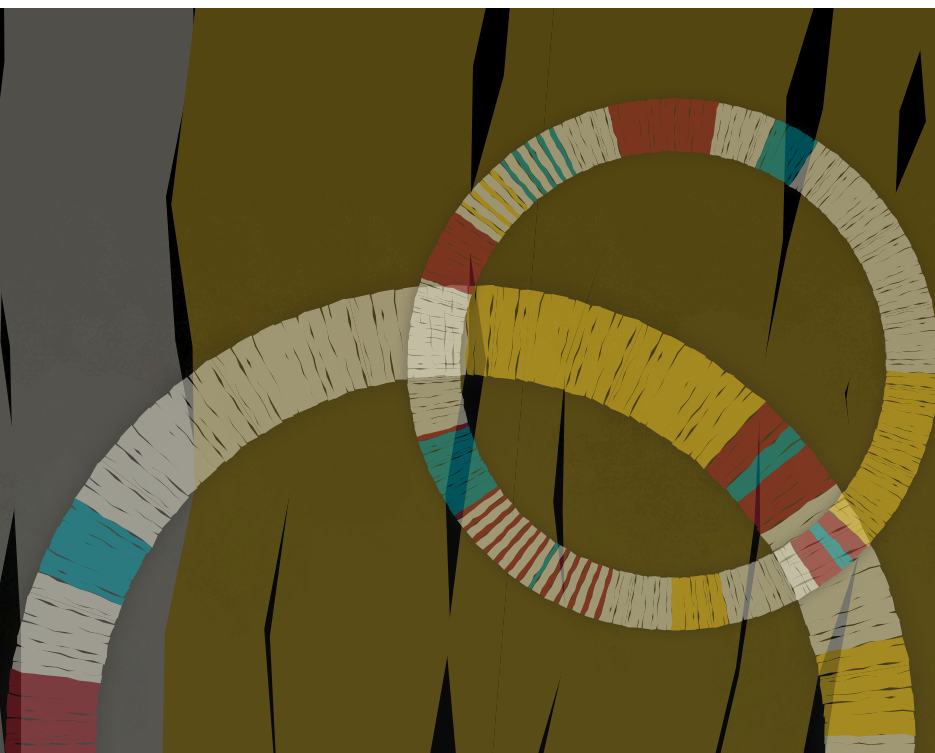
Much of the emergency preparedness resources available are focused on advice and guidance for *individuals* to be prepared. While essential, reliance upon individual preparedness alone is not a sufficient strategy for an emergency response. At some point, interaction with responders is inevitable, even if it is physically distant as with mass communications or as involved as individual transport and sheltering. Systems and policies become especially important at those points of interaction.

“Policy” is a broad term and can be understood as a law, regulation, procedure, administrative action, incentive, or voluntary practice of governments and other institutions.¹ Policies can be thought of as “hard-wiring” approaches and strategies into the practices of an organization. As such, the hard-wiring removes the uncertainty of solely relying on individual knowledge or a well-intentioned leader.²

This resource specifically focuses on how operational policies in times of emergencies or disasters can be leveraged to be inclusive and equitable for people who live with dementia and reside in Tribal community settings.

1 <https://www.cdc.gov/policy/analysis/process/definition.html>

2 Substance Abuse and Mental Health Services Administration. SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. HHS Publication No. (SMA) 14-4884. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.



HOW NATIVE PEOPLE LIVING WITH DEMENTIA MIGHT EXPERIENCE EMERGENCIES

Understanding the mental, physical, social and emotional experiences of people living with dementia during emergency situations can help Tribal planners and policy makers ensure their services are inclusive, equitable and have the best outcomes.

MAY HAVE DIFFICULTY COMMUNICATING SYMPTOMS

May not recognize or be able to communicate that they have been injured or are unwell.

MAY BE UNABLE TO PROCESS INFORMATION

May have limited ability to understand directions and may forget them.

HAVE MEMORY DIFFICULTIES

People may forget recently learned information. They often need clues about daily activities, even hydration.

MAY BECOME UPSET OR AGITATED

Heightened emotions or confusion due to unfamiliar settings can lead to agitation.


IN EMERGENCY SITUATIONS PEOPLE WHO LIVE WITH DEMENTIA:

MAY EXPERIENCE PAIN DIFFERENTLY

May have a hypersensitive pain response that they are not able to communicate.

ARE LIKELY TO HAVE ADDITIONAL HEALTH ISSUES

Chronic conditions, such as diabetes or heart disease, are common among people with dementia. Many people with dementia, and those who care for them, may be managing multiple health issues that must be considered.



**MAY HAVE DIFFICULTY
INTERPRETING WHAT THEY
HEAR OR WITH VISION**

Loud, noisy rooms or situations may be disorienting. They may have a smaller field of vision.

**MAY HAVE
DIFFICULTY WITH
MULTIPLE TASKS**

This can pose difficulty in following a plan.

 **MENTAL**

 **PHYSICAL**

 **SOCIAL**

 **EMOTIONAL**

CAN BE STRESSED, FRUSTRATED, AND OVERWHELMED

This can be due to a reduced individuals' ability to recognize their environment and understand the context of the situation.

**MAY BE MORE LIKELY
TO BECOME DEPRESSED**

Due to changed abilities, autonomy and isolation, some people living with dementia may become depressed.

**MAY WANDER OR BE
PRONE TO GETTING LOST**

Memory difficulty and likelihood of becoming confused puts people at risk. The stress of emergency situations increases a person's potential to wander or hide.

**CAN DEVELOP
DELERIUM EASILY OR
HAVE HALLUCINATIONS**

Reorienting someone may be less effective than working with them in their reality.

MAY RELY HEAVILY ON FAMILY MEMBERS OR CAREGIVERS

Without their caregivers, people with dementia are at higher risk for poor health, injury, abuse and isolation. Complicating matters, they may not be able to remember their caregiver's name or how to reach them.

TRIBAL POLICY TIPS FOR EMERGENCY MANAGEMENT

SUMMARY OF TRIBAL POLICY TIPS

1

POLICY TIP #1:

When requesting an emergency declaration and assessing the type of federal assistance that may be needed, consider the amount and type of assistance that will be required to support those in your Tribal community who live with dementia, ranging from communications, shelter and evacuation assistance to continuity of medical services. *[page 8]*

2

POLICY TIP #2:

When identifying populations that may need specific services in disaster or emergency situations in planning documents, avoid terms such as “disabled” that may contribute to stigma. Seek out words or phrases in the Native language that may best fit the policy need. *[page 9]*

3

POLICY TIP #3:

Adopt a function-based approach, or one that is based on individuals’ capabilities rather than labels when defining special populations in Tribal emergency operations plans and policies. *[page 9]*

4

POLICY TIP #4:

Consider **CONNECTION** (to people, culture and nature) as a functional need during emergencies or disasters to preserve the protective effects of culture and belonging. *[page 11]*

5

POLICY TIP #5:

Review and update Tribal emergency plans and procedures to include and accommodate American Indian and Alaska Native people who may have functional needs during an emergency. *[page 12]*

6

POLICY TIP #6:

Considerations for the development and use of identification systems should include clear stipulations for:

- With whom the information will be shared.
- How information will be used.
- Security measures in place for protecting information.
- The type of help that might be available.
- Limitations on help (i.e., [if] help is not guaranteed). *[page 15]*

TRIBAL POLICY TIPS FOR ACKNOWLEDGING PEOPLE'S UNIQUE VULNERABILITIES

7

POLICY TIP #7

Incorporate culturally relevant dementia education and trauma-informed skill building in trainings for emergency responders. *[page 18]*

8

POLICY TIP #8

Create Tribal emergency communication policies to direct the use of a variety of communication methods and strategies to be inclusive of American Indians and Alaska Natives who live with dementia. *[page 17]*

9

POLICY TIP #9:

With the input of Tribal members living with dementia and their caregivers, examine and evaluate the design of facilities to increase access, simplify processes, connect to culture and reduce environmental stressors. *[page 19]*

10

POLICY TIP #10:

Enable Tribal emergency policies that maintain a sense of familiarity, routine and security for those who live with dementia. *[page 20]*

TRIBAL POLICY TIPS FOR ACKNOWLEDGING THE ROLE OF CAREGIVERS

11

POLICY TIP #11:

Recognize and treat caregivers as partners by Tribal health, social service, public safety and emergency personnel. *[page 22]*

12

POLICY TIP #12:

Create or extend Tribal policies to provide physical, emotional and financial relief for caregivers during emergencies. *[page 23]*

13

POLICY TIP #13:

Create or amend health facility policies to provide the best possible scenarios to maintain the physical, social and emotional connection between the patient and caregiver. *[page 23]*



EMERGENCY MANAGEMENT

Emergency Declarations

Emergency declarations are the most pivotal policy moment for Tribes to activate their response to public health emergencies. As sovereign nations, Tribes may declare emergencies through multiple mechanisms (see Resources below). Once an emergency response is approved, a cascade of policies and procedures across the Tribe may be activated, such as through emergency operations plans and incident command systems. The incident command system allows responders from different agencies/entities to coordinate a response across Tribal entities and often with entities outside the Tribe. The response can affect practically every aspect of Tribal operations - communications, transportation, health services, social services, education, public works, etc. Including the needs of those who live with dementia is a crucial aspect of building equity in an emergency response.

When seeking federal emergency assistance, such as through the Stafford Disaster Relief and Emergency Assistance Act, a Tribe will work with the Federal Emergency Management Agency (FEMA). FEMA has assigned regional Tribal liaisons that are available for support and technical assistance. FEMA also offers technical “assistance from Regional Disability Integration Specialists or other Disability Integration Advisors to help Tribal representatives identify and meet the accessibility needs of all people with disabilities and those with accessibility and functional needs, to afford participation in Stafford Act assistance.”³



POLICY TIP #1:

When requesting an emergency declaration and assessing the type of federal assistance that may be needed, consider the amount and type of assistance that will be required to support those who live with dementia, ranging from communications, shelter and evacuation assistance to continuity of medical services.

RESOURCES

- [Emergency Declarations and Tribes: Mechanisms Under Tribal and Federal Law](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4703113/)
- [Tribal Affairs | FEMA.gov](https://www.fema.gov/about/organization/tribes)

³ FEMA (2017). Tribal Declarations Pilot Guidance. p.6

Identifying Vulnerable Populations

One important policy strategy to ensure everyone is provided aid, services and communications equitably during an emergency or disaster is to ensure that vulnerable Tribal populations are identified in emergency policies and procedures.

Emergency operations plans may direct healthcare services or programs to adjust services for specific segments of the population. For example, terms that have been used include people with “special needs” “special populations” “disabled” “handicapped” “vulnerable” or “at risk individuals”. “Children” and “elders” have also been used as broad categories.

As emergency policies may span across several Tribal divisions, programs and services, they may include communications, transportation, healthcare, social services, and public safety, among others.

While there is no single definition of how specific populations should be defined by the community, consider using less stigmatizing terms such as “people living with disabilities” or “people/populations experiencing risks” rather than language that defines people by their conditions. For Alzheimer’s disease and other dementias, expressing these needs as “unique vulnerabilities related to dementia” adds specificity and clarity, whereas a broad “special needs” category may not work because it cannot be operationalized.⁴ There may be a word or phrase in the Native language that best describes people with unique vulnerabilities which could be used.

2

POLICY TIP #2:

When identifying populations that may need specific services in disaster or emergency situations, avoid terms such as “disabled” that may contribute to stigma. Seek out words or phrases in the Native language that may best fit the policy need.

A Functional-Needs Approach

A function-based approach reflects providing services based on the capabilities of an individual, not a person’s condition or demographic label (children, the elderly, homeless, diabetic, etc.). For example, people who use assistive devices such as wheelchairs may include people of all ages and health status. This need is a factor in providing services such as transportation during an emergency, regardless of age or health status.

3

POLICY TIP #3:

Adopt a function-based approach, or one that is based on individuals’ capabilities rather than labels when defining special populations in Tribal emergency operations plans and policies.

The National Response Framework (NRF), the federal guide to emergency planning, used by many Tribes, describes a whole community approach that includes serving, among others,

⁴ Kailes, June Isaacson, Enders, Alexandra. 2007. Moving Beyond “Special Needs”: A Function-Based Framework for Emergency Management and Planning *Journal of Disability Policy Studies* Vol. 17/No. 4/ Pp. 230–237

individuals with access and functional needs. Access and functional needs refer to persons who may have additional needs before, during, and after an incident in functional areas, including but not limited to:

- Communication
- Maintaining health
- Maintaining independence and self-determination⁵
- Support
- Transportation

Functional Needs



COMMUNICATION

Tribal members who have limitations that interfere with the receipt of and response to information will need that information provided in methods they can understand and use. They may not be able to hear verbal announcements, see directional signs, or understand how to get assistance because of hearing, vision, speech, cognitive, intellectual limitations, and/or limited English proficiency. Their own ability to communicate may be limited as well.



MAINTAINING HEALTH AND MEDICAL CARE

Tribal members who are not self-sufficient or who do not have adequate support from caregivers, family, or friends may need assistance from trained medical professionals with managing health conditions. *Note that people who rely upon electricity to power their medical devices may need additional considerations such as access to portable generators.*



MAINTAINING INDEPENDENCE AND SELF-DETERMINATION

Tribal members requiring support to be independent in daily activities may lose this support during the course of an emergency or a disaster. This support may include supplies, medical equipment, and/or attendants or caregivers. Supplying needed support to these individuals will enable them to maintain their pre-disaster level of independence. *Note that maintaining independence, such as living in their home may be possible only through the direct assistance of a caregiver.* Self-determination reflects a core value that aims to promote an individual's capacity for control over their own lives. People who live with dementia may need supervision.



SUPPORT

Before, during, and after an emergency, Tribal members may lose the support of caregivers, family, or friends or may be unable to cope in a new environment (particularly if they have dementia or psychiatric conditions such as schizophrenia or intense anxiety). If separated from their caregivers, people living with dementia may be unable to identify themselves and, when in danger, may lack the cognitive ability to assess the situation and react appropriately.

⁵ Dept. of Homeland Security. 2019. National Response Framework, 4th Ed., p.5



TRANSPORTATION

Tribal members who cannot drive or who do not have a vehicle may require transportation support for successful evacuation. This support may include **accessible** vehicles (e.g., lift equipped or vehicles suitable for transporting individuals who use oxygen) or information about how and where to access mass transportation during an evacuation.⁶

Tribal nations may wish to identify additional functional needs specific to their populations such as:



CONNECTION

Closures, physical distancing and stay at home orders, and loss of life have isolated people from connections to their families, their peers, and their Native language speakers, cultural leaders, and even nature. Additionally, people may be disconnected from regular activities they depend upon for social, emotional, spiritual and cultural connection such as elder lunch programs, ceremonies, social gatherings and subsistence activities. Losing connection to community, activities and nature can have effects on mental and physical health. Stress and social isolation can also negatively impact health and immune function.⁷ In Tribal cultures where interconnectedness is deeply understood and highly valued, losing connection affects the entire community.

“CONNECTION”
AS A
FUNCTIONAL
NEED

4

POLICY TIP #4:

Consider **CONNECTION** (to people, culture and nature) as a functional need during emergencies or disasters to preserve the protective effects of culture and belonging.

EXAMPLE

People may find connection in people, language, and meaningful objects. An example of the consideration of connection would be a transportation policy that allows people to carry medicine bags with them during transport.

RESOURCES

- [The National Response Framework](https://www.fema.gov/emergency-managers/national-preparedness/frameworks/response)
<https://www.fema.gov/emergency-managers/national-preparedness/frameworks/response>
- [The Partnership for Inclusive Disaster Strategies](https://disasterstrategies.org/)
<https://disasterstrategies.org/>

6 Federal Highway Administration. U.S. Department of Transportation. “Evacuating Populations with Special Needs, Routes to Effective Evacuation Planning Primer Series.” April 2009.
https://ops.fhwa.dot.gov/publications/fhwahop09022/sn1_overview.htm

7 Holt-Lunstad et al. (2010) concluded that the influence of social relationships on the risk for death is comparable to the risk caused by other factors like smoking and alcohol use, and greater than the risk associated with obesity and lack of exercise. Likewise, other researchers have highlighted the detrimental impact of social isolation and loneliness on various illnesses, including cardiovascular, inflammatory, neuroendocrine, and cognitive disorders (Bhatti and Haq, 2017; Xia and Li, 2018).

Emergency Management Plans

Emergency preparedness and response refers to the steps taken, before, during and after natural and human-made disasters or emergencies to ensure public safety. There are four phases of emergency management that complete the life cycle of a disaster/emergency. These four phases are mitigation, preparedness, response, and recovery. (Figure 3). A Tribe may have a separate plan for each phase or a combined plan which includes all phases. Building policy components throughout each phase to meet the needs of all populations allows for a more equitable response and better outcomes for all who may be affected.



FIGURE 3 EMERGENCY MANAGEMENT CYCLE

1) **Mitigation** — preventing or reducing the effects of future disasters/emergencies

2) **Preparedness** — preparing equipment and resources for when a disaster or emergency occurs;

3) **Response** — responding to a disaster/emergency and;

4) **Recovery** — recovering from a disaster/emergency.

5

POLICY TIP #5:

Review and update Tribal emergency plans and procedures to include and accommodate American Indian and Alaska Native people who may have functional needs during an emergency.

EXAMPLES

In order to ensure all groups are represented, a Tribe may wish to use an existing committee or establish a new one to advocate for those with functional needs. Sample policy language could read “A committee of representatives from the community and programs who serve people with functional needs will inform the operations command. The committee will consist of a representative from the community, the Aging Program, Social Services, Health Services, Disability Services, Mental Health Services, Foster Care and Education.” Or, as related to communications, sample language could include: “The Tribal Public Information Officer will consult with subject matter experts on communications messages and channels for reaching people with functional needs, such as needs related to communication, maintaining health, maintaining independence, self-determination and security, transportation and maintaining connection to culture.”

PREPAREDNESS RESOURCES

- Tribal Community Emergency Preparedness Toolbox (The American Indian Health Commission, Washington State) <https://aihc-wa.com/aihc-emergency-preparedness/>
- Administration for Community Living General Emergency Preparedness Resources <https://acl.gov/emergencypreparedness>

Response Resources

- PUBLIC HEALTH WORKBOOK: To Define, Locate, and Reach Special, Vulnerable, and At-risk Populations in an Emergency (Centers for Disease Control and Prevention) (CDC) https://emergency.cdc.gov/workbook/pdf/ph_workbookfinal.pdf
- Bureau of Indian Affairs Emergency Management <https://www.bia.gov/bia/ojs/emd>

Recovery Resources

- Pre-Disaster Recovery Planning Guide for Tribal Governments, Federal Emergency Management Agency (FEMA) <https://www.fema.gov/sites/default/files/2020-07/pre-disaster-recovery-planning-guide-for-tribal-government.pdf>

Mitigation Resources

- TRIBAL MITIGATION Planning Handbook https://www.fema.gov/sites/default/files/2020-06/fema-tribal-planning-handbook_05-2019.pdf



USE OF IDENTIFICATION SYSTEMS

Many people who live with dementia are at risk of wandering and becoming disoriented in their surroundings, which may become even more of a risk during a crisis. During emergency or disaster situations, they may become separated from their caregivers.



Knowing who and where the Tribal populations with unique vulnerabilities are located, such as those living with dementia, can be crucial to protecting their health and safety and that of those who care for them. Maintaining accurate address and contact lists, or registries, can be challenging from a logistical and civil rights perspective. When health information is involved, the Health Insurance Portability and Accountability Act (HIPPA) will factor in as well. Developing an identification system for emergencies is complicated and it is best to include multiple partners and legal experts, if accessible, for planning. Community Health Representatives and family members are often the most knowledgeable about peoples' functional needs in their communities and should also be included in designing or adopting identification systems.

A registry is a *voluntary* database of individuals who meet the eligibility requirements for receiving additional emergency response services based on specific needs. Registries or lists may already be available through health systems (e.g. diabetes registries), transportation systems or existing emergency management registries. It is likely that multiple layers in the response effort may require access to different types of lists, or registries. For example, those responsible for evacuation will benefit more from location data and those responsible for medication management may benefit more from accurate contact information. The need for data sharing agreements should be considered as well.

Registries and lists have limitations. For example, disease registries that rely upon diagnoses or conditions doesn't necessarily speak to individuals' functional needs during an emergency. Similarly, there may be individuals who are not "registered" anywhere who have significant needs during emergencies. Additionally, a registry is useful if continually updated. As Alzheimer's and dementia is undercounted in Indian Country and services may be underdeveloped, relying solely upon an Alzheimer's registry may not be the most useful in emergency situations in serving this population. Using additional means to identify people with cognitive difficulties who may need functional assistance would be a sensible action.

An identification system needs to identify not only the person but their assistive equipment *and* their supportive people. For example, someone who uses a walker or oxygen tank will require transportation that can accommodate their equipment. Similarly, someone who has difficulty following complex directions or is easily agitated, such as with dementia, may need their family member or caregiver to be present. Just as an emergency response would accommodate someone's walker or use of oxygen, accommodating someone's family member or caregiver may be equally life-sustaining for an individual with brain health challenges.

The nature of the emergency will also factor in who needs to be identified and how they will be identified. COVID-19 contact tracing has concentrated new attention and technologies to quickly locate and communicate with at-risk individuals. These procedures and case management technologies may be an excellent source for adapting to other emergency situations.

Other identification strategies include medical jewelry and wallet cards to assist emergency personnel in quickly identifying medical needs. They often include diagnoses, transplants, implants, medications, and importantly, emergency contact information. They may simply be engraved with information or more high tech with a scannable QR code. For example, the Alzheimer's Association offers a bracelet that includes a 24/7 wandering support system. As medical jewelry is customizable, they can include functional needs, and family or caregiver's information. Temporary bracelets may also be effective in situations where large numbers of people are being moved or served at once.

PRIVACY CONCERNS

Protecting the privacy and rights of Tribal members doesn't diminish during an emergency. Concerns about privacy could be a factor of why someone may or may not volunteer their personal and health information. This could affect the buy-in and uptake of an identification system. Note that identification systems operating outside the authority of the Tribe may have Tribal data sovereignty considerations as well.



POLICY TIP #6:

Considerations for the development and use of identification systems should include clear stipulations for:

- With whom the information will be shared.
- How information will be used.
- Security measures in place for protecting information.
- The type of help that might be available.
- Limitations on help (i.e., [if] help is not guaranteed).⁸

IDENTIFICATION SYSTEMS RESOURCES

- US Department of Health and Human Services (HHS) Health Information Privacy: [Emergency Response | HHS.gov](https://www.hhs.gov/hipaa/for-professionals/special-topics/emergency-preparedness/index.html)
<https://www.hhs.gov/hipaa/for-professionals/special-topics/emergency-preparedness/index.html>
- [Planning for an Emergency: Strategies for Identifying and Engaging At-Risk Groups A guidance document for Emergency Managers \(CDC\)](https://www.cdc.gov/nceh/hsb/disaster/atriskguidance.pdf)
<https://www.cdc.gov/nceh/hsb/disaster/atriskguidance.pdf>
- [Contact Tracing: Using Digital Tools \(CDC\)](https://www.cdc.gov/coronavirus/2019-ncov/downloads/digital-contact-tracing.pdf)
<https://www.cdc.gov/coronavirus/2019-ncov/downloads/digital-contact-tracing.pdf>

⁸ Centers for Disease Control and Prevention (CDC). Planning for an Emergency: Strategies for Identifying and Engaging At-Risk Groups. A guidance document for Emergency Managers: First edition. Atlanta (GA): CDC; 2015. p. 6

EDUCATION AND TRAINING

Education and training is a cornerstone of an effective public health emergency response. People living with dementia may experience memory loss and confusion, and how that is interpreted and responded to respectfully may be unique to the culture and history of the community. Emergency responders, public safety, healthcare and social services staff will benefit from understanding how people with dementia in their community experience and navigate the world.

Training policies may include all Tribal employees, specific divisions, departments or programs or be required in emergency preparedness plans for those involved in response efforts. They may include specific trainings or just require a training on the topic of dementia. While there is an abundance of information and training on Alzheimer's and dementia, incorporating a cultural component may require the addition of building skills to develop cultural insights (see Training Resources).

TRAINING RESOURCES

- For adapting trainings, see [Culture and Caregiving: Adapting the Savvy Program to Native Culture](https://www.nicoa.org/elder-resources/savvy-caregiver/culture-and-caregiving-adapting-the-savvy-program-to-native-culture/) (National Indian Council on Aging).
<https://www.nicoa.org/elder-resources/savvy-caregiver/culture-and-caregiving-adapting-the-savvy-program-to-native-culture/>
- [NIHB Brain Health Action Institute for Tribal Nations Online Module](https://nihb.org/brain-health/online-module/story.html), see, Unit 3, Cultural Considerations for Brain Health in Indian Country
<https://nihb.org/brain-health/online-module/story.html>
- [Approaching Alzheimer's: First Responder Training](https://training.alz.org/products/4021/approaching-alzheimers-first-respondertraining) (Alzheimer's Association)
<https://training.alz.org/products/4021/approaching-alzheimers-first-respondertraining>.
- [The Savvy Caregiver](https://www.nicoa.org/elder-resources/savvy-caregiver/culture-and-caregiving-adapting-the-savvy-program-to-native-culture/), (National Indian Council on Aging)
<https://www.nicoa.org/elder-resources/savvy-caregiver/culture-and-caregiving-adapting-the-savvy-program-to-native-culture/>
- [Dementia Dialogues®](https://sc.edu/study/colleges_schools/public_health/research/research_centers/office_for_the_study_of_aging/projects_programs/dementia_dialogues/index.php) is a 5-module online course for caregivers, medical professionals, emergency responders, family members, service professionals, among others.
https://sc.edu/study/colleges_schools/public_health/research/research_centers/office_for_the_study_of_aging/projects_programs/dementia_dialogues/index.php

Trauma-informed Approaches

Emergencies themselves can be traumatic events, but American Indians and Alaska Natives' individual and collective histories may also be underlying factors affecting how someone might react or behave. For example, if someone 'acts out' or doesn't cooperate, you should consider if past or current trauma may be shaping their response and try to eliminate or minimize potential triggers (i.e. loud noises, chaotic settings, family separation, etc.). Understanding how past and present trauma affects people, and developing trauma-informed skills for staff across the response system can contribute to both better short-term and long-term outcomes.



POLICY TIP #7:

Incorporate culturally relevant dementia education and trauma-informed skill building in trainings for emergency responders.

TRAUMA TRAINING RESOURCES

- Substance Abuse and Mental Health Services Administration's (SAMHSA) Concept of Trauma and Guidance for a Trauma-Informed Approach
https://ncsacw.samhsa.gov/userfiles/files/SAMHSA_Trauma.pdf
- Tips for Disaster Responders: UNDERSTANDING HISTORICAL TRAUMA WHEN RESPONDING TO AN EVENT IN INDIAN COUNTRY (SAMSHA)
<https://store.samhsa.gov/sites/default/files/d7/priv/sma14-4866.pdf>
- 6 Guiding Principles To A Trauma-Informed Approach (CDC, SAMSHA)
https://www.cdc.gov/cpr/infographics/00_docs/TRAINING_EMERGENCY_RESPONDERS_FINAL.pdf

6 GUIDING PRINCIPLES TO A TRAUMA-INFORMED APPROACH



CDC Center for Preparedness and Response.



COMMUNICATION

Communication access addresses the needs of individuals who require assistance, with the receipt of information they can understand and use due to hearing, vision, speech, cognitive, or intellectual disability, and/or with limited English.⁹ Regardless of the emergency, some level of communication will be necessary to convey important information and instructions. The need for community members to adequately receive and understand communications underpins a successful emergency response. A variety of communication methods will likely be needed. The use of translators or the use of the native language may also be necessary, not only for the messaging to be fully understood but also to retain connection to the Tribal culture. Native speakers and language programs may be an excellent source for developing messaging. For those living with dementia, they may have trouble following directions or may forget them. They may respond better to visuals, familiar faces, familiar scenes or objects.

Strategies for Communicating with people living with dementia:

- If instructions are needed to be followed, communications that are simple and one step at a time.
- Use of visuals
- Speaking slowly
- Avoid fear-based communications; use words and phrases to provide reassurance
- Communications that connect to past positive events or familiar people or living things; ones that trigger positive emotions;
- Incorporating traditional stories or lessons in communications
- Use native language and offer translation services when needed
- Recognize that caregivers or family members may be instrumental in interpreting messaging.



POLICY TIP #8:

Create Tribal emergency communication policies to direct the use of a variety of communication methods and strategies to be inclusive of American Indians and Alaska Natives who live with dementia.

COMMUNICATION RESOURCES

- [Effective Communications for People with Disabilities: Before, During, and After Emergencies | NCD.gov](https://www.ncd.gov/publications/2014/05272014)
<https://www.ncd.gov/publications/2014/05272014>
- [Ensuring Language Access And Effective Communication During Response And Recovery: A Checklist For Emergency Responders](https://www.hhs.gov/guidance/document/ensuring-language-access-and-effective-communication-during-response-and-recovery)
<https://www.hhs.gov/guidance/document/ensuring-language-access-and-effective-communication-during-response-and-recovery>

⁹ Kailes, June Isaacson. “Defining Functional Needs – Updating CMIST By June Isaacson Kailes Disability Policy Consultant.” The Partnership for Inclusive Disaster Strategies. July 13, 2020.

MEDICAL FACILITY ACCESS

Emergency or disaster situations may hamper maintaining health in many ways. People may lose access to medications, supplies, mobility devices and family members or caregivers. There may be changes to the way care is accessed or access itself may be limited due to safety protocols.

People who live with dementia may be sensitive to their surroundings. Noisy, confusing, unfamiliar environments may be overwhelming and may cause stress. The set up and flow of a healthcare facility, whether permanent or temporary, can contribute to someone's ability to fully access care. Facility design is also a way to support the safety and security for those who live with dementia, through elements that connect to culture.

Seeking the input of those who live with dementia and their caregivers is a best practice planning strategy that can inform design elements that contribute to a dementia-friendly facility.



POLICY TIP #9:

With the input of Tribal members living with dementia and their caregivers, examine and evaluate the design of facilities to increase access, simplify processes, connect to culture and reduce environmental stressors.

EXAMPLES

- Facility policies that allow patients to remain in a familiar environment such as their vehicle rather than a busy, noisy waiting area.
- Patient flow processes that reduce movement throughout the facility and limit the number of interactions with multiple healthcare staff.
- Policies that recognize the importance of and allow traditional medicine practices.

RESOURCES

- [Community Engagement – Primary Healthcare Performance Initiative](https://improvingphc.org/improvement-strategies/population-health-management/community-engagement) (references SouthCentral Foundation's Nuka System of Care)
<https://improvingphc.org/improvement-strategies/population-health-management/community-engagement>
- [Universal Design in Healthcare Institutions Manual](https://www.ua.undp.org/content/ukraine/en/home/library/democratic_governance/universal-design-in-health-care-institutions.html) – United Nations Development Programme
https://www.ua.undp.org/content/ukraine/en/home/library/democratic_governance/universal-design-in-health-care-institutions.html
- [Universal Design for Healthcare Facilities](https://cs.uwaterloo.ca/~jhoey/teaching/cs793/wiki/uploads/universal-design-for-health-care-facilities-1.pdf) – Joint Commission of Accreditation of Healthcare Facilities
<https://cs.uwaterloo.ca/~jhoey/teaching/cs793/wiki/uploads/universal-design-for-health-care-facilities-1.pdf>

SAFETY AND SUPPORT

Providing safety and support may differ according to individual need. This may often include supervision for people who live with dementia and who may rely upon a trusted family member or caregiver for daily living. Safety and support may also be needed by those who find it difficult to cope in new or strange environments. Routine and familiarity are essential to those living with dementia.

“Daily routines help reduce stress and anxiety. Persons [living] with dementia thrive on familiarity. Familiarity is important because dementia gradually impairs a person’s ability to plan, initiate, and complete an activity. By creating an environment of familiar routines and activities, it allows them to feel comforted and calm. If they can still perform an activity, they can still retain their sense of control and independence”.¹⁰



POLICY TIP #10:

Enable Tribal emergency policies that maintain a sense of familiarity, routine and security for those who live with dementia.

EXAMPLES:

- Emergency evacuation policies that limit, reduce or defer any changes in familiar environments. Moving a person from their familiar and secure environment as a last option.
- If relocation is unavoidable, policies should involve and allow caregivers in relocation options and procedures.
- Implement policies that allow medicine bags, healing or protective objects, and people and activities that make the person feel secure and comfortable. This may be especially relevant for transportation and sheltering policies.
- Emergency operations or temporary facility procedures that maintain routines and activities of daily living.

¹⁰ Alzheimer’s Project ForOurCaregivers.com. THE IMPORTANCE OF ROUTINE AND FAMILIARITY TO PERSONS WITH DEMENTIA. June, 2020. <https://www.alzheimersproject.org/news/the-importance-of-routine-and-familiarity-to-persons-with-dementia/> Accessed 5/11/21





FAMILY MEMBERS AND CAREGIVERS

For people living with Alzheimer’s disease and other dementias, carrying out tasks of daily living may become more difficult as their symptoms worsen. In these cases, a caregiver can assist with these tasks and ensure a greater quality of life for them. Because caregivers are critical to the wellbeing of people with cognitive impairments, it is vital to be inclusive of their roles and experiences when forming policies for emergency situations.

WHO AND WHAT ARE CAREGIVERS?

Caregivers can come from many backgrounds and serve during any stage of dementia. They may be a professional caregiver, in which case, they are paid to provide services to support those living with challenges. More common, caregivers can be informal such as friends or family members who do not receive any form of financial compensation in exchange for their care. When someone lives with family members, in multi-generational households, there may be several people taking responsibility for a loved one. In Tribal communities, family members may not consider themselves caregivers but simply fulfilling their role as relatives.

Defining “caregiver” is important when considering including them in policies. In an example from a Tribal code, “Caregiver” means: (A) a person who is required by law, contract, or tribal custom to provide services or resources to an elder or vulnerable adult; or (B) a person who volunteers to provide services or resources to an elder or vulnerable adult; or (C) an institution or agency which is required by law or agreement to provide services or resources to an elder or vulnerable adult; or D) a person who has undertaken authority to act for the elder or vulnerable adult under a power of attorney, conservatorship, guardianship, representative payee, protective payee, or similar relationship.¹¹

The following are some statistics related to U.S. caregivers:

- Nearly one-third of caregivers are 65 years or older;
- Approximately two-thirds of dementia caregivers are women and over one-third are daughters;
- Approximately 40% of dementia caregivers have a college degree or a higher education;
- 41% of caregivers have a household income of \$50,000 or less;
- Nearly one-fourth of dementia caregivers also care for a child in addition to an aging parent.¹²
- In 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contribution was approximately \$470 billion.¹³

11 Lummi Nation Code of Laws. Title 5B. Elder and Vulnerable Adult Protection Code https://narf.org/nill/codes/lummi/5B_Elder.pdf

12 Alzheimer’s Association. (2021). 2021 Alzheimer’s disease facts and figures. *Alzheimer’s Dementia*, 17(3)

13 Recognition of Family Caregivers in Managed Long-Term Services and Supports. AARP Public Policy Institute, April 2020. <https://www.aarp.org/content/dam/aarp/ppi/2020/04/recognition-of-family-caregivers.doi.10.26419-2Fppi.00090.001.pdf> accessed 3/16/21

UNIQUE RISKS FOR CAREGIVERS

Caregivers provide an essential role in helping those who live with dementia, but the work can have a considerable impact on their own health. The stress caregivers may experience can come from primary stressors, such as patient behavior symptoms or secondary stressors that are unrelated to their elder's diagnosis, such as social isolation. While caregiving in Indian Country is not well studied, dementia caregivers may be subject to general health risks such as depression, anxiety, insomnia, chronic stress, social isolation, and feelings of loneliness. These risks may consequently predispose caregivers to develop certain health conditions such as cardiovascular disease, stroke, or systemic inflammation.¹⁴

CAREGIVING IN EMERGENCY SITUATIONS

Caregivers can be highly instrumental in emergency situations. They can provide functional and communication support to the situation and provide emotional support and advocacy for the person they support. While not comprehensive, below are several policy options to ensure the health of the caregiver is maintained in emergency situations:

Partnerships between Indian Health Service and/or Tribal health personnel and family caregivers are needed to achieve high quality and sustainable care. According to the World Health Organization (WHO), partnerships in care should be based on trust, equality, mutual understanding, shared goals, and shared accountability. This is reflected in policy documents, such as the [United Kingdom strategy for family caregivers](#), which emphasizes that healthcare personnel should consider family caregivers as partners in care and recognize their unique expertise.¹⁵



POLICY TIP #11:

Recognize and treat caregivers as partners by Tribal health, social service, public safety and emergency personnel.

The closure policies of the COVID-19 pandemic left many people without the support they rely upon for the physical and emotional needs for their family members. Fitness centers and programs, cultural programs and elder lunch sites were closed, leaving the caregivers with the responsibility of finding ways to meet those needs as well as meeting the new needs of the pandemic. While many programs stepped up with wellness packages and food delivery, caregivers may have borne the brunt of the added stress to an already high stress situation. Policies that recognize and support the caregiver role can help reduce this stress and the negative health effects produced by stress. These may include workplace policies that provide additional time off for family caregiving, financial compensation programs for caregivers who expend resources to meet the needs of their family members, and respite programs.

14 Kovaleva M, Spangler S, Clevenger C, Hepburn K. Chronic Stress, Social Isolation, and Perceived Loneliness in Dementia Caregivers. *J Psychosoc Nurs Ment Health Serv*. 2018 Oct 1;56(10):36-43.

15 Häikiö, K., Sagbakken, M., & Rugkåsa, J. (2020). Family caregivers' involvement strategies in response to sub-optimal health services to older adults living with dementia — a qualitative study. *BMC Geriatrics*, 20(1), 290. <https://doi.org/10.1186/s12877-020-01663-z>

For a Tribal policy example, the Swinomish Tribe recognizes the relationship between elders and their families and caregivers by including services for families and caregivers as needed in their elder protection plans.¹⁶

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POLICY TIP #12:

Create or extend Tribal policies to provide physical, emotional and financial relief for caregivers during emergencies.

Separation from caregivers poses physical, mental and emotional risks to those living with dementia. Stress and social isolation can negatively impact health and immune function, and so reducing social isolation is essential during a time when individuals require strong immune function to fight off threats such as a novel virus.¹⁷

COVID-19 isolation policies in facilities challenged the relationship between caregivers and patients to heartbreaking points of people dying alone in hospital beds while caregivers and family members watched from the windows or said their goodbyes on the phone. The effects of these policies on family members and healthcare personnel who had to enforce these policies will not be known for some time.

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POLICY TIP #13:

Create or amend health facility policies to provide the best possible scenarios to maintain the physical, social and emotional connection between the patient and caregiver.

CAREGIVING RESOURCES

- [Services for Native Americans \(OAA Title VI\)](https://acl.gov/programs/services-native-americans-ooa-title-vi) (The Administration for Community Living caregiver services grants).
<https://acl.gov/programs/services-native-americans-ooa-title-vi>
- [National Indian Council on Aging LTSS Compass, Caregivers Corner](https://nicoaltsscompass.org/community-resources/caregivers-corner/)
<https://nicoaltsscompass.org/community-resources/caregivers-corner/>
- [State Policy Innovations to Support Family Caregivers](https://www.nashp.org/state-policy-innovations-to-support-family-caregivers/) (National Academy for State Health Policy)
<https://www.nashp.org/state-policy-innovations-to-support-family-caregivers/>
- [Recognition of Family Caregivers in Managed Long-Term Services and Supports](https://www.aarp.org/content/dam/aarp/ppi/2020/04/recognition-of-family-care-givers.doi.10.26419-2Fppi.00090.001.pdf) American Association of Retired People (AARP)
<https://www.aarp.org/content/dam/aarp/ppi/2020/04/recognition-of-family-care-givers.doi.10.26419-2Fppi.00090.001.pdf>


¹⁶ Swinomish Tribal Code, 7-12.210 Services for the Family or Caregiver. https://narf.org/nill/codes/swinomishcode/7_12.pdf, accessed 5/9/21.

¹⁷ Maya Gordon, Maya, Kroon, Matthew, Reilly, Carolyn, Clair, Ruta. (2021). The effects of social isolation on well-being and life satisfaction during pandemic. HUMANITIES AND SOCIAL SCIENCES COMMUNICATIONS | 8:28 | <https://doi.org/10.1057/s41599-021-00710-3>

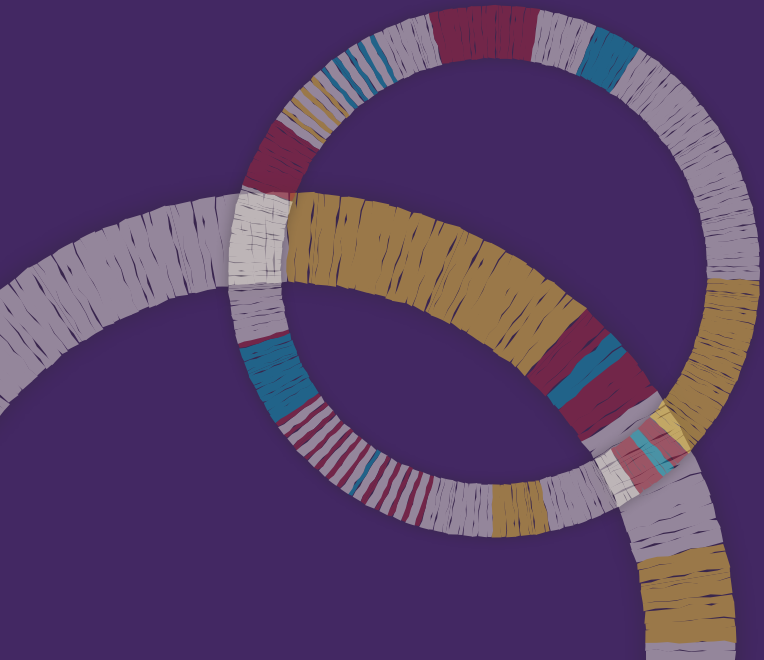
CONCLUSION

Tribal Nations are known for caring for all in their communities. This value of inclusion extends throughout Tribal programs and services. People who live with brain health challenges and dementia, including Alzheimer's disease, may have unique vulnerabilities when faced with a disaster or emergency. Communications, transportation, and medical care access may be challenging during these times. Caregivers, such as family members, are often so integral to someone's ability to navigate the situation that they may not be able to function well or at all without their caregivers. Understanding and recognizing the capabilities and needs of those who live with dementia, including their need for connection to people, culture and nature, is essential for positive social, emotional and physical outcomes. Accounting for those needs in Tribal policies and procedures is vital to a smooth, just and equitable emergency response.





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