



Road Map for American Indian and Alaska Native Peoples



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About the Cover: The photos on the cover represent tribal Elders as leaders, teachers, storytellers and artists. They are knowledge keepers and language holders. Their health and safety is an American Indian and Alaska Native community priority. This book is dedicated to their well-being.

Foreword

Welcome to the second edition of the *Healthy Brain Initiative: Road Map for American Indian and Alaska Native (AI/AN) Peoples*. Thank you for being part of this work to ensure everyone has the opportunity to live life with the healthiest brain possible. This updated edition was developed with respect for the diverse history, cultures, traditions and practices of AI/AN people across the country. In this Road Map, you will find examples of how AI/AN communities used the first edition to advance brain health and support Elders living with dementia.

The Road Map focuses on health equity through a strength-based approach, drawing on the traditional practices and cultural activities that have kept AI/AN communities healthy for thousands of years. It reflects

input from the Leadership Committee and over 200 additional community members and professionals working in AI/AN communities.

As you use this Road Map, we encourage you to share your successes, discuss your challenges and help grow the diverse group of public health professionals working to take a life course approach to brain health. Together we can continue to build healthy communities and support Elders living with dementia and the circle of caregivers surrounding them.

In gratitude,

 Lisa C. McGuire

Lisa C. McGuire and Carl V. Hill

Leadership Committee Co-Chairs



A Note About Terminology

Throughout the Road Map, the term *American Indian and Alaska Native* and its abbreviation *AI/AN* are used. The Leadership Committee chose to use this term because this is the classification used by the U.S. Census, Indian Health Service, and the National Congress of American Indians. The term *American Indian and Alaska Native communities* (or *AI/AN communities*) refers to the many tribes, nations, pueblos, bands, villages and urban AI/AN communities throughout the United States. AI/AN is also inclusive of individuals that are enrolled in state recognized tribes as well as descendants of state or federally recognized tribes. The authors hope that the use of these terms will allow individual communities to see themselves included in the recommendations, even though how they may choose to implement the recommendations will vary. When information is specific to one group, these abbreviations are not used, and the specific tribe or community is listed. The Glossary toward the end of the Road Map defines additional public health and Alzheimer's related terms.

Public Health Action Agenda at a Glance



E DOMAIN: ENGAGE COMMUNITIES AND SHARE KNOWLEDGE



OUTCOME: Increase public knowledge about brain health, risk factors for dementia and benefits of early detection and diagnosis

- E-I Engage AI/AN communities to increase awareness and share knowledge about brain health across the life course.
- E-II Work with local school systems to add brain health and dementia awareness content to learning plans.

OUTCOME: Increase public knowledge and use of services for people living with dementia and their caregivers

- E-III Provide information on how to recognize signs of dementia and increase awareness of services, care and social support for people living with dementia and their caregivers.
- E-IV Ensure caregivers have information about their important roles and how to support their own health and well-being.



W DOMAIN: BUILD A REPRESENTATIVE AND SKILLED WORKFORCE



OUTCOME: Increase knowledge and skills of current and future workforce

OUTCOME: Reduce stigma and bias about cognitive decline

- W-I Provide ongoing training to health care providers to support culturally centered and appropriate conversations about brain health and dementia.
- W-II Provide training to community health and direct service workers who work in AI/AN communities about brain health and the ways dementia disproportionately impacts those they serve.



**M DOMAIN:
MEASURE, EVALUATE
AND USE DATA**



OUTCOME: Increase data availability, quality and utilization

- M-I Support data sovereignty through local data collection to help plan, implement and evaluate programs and approaches for dementia and caregiving in AI/AN communities.
- M-II Encourage health care providers to assess for mild cognitive impairment and dementia, document in medical records and discuss findings with their patients.

OUTCOME: Increase data-informed decision making and action

- M-III Put data into action by sharing findings with AI/AN leaders, community members and organizations to help inform awareness efforts, resource needs, programs and policies.



**P DOMAIN:
STRENGTHEN POLICIES
AND RELATIONSHIPS**



OUTCOME: Increase community partnerships

- P-I Build relationships within and outside of the health and public health sectors to strengthen sustained commitments to brain health and its physical, mental, emotional and spiritual impacts across the life course.

OUTCOME: Increase policy action and implementation

- P-II Engage AI/AN leaders to increase awareness about the indigenous and social determinants of health associated with brain health, dementia and caregiving.
- P-III Equip AI/AN leaders with policy options to improve brain health across the life course and reduce stigma about dementia.

OUTCOME: Increase integration with other chronic disease efforts

- P-IV Build on existing AI/AN chronic disease, aging and disability programs and policies to include brain health.

Introduction

The *Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples* offers actions to improve brain health throughout life. It promotes health equity by using a strength-based approach that honors the diverse American Indian and Alaska Native (AI/AN) cultures and incorporates the indigenous determinants of health. It is developed with respect to tribal sovereignty and is influenced by the traditions of AI/AN peoples.

In 2019, the Alzheimer's Association and the Centers for Disease Control and Prevention (CDC) published the *Healthy Brain Initiative, Road Map for Indian Country* — the first-ever public health guide focused on addressing dementia in AI/AN communities. This second edition builds on what was learned from the implementation of the first Road Map. It can help professionals conducting public health work with tribes, nations, pueblos, bands, villages and urban Indian organizations select and pursue strategies for the AI/AN communities they serve to improve brain health, address dementia and better meet the needs of caregivers. This includes tribal public health professionals and tribal professionals with public

health experience working in community and clinical health settings.

This Road Map is part of the Healthy Brain Initiative Road Map Series. There have been four iterations of the *Healthy Brain Initiative: Road Map for State and Local Public Health* at the time of this publication, with the most current covering the time period of 2023–2027. All the Road Maps seek to advance the vision of the Healthy Brain Initiative that everyone deserves a life with the healthiest brain possible.

Real-life examples and stories of communities in action are included throughout this public health guide to prompt actions that improve brain health and make a difference in the lives of people living with dementia and their caregivers. Many of the communities in action stories are examples of how the *Road Map for Indian Country* was used as a framework for public health action. The Glossary defines public health and Alzheimer's related terms used in the document. More information about the leaders who guided the development of this Road Map and the process used is provided in the appendices.



Strengths in American Indian and Alaska Native Communities

There are 574 federally recognized and sovereign American Indian tribes, nations, pueblos, bands and Alaska Native villages in the United States, as well as state recognized tribes and many other communities without federal or state recognition. All have their own history, traditions, cultures and practices.² It is estimated that approximately 87% of American Indian and Alaska Native (AI/AN) peoples live in urban areas, which has resulted in a mixing of practices and a coming together of communities.³ These strengths, which are the foundation of the indigenous determinants of health (see Table 1, page 10), build resilience for members of those communities and should be incorporated when planning public health action. This section describes some of the strengths of AI/AN communities as they relate to public health and brain health across the life course. While the strengths

are grouped into common categories, they may be expressed differently in each community.

VALUE OF AND RESPECT FOR ELDERS

Elders are highly revered and are often leaders in their community due to their wisdom, particularly when it comes to traditions and cultural values. They play a critical role in transmitting knowledge and practices to future generations, a key element of indigenous determinants of health. These cultural practices and traditions have been shown to be protective factors in AI/AN communities. As pillars and role models in their communities, Elders are integral to the community, treated with respect and involved in decision making whenever possible.⁴ While some communities designate an age for Elder status, others do not.

STRENGTH-BASED APPROACH

Strength-based approaches emphasize the cultural resilience, knowledge and values of American Indian and Alaska Native communities, such as the teachings of Elders, to achieve health equity. By focusing on strengths rather than deficits, these approaches empower AI/AN communities to leverage their traditions and wisdom in health care and education, fostering culturally relevant solutions that address health disparities and promote well-being.¹

WHO ARE ELDERS? EXAMPLES FROM TWO COMMUNITIES

Elders in Bristol Bay, Alaska

“Elder status is not determined by reaching a certain age (e.g., 65 years), but instead is designated when an individual has demonstrated wisdom because of the experiences he or she has gained throughout life.”^{5,6}

Elders in the Tunica-Biloxi Tribe

“Tribal Elders are considered to be the ‘Wisdom Keepers’ of any Tribal Family. They are the footing of strength, exuding grace, wisdom and gentleness in their actions and words. They are the essential portal to keeping our tradition and culture alive in a world that is ever evolving with every generation; resembling a place where wisdom and intuition converges with modern day intelligence and knowledge.

Tribal Elders, in their own right, are our teachers of life, respect and values. They instill the sense of rightness, the importance of acceptance and understanding, kindness, love and forgiveness. Most importantly, they teach us how to be good listeners, which is chief in making wise decisions. The Elders are the core of our existence.”⁷



IMPORTANCE OF FAMILY AND COMMUNITY

Family and collective well-being is central to AI/AN culture, typically extending far beyond blood relatives.⁸ AI/AN peoples often consider their tribal community their family; many even see all other AI/AN peoples as their relatives.⁹ Regardless of how one defines family, this overall mindset values tribal identity and community connectedness, coming together and ensuring that no one is alone.

This is especially true when caring for Elders in the community. For many, it is unacceptable for Elders to be moved from their homes and placed in nursing homes or other long-term settings.¹⁰ The entire community will come together to support and care for an Elder if that means the Elder can age in their home. This is one reason why many AI/AN people who care for Elders do not consider themselves “caregivers.”

From their perspective, they are simply doing what they can to ensure that the Elder can remain in the community and continue to share knowledge and wisdom.^{11,12}

RESILIENCE

AI/AN peoples continue to overcome historical and contemporary challenges and loss of culture through community resilience.¹³ These challenges largely come from policies that have negatively affected their livelihood, such as the forced removal of communities from their ancestral lands and involuntary placement of children into boarding schools.^{14,15} These policies, which were developed to terminate or assimilate American Indian people, resulted in the loss of language, culture and traditions.¹⁶ All of this resulted in the loss of many Elders and family members, and led to historical, intergenerational and contemporary harms that continue to leave a lasting effect on their health and even influence their genes.^{17,18,19}

WHO ARE CAREGIVERS?

Because caregiving is a common part of AI/AN family culture, the term **caregiver** is not often used. Many tribal nations do not have a traditional word for caregiving, using community, family or Elder helper instead. Whenever **caregiver** (or **caregivers**) is used in this Road Map, it means the individual or group of people caring for a person living with dementia. This can be a direct family member, friend or relative and is often not a single person.

Despite this, tribal communities are resilient and have overcome much adversity. This resilience is often driven by the indigenous determinants of health, such as culture, family and social connectedness through traditional practices, and the presence of Elders in family and community. An example of this is the relocation program that sought to displace American Indian peoples in the 1950s by moving them away from their land and culture and into cities.²⁰ With large numbers relocating from reservations and rural areas to cities, urban Indian communities began to form. Many AI/AN communities saw the urbanization of their tribes as an outgrowth of policies designed to take them off their lands.²¹ In response to this change, urban Indian organizations were created in 1972 to provide health-related services.²² Additional legislation in 1973 gave tribal governments more self-determination and control over the management of their resources and programs.^{23,24} Now, with over 85% of AI/AN peoples living in urban areas, urban Indian organizations have become a major source for primary care, traditional healing and medicine, behavioral health, and social and community services including Elder services.²⁵

SOCIAL AND INDIGENOUS DETERMINANTS OF HEALTH

Social determinants of health are the non-medical factors that can drive health outcomes.²⁶ They make up the environment in which people are born, live, learn, work, play, worship and age. Social determinants of health can be grouped into five key areas: economic stability, access to quality education, access to quality health care, the built environment, and social and community involvement.^{26,27} These factors may have a greater impact on health than genetics.²⁷ They can also be used as a way to identify community strengths that at the surface may not seem health related.²⁸

Indigenous determinants of health are becoming a more commonly used concept in public health planning for AI/AN peoples.²⁹ Various definitions of this concept share a common approach of focusing on the strengths of indigenous communities. One of these approaches is highlighted in Table 1 (page 10).

Addressing dementia in AI/AN communities requires a holistic life course approach that respects and integrates indigenous knowledge, promotes cultural safety, and tackles the root social determinants of health that contribute to the disparities in dementia prevalence and outcomes while providing support for and uplifting the restorative indigenous determinants of health.

Table 1: Examples of Indigenous Determinants of Health Impacting AI/AN Peoples³⁰

Indigenous Determinants of Health	Examples
Indigenous Knowledge	<ul style="list-style-type: none">• Ways to be in community, such as benefiting from prayer, mutual aid, cultural connectedness and shared experiences that support wellness• Ways to process, understand, teach and take collective action for various causes
Language and Identity	<ul style="list-style-type: none">• Speaking indigenous languages with other speakers• Reclaiming traditional knowledge, beliefs and practices and passing them on to future generations
Land and Kinship	<ul style="list-style-type: none">• Recognizing and reaffirming that indigenous peoples are rooted in traditional understandings of specific places• Connecting to the geography of a people and to one another
Sovereignty	<ul style="list-style-type: none">• Sovereign rights of tribal governments to ensure health and safety of their people• Governance practices, both current and traditional, that support wellness
Structural and Systemic Factors	<ul style="list-style-type: none">• Historical mistreatment• Economic environment• Access to services• Equitable access to goods and services• Higher rates of AI/AN children in the child welfare system

Table 1 showcases examples of indigenous determinants of health that impact AI/AN communities as described by Seven Directions, a Center for Indigenous Public Health.

FOCUS ON HOLISTIC HEALTH

Some of the indigenous determinants of health (see Table 1) highlight the importance of a holistic approach to health like intergenerational holistic health, indigenous ways of knowing, cultural connectedness, and cultural sense of belonging and identity. Others focus on connections to the earth and land and the importance of being in community.³¹ These concepts relate directly to healthy behaviors known to improve brain health such as physical activity, healthy diet and cognitive engagement. They also help lower the risk of dementia and other chronic conditions like hypertension, diabetes and obesity, which also affect brain health.

The concept of holistic health has been used by AI/AN peoples for generations and is often symbolized as a medicine wheel or medicine hoop.^{32,33} Although the form and meaning varies from tribe to tribe, one of the most well-known versions of the medicine wheel focuses on holistic health and well-being. Made up of four quadrants — physical, mental, emotional and spiritual well-being — the medicine wheel is a reminder of the importance of full-body health and a source of resilience for AI/AN peoples. The colors can represent the four directions (East, South, West and North), stages of life (birth, youth, adulthood and death), seasons, elements of nature, animals or ceremonial plants.³³ An example of a medicine wheel created by the Spirit Lake Senior Services program is featured in the Communities in Action section (see page 61).





Dementia Facts

Dementia is often a terminal syndrome that causes loss of memory and other thinking abilities serious enough to interfere with daily life. One of the more common causes of dementia is Alzheimer's disease, a degenerative brain disease. Dementia is not a normal part of growing older.³⁴

Figure 1: The Continuum of Dementia

This figure shows the life course view for people who develop dementia. It begins at the left with healthy cognitive functioning and moves to the right through the pre-symptomatic and mild cognitive impairment stages, then to mild, moderate and severe dementia. Not everyone moves through this continuum; for example, some people will spend their life in healthy cognitive functioning or with mild cognitive impairment and will not develop dementia.

Similar to other complex diseases, a diagnosis of Alzheimer's or other dementia-causing disease can be thought of as a continuum along the life course. Figure 1 shows this continuum and the different phases of dementia as the disease progresses.³⁴

Vascular disease, Lewy body disease, frontotemporal degeneration, Parkinson's disease and hippocampal sclerosis are examples of other diseases that cause dementia. The most common dementia is caused by

more than one disease and is known as "mixed dementia." There are many other diseases, disorders and conditions that can also cause dementia-like symptoms and might be treatable, which is why it is important to discuss symptoms with a health care provider. The variety of symptoms along with the age of onset, intensity and other characteristics of symptoms experienced depend on the underlying causes, the lived experience of each individual and access to appropriate clinical and non-clinical supports.³⁵



ALZHEIMER'S DISEASE OR DEMENTIA?³⁵

Many people wonder what the difference is between Alzheimer's disease and dementia. Dementia is an overall term for a particular group of symptoms. The characteristic symptoms of dementia are difficulties with memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. Changes to the brain cause dementia, and many different brain changes can lead to dementia.

Alzheimer's disease is one cause of dementia. The brain changes of Alzheimer's disease include the excessive accumulation of the protein fragment beta-amyloid and an abnormal form of the protein tau, as well as damage to and destruction of neurons. The brain changes of Alzheimer's disease are the most common contributor to dementia. Dementia caused by Alzheimer's disease is called Alzheimer's dementia.

The facts presented in this section come from studies and surveys of different groups of American Indian and Alaska Native (AI/AN) peoples. Where possible, the relevant groups are noted in the text. The majority of the data presented are from national surveys or from medical records data that included AI/AN identification. Terminology used in this section is from the cited study

and may differ from the terminology used elsewhere in this Road Map.

The prevalence of dementia among AI/AN people is high — and likely to grow.

Overall, there is less information about dementia among AI/AN peoples than for other populations. However, new studies are published every year, and the science base continues to evolve. The picture that is forming is that cognitive impairment and dementia are as common or more common in American Indian and Alaska Native peoples than in other racial or ethnic groups studied.³⁶

- In 2014, an estimated 10.5% of AI/AN people aged 65 and older with Medicare had a diagnosis of dementia.³⁷
- Analysis of the Strong Heart Study, a population-based cohort of 11 tribes, suggests over half (54%) of older American Indian individuals aged 70–95 have some form of cognitive impairment, including approximately 35% with mild cognitive impairment and 10% with dementia. This rate is higher than the rates of mild cognitive impairment and dementia in other racial and ethnic groups in the United States.³⁸
- Behavioral Risk Factor Surveillance System (BRFSS) data, a representative sample of the U.S. population, shows 1 in 6 AI/AN adults aged 45 and older reports experiencing worsening thinking or memory difficulties that could be a sign of future dementia risk.³⁹

MORE ABOUT MILD COGNITIVE IMPAIRMENT (MCI)

Subtle cognitive changes in memory and thinking are often a feature of “normal aging.”⁴⁰ For some individuals, however, these changes are serious enough to be considered mild cognitive impairment (MCI) and part of the continuum of cognitive decline. MCI is an early stage of memory loss or other type of cognitive ability loss (such as language or visual/spatial perception) in individuals who maintain the ability to independently perform most activities of daily living. Individuals with MCI may have a higher risk of developing dementia.⁴⁰ While not everyone with MCI will develop dementia, an estimated 15% of individuals with MCI develop dementia after two years, and about one-third of people with MCI develop dementia due to Alzheimer’s disease within five years.^{41,42}



1 in 6

AI/AN ADULTS AGED 45 AND OLDER REPORT MEMORY OR THINKING DIFFICULTIES

- Age is the greatest risk factor for dementia.⁴³ There are nearly one million AI/AN people aged 65 and older.⁴⁴ The number of AI/AN people aged 65 and older living with dementia is expected to increase from an estimated 27,000 in 2014 to a projected 156,000 in 2060.⁴⁵
- BRFSS data show that 71.7% of AI/AN adults have at least one of five major risk factors for cognitive decline (diabetes, obesity, physical inactivity, hypertension or smoking).⁴⁶

The pattern of cognitive impairment and dementia among AI/AN people may be different from other populations.

- The health disparities that AI/AN individuals experience are a result of numerous systemic inequities.⁴⁷ This increases the risk that AI/AN older adults could experience signs of cognitive impairment sooner than other older adults in the U.S.⁴⁸
- A study on dementia diagnostic rate estimates found that 14% of AI/AN Indian Health Service (IHS) patients with a dementia diagnosis had younger-onset dementia (between the ages of 45 and 64) during the study period from 2016 through 2020. Globally, fewer than 10% of dementia cases are younger-onset.^{49,50}

- Data from the National Resource Center on Native American Aging give insight into urban Native Elders' views on their brain health:
 - 13.9% of urban Native Elders survey respondents reported that confusion is getting worse or happening more often, and 20.5% reported memory loss is getting worse or happening more often.⁵¹
 - However, very few urban Native Elders survey respondents said that they have been diagnosed with Alzheimer's disease (0.9%), dementia (1.3%), or other problems with memory or thinking (7.5%).⁵¹

AI/AN peoples may have different perceptions of memory and dementia.

Some AI/AN communities may perceive dementia as a normal part of aging or accompanying the transition to the next world.⁵² Others gauge memory by the ability to recall the distant past and as a result the effects of dementia may go unnoticed. Some tribal languages do not have a word for dementia. Whatever the perceptions, education and knowledge sharing can encourage helpful conversations with family and health care providers, so people experiencing any form of cognitive impairment are not invisible or ignored and can receive needed treatment, care and support.⁵³

Results from a survey conducted in 2020 by the Alzheimer's Association showed:

- About two-thirds (65%) of AI/AN adults say that they know someone with Alzheimer's.⁵⁴

35%

OF AI/AN ADULTS SAY THAT
THEY DO NOT EXPECT TO
LIVE LONG ENOUGH TO
DEVELOP ALZHEIMER'S

- One in four (25%) of AI/AN adults say that they are worried about developing Alzheimer's disease.⁵⁴
- More than one-third of AI/AN adults (35%) say that they do not expect to live long enough to develop Alzheimer's.⁵⁴
- More than half (53%) of AI/AN adults believe that significant memory or cognitive losses are a normal part of aging.⁵⁴
- AI/AN adults are twice as likely as White adults (9% compared with 4%) to say they would not see a doctor if experiencing thinking or memory problems.⁵⁴

Caregiving is part of family culture.

A strength of AI/AN cultures is that they hold great esteem for Elders and are likely to take care of their Elders at home.⁵³ Caregivers for people living with dementia often assist with activities of daily living such as personal care, household management, medication and health care management and coordination of financial matters. Providing caregivers with resources and information about their important role and available support can help them maintain their own health and well-being.⁵⁵

- One in four AI/AN adults are caregivers⁵⁶ and 5.4% of AI/AN adults reported that they are caregivers of people living with dementia.⁵⁷
- More than half (53.2%) of AI/AN caregivers of people living with dementia provide at least 20 hours of care per week and 60.3% have provided care for at least two years.⁵⁶
- Among AI/AN caregivers of people living with dementia, 23.4% also have a child in the home, meaning they are caring for both a child or grandchild as well as an older adult with dementia (often referred to as the “sandwich generation”).⁵⁶
- More than one-fourth (27%) of AI/AN caregivers of people living with dementia report being treated with less respect than others by health care providers.⁵⁴

53%

OF AI/AN ADULTS BELIEVE
THAT SIGNIFICANT MEMORY
OR COGNITIVE LOSSES ARE
A NORMAL PART OF AGING

- One study gives more insight into caregiving for any condition from the perspective of the Hopi Tribe:
 - Caregivers on the Hopi Reservation say they have difficulties with not having enough time for family and/or friends (88.6%), having financial burdens (75.0%) and not having enough time for themselves (61.4%).

- Over 77% of caregivers on the Hopi Reservation would not consider placing their relative in an assisted living facility.⁵⁸

Barriers limit access to care.

Alzheimer's continues to top the list of the most expensive diseases in America, creating especially difficult barriers for AI/AN people trying to access health care and culturally centered services.

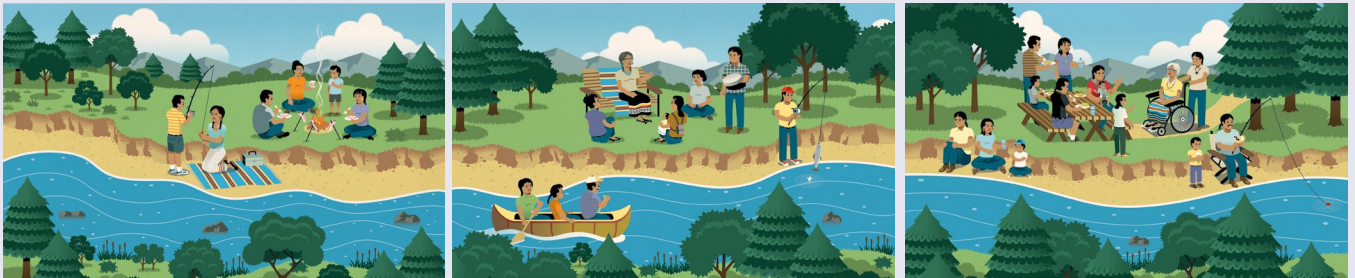
- AI/AN Elders are especially affected by inequities in health care services, housing, economic security and other services needed to grow older with dignity.⁴⁷
- AI/AN Elders experience limited access to long-term care resources and facilities. When these resources are available, they often do not meet Elders' cultural needs.⁴⁷
- The Native Urban Elders needs assessment showed the most commonly reported types of health care coverage were Medicare (50.2%) and the Indian Health Service (30.1%). The greatest reported barrier to receiving health care was cost (18.2%).⁵⁹
- The average total annual health care costs for AI/AN adults with dementia who access services through IHS and tribal health programs was 70% higher than for AI/AN adults without dementia.⁶⁰
- AI/AN adults with dementia have more chronic health conditions than those without dementia, further complicating care.^{60,61,62,63}



Taking a Public Health Approach to Dementia

Public health interventions work to prevent disease and improve the health of people in communities through all stages of life. They focus on three prevention strategies and a variety of tools that are classified as **primary, secondary and tertiary prevention strategies**.^{64,65}

Throughout this section, the image of a family by a river is used to illustrate these prevention strategies at work in an American Indian or Alaska Native (AI/AN) community. The story focuses on a woman moving through different phases of life. She begins healthy but then starts to show early signs of dementia and is ultimately diagnosed with Alzheimer's disease. Throughout her journey, she is supported by her family, community and culture. Each image shows examples of primary, secondary and tertiary prevention strategies and the text outlines examples of public health actions in these areas.



PRIMARY PREVENTION

In this first image, the woman and her family are engaging in healthy activities while enjoying a picnic by the river. They are eating healthy traditional foods and actively teaching or learning new skills. The woman is teaching her child to fish. They are all engaged with their community, culture and nature supporting holistic health.

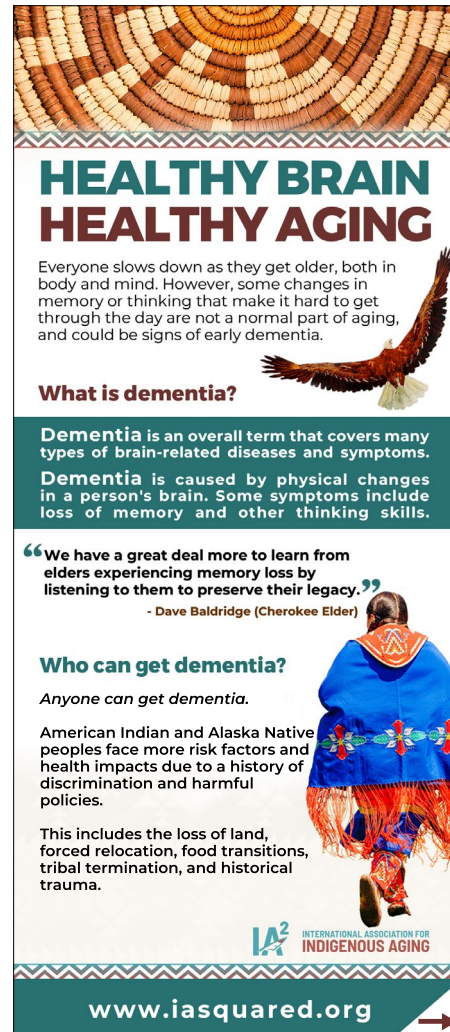


Primary prevention is intervening before health effects or conditions occur.

There are many opportunities to use primary prevention and to improve brain health through educational messages, programs and policies (see Figure 2). Primary prevention strategies help overall health, including brain health, and reduce the risk of many conditions. The possible risk factors for dementia include traumatic brain injury, midlife hypertension, midlife obesity, diabetes, physical inactivity, smoking commercial cigarettes, poor sleep quality, poor nutrition, depression and hearing loss.⁶⁶ By supporting healthy environments that promote the indigenous determinants of health, public health primary prevention strategies can reduce the impact of chronic diseases, improve brain health in communities and support and respect the culture.

A strong public health response in primary prevention focuses on supporting AI/AN community strengths to create opportunities for safe physical activity, increase access to healthy and traditional foods, and learning, practicing and teaching tribal languages. Supporting the indigenous determinants of health by supporting traditional activities can also support behaviors that reduce the risk of dementia.

Figure 2: Ways to Address the Risk of Dementia



Many prevention tools have been adapted for AI/AN peoples. A few are featured throughout this section.

Source: iasquared.org/brain-health/

SECONDARY PREVENTION

As time passes, the woman is now a grandmother, passing down stories to her grandchildren. She and her family have noticed changes in her memory and behavior and have talked about these changes with each other and with her doctor. While the family has found some of these conversations difficult and stressful, they are sure that being honest and proactive is the best way to support her and help her take advantage of available diagnostic and treatment services.

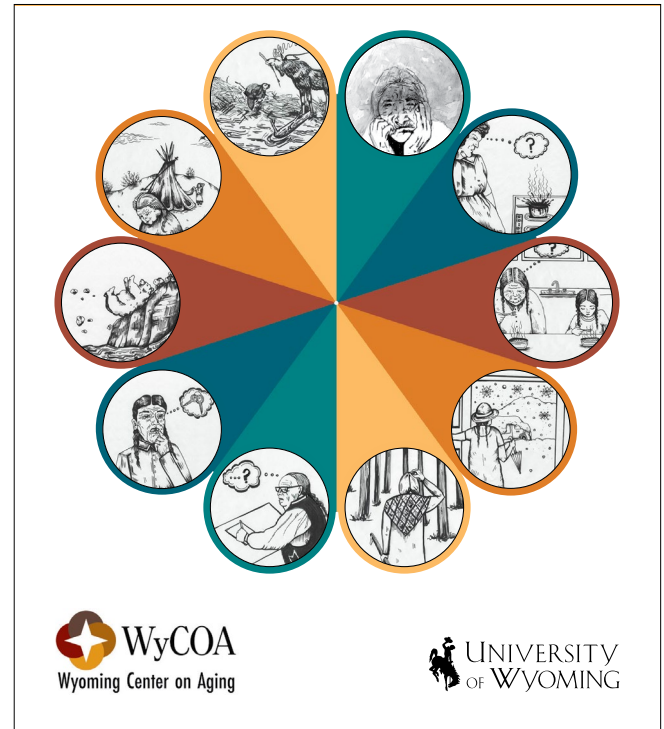


Secondary prevention is detecting diseases in the earliest stages before the onset of more severe symptoms. This includes early detection and diagnosis of mild cognitive impairment and dementia. Diagnosis is important at every stage of dementia.

Individuals with mild cognitive impairment can independently perform most activities of daily living (see Figure 3). At this stage, early detection and diagnosis may slow the disease process by providing opportunities to access available treatments or clinical trials, or to engage in healthier behaviors. Early detection of cognitive issues also allows clinicians to identify potentially reversible or treatable causes, including vitamin deficiencies and medication side effects. Early detection and diagnosis can also reduce the financial and emotional impact by giving families more time to prepare, which can help protect the family and Elder from fraud, financial exploitation and abuse.^{47,67,68}

A strong public health response in secondary prevention focuses on reducing barriers to early detection and diagnosis. An example of this is providing tools and training to prepare families and caregivers to recognize and talk about the early signs of memory loss and thinking difficulties so they can seek diagnosis and resources earlier. This can allow family members experiencing memory and thinking problems to be supported and continue to live and thrive in their communities. It also involves training

Figure 3: Early Signs of Memory Change



This resource was created by the Wyoming Center on Aging in collaboration with Eastern Shoshone and Northern Arapaho tribal members.⁶⁹

health care providers to support culturally centered, appropriate conversations about brain health and dementia, and accurately assess cognitive impairment. When detection and diagnosis happen earlier, there is more time to plan for the future with more opportunities for treatment or participation in clinical trials.

TERTIARY PREVENTION

Time continues to pass, and the family has expanded to include a fourth generation. The woman, now a great-grandmother, has been diagnosed with Alzheimer's disease. Her extended family, along with other tribal and community members, continue to help her stay connected to the land by supporting her and sharing a healthy traditional meal. They embrace their roles as caregivers, help her manage activities of daily life and support her continued involvement in the community. They respect her as an Elder and encourage her to continue to share her wisdom, language, stories and traditions with her family and community. They also support each other by sharing the responsibilities of caring for their loved one.



Tertiary prevention is managing a disease and its symptoms to slow the progression and prevent or reduce negative health effects and maintain quality of life. It also encompasses prevention of complications, support for caregivers and management of comorbidities (other diseases or conditions that a person has at the same time, such as diabetes or heart disease).

As mild cognitive impairment progresses, dementia symptoms become noticeable and the disruption to memory, thinking and everyday life can range from mild to severe. At this point, tertiary prevention strategies can connect the person living with dementia and their caregivers to treatment and support services to help preserve their independence and quality of life for as long as possible.

There are many ways public health professionals can help communities have moments like the one in the story by making support services accessible to people living with dementia and their caregivers. The culture, customs and traditions of AI/AN peoples can sustain and reinforce these efforts. Involving Elders in community gatherings (like those depicted in the story),

Powwows, harvest celebrations and other traditions brings cultural and community connectedness for all involved. In addition to community events, caregivers play an important day-to-day role in helping to reduce potential challenges such as wandering, medication mistakes, difficulties in paying bills and potential for dangerous situations. The role caregivers play helps them stay involved in addition to helping the person living with dementia.

A strong public health response in tertiary prevention can help maintain the health, well-being and independence of people living with dementia and their caregivers and reduce associated costs. Respite programs can actively involve caregivers and be tailored and flexible to meet the specific and evolving needs, culture and customs of people living with dementia.

The actions in this Road Map go into more detail about each of these public health strategies and how public health professionals working with AI/AN communities can plan and implement them. In Appendix D (see page 77), the actions are shown in a table with the levels of prevention the action has the potential to influence.

EXAMPLES OF SUCCESSFUL PUBLIC HEALTH PROGRAMS TO IMPROVE HEALTH AND WELL-BEING IN COMMUNITIES

Several public health efforts funded by CDC and IHS specifically focus on the health and well-being of AI/AN communities. These programs address chronic disease and risk factors, use data and promote strengths in AI/AN communities in similar ways as the strategies proposed in the Road Map. Integrating brain health messaging into these already established programs and learning from their sustainability efforts can help accelerate the implementation of brain health programs and messaging.

Here are a few examples:

- The Special Diabetes Program for Indians (SDPI)
- Racial and Ethnic Approaches to Community Health (REACH)
- Healthy Tribes
 - Good Health and Wellness in Indian Country
 - Tribal Epidemiology Centers Public Health Infrastructure
 - Tribal Practices for Wellness in Indian Country





Public Health Action Agenda

USING THE ROAD MAP

The framework of the *Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples* consists of four domains (see Figure 4, page 30). **Culture is Health** unites the four domains, emphasizing the importance of culture in the ability of AI/AN communities to achieve optimal health.⁷⁰ The domains are surrounded by four important areas of public health practice.

This framework is based on the 10 Essential Public Health Services,⁷¹ which describe the activities that

public health professionals in all communities can undertake. These core activities of public health guide the structure of the Healthy Brain Initiative Road Map Series.

The order of the domains was determined based on feedback from AI/AN community leaders and public health professionals, who felt it was important to begin the Action Agenda with a focus on the community (see discussion of listening sessions in Appendix A, page 72).

Working with such a tribally well represented group as the Leadership Committee on the Healthy Brain Initiative Road Map has been an inspiration as we look to bring needed resources to AI/AN communities. I look forward to our continued collaboration and feedback as this is rolled out to tribal leaders and public health professionals.

Will Funmaker (Ho-Chunk Nation), Leadership Committee



A list of 13 actions (see Public Health Action Agenda at a Glance, page 2) is offered for public health professionals working in AI/AN communities. The actions are flexible and adaptable to meet the needs of different communities. They recognize that some AI/AN communities may be in the process of initiating activities in this area; others will be further along and have ongoing efforts on which to build. In addition, the actions consider the range of funding and staffing resources that may be available. Some actions require little to no funding or staff time; some create opportunities to grow and expand; and others are more complex or ambitious actions for programs with higher funding and staffing levels.

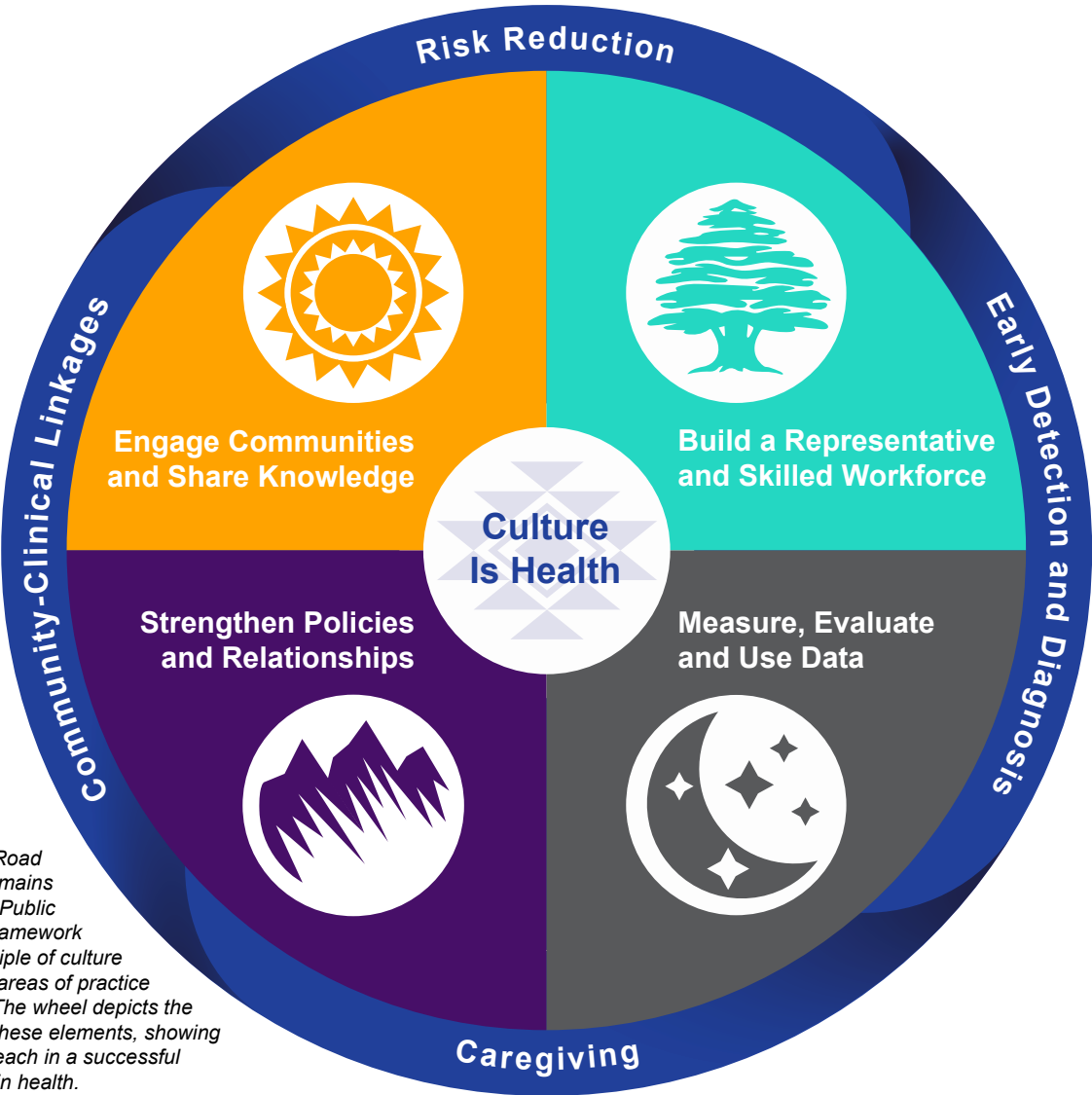
While the actions are written for local public health professionals working in AI/AN communities, they can have an even broader impact if they are reinforced by a national strategy. This Road Map aims to guide local multi-sector collaboration, but it can and should also be a tool for national leaders to identify ways they can contribute to shared goals and outcomes. National organizations — federal, nonprofit and tribal-serving organizations — play an important role in accelerating and supporting the work in specific AI/AN communities. Potential complementary actions at the national level are detailed in a later chapter of the Road Map (see Advancing Brain Health Together, page 49).

KEY QUESTIONS TO GET STARTED

As planning begins, public health professionals can use the following questions to make it easier to choose which actions to take.

1. How do you define your community?
2. What are the most urgent or most common needs of your community related to cognitive health, dementia and Alzheimer's disease?
3. Which Road Map actions best fit your community's priorities and capabilities?
4. What data and other information can be used to identify a starting place?
5. How can the identified actions best be incorporated into existing initiatives? Are new initiatives needed?
6. Who are potential partners? Could any current relationships or networks be leveraged to accelerate action?
7. What are new and existing funding sources and how can they be secured?
8. How will implementation and impact be evaluated? How will progress be shared with the community and local leaders?

Figure 4: Framework for the Healthy Brain Initiative Road Map



The framework for the Road Map consists of four domains built from the Essential Public Health Services. This framework is centered on the principle of culture and surrounded by the areas of practice across the life course. The wheel depicts the interconnectedness of these elements, showing the essential nature of each in a successful strategy to improve brain health.



Engage Communities and Share Knowledge: Public health engages with AI/AN communities to understand how knowledge can be shared. Public health professionals in the community can then share practices to increase awareness about the factors that influence brain health and ways to maintain or improve cognitive health and ultimately quality of life.

The sun icon symbolizes warmth, energy and growth as communities engage and share knowledge together.



Build a Representative and Skilled Workforce: Public health is responsible for training and preparing the public health and health care workforce to provide culturally centered and appropriate care to people at risk for or living with dementia while also supporting caregivers.

The cedar tree icon represents protection and healing. The diverse uses of the tree call to mind the roles of the different members of the workforce.



Measure, Evaluate and Use Data: Public health supports data sovereignty while working with communities to monitor health status, identify and solve community health problems, and evaluate effectiveness, accessibility and quality of health improvement programs. Findings are shared with the community and used to inform programs and policies to improve brain health across the life course.

The moon icon symbolizes the moon's role as a guide and a timekeeper, signifying transformation and the importance of measurement and data.



Strengthen Policies and Relationships: Public health strengthens, supports and mobilizes community partnerships to improve brain health. Public health also creates, champions and implements supportive policies and plans by increasing awareness of dementia and its impact among tribal leadership.

The mountain range icon signifies strength and sacredness, representing the power of policies and relationships.

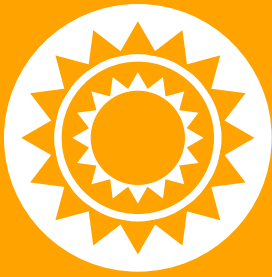
HELPFUL TOOLS

To support the work of AI/AN leaders, the Alzheimer's Association, CDC and the International Association for Indigenous Aging (also known as IA²) offer tools and resources that will be updated and expanded over time.

- Topic-specific resources: short briefs on overarching issues related to brain health
- Implementation guide
- Evaluation tools

Additional resources are available at alz.org/HBIRoadMapAIAN, cdc.gov/aging-programs and iasquared.org/brain-health.





E DOMAIN:

Engage Communities and Share Knowledge

OUTCOME: Increase public knowledge about brain health, risk factors for dementia and benefits of early detection and diagnosis

- E-I Engage AI/AN communities to increase awareness and share knowledge about brain health across the life course.
- E-II Work with local school systems to add brain health and dementia awareness content to learning plans.

OUTCOME: Increase public knowledge and use of services for people living with dementia and their caregivers

- E-III Provide information on how to recognize signs of dementia and increase awareness of services, care and social support for people living with dementia and their caregivers.
- E-IV Ensure caregivers have information about their important roles and how to support their own health and well-being.

This Road Map brings the voices and wisdom of our Alaska Native Elders to the conversation on brain health and how to age in a good way. It raises awareness and understanding of brain health in a way that honors and protects the cultural values, wisdom and strengths within our AI/AN communities.

Jordan P. Lewis (Aleut and Sugpiaq, Native Village of Naknek), Leadership Committee

Engaging communities to share knowledge about brain health across the life course is critical to increasing awareness. Sharing information with the community can take many forms. In this domain, the focus is on sharing information about brain health and caregiving and how community traditions, cultures and practices can contribute to improved brain health. It is also important to share information on how to recognize the signs of dementia early to help link community members and their caregivers to appropriate health care and social support.

For AI/AN peoples, the concept of community is deeply rooted. They may feel a sense of community if they share a particular area such as a neighborhood, town, city or reservation. Community can also extend beyond a geographic boundary and encompass all tribal citizens, even those living in different states or in different parts of the world. Communities encompass

places, culture, values and experiences. The people in these communities can best reinforce and support healthy behaviors and reduce the risk of dementia across the life course, such as eating a healthy diet, getting regular physical activity and not smoking commercial cigarettes or using other commercial nicotine products. Strength-based messaging for AI/AN communities on how to integrate healthy behaviors into daily life can affect brain health, particularly when incorporating them into traditional practices around food, spirituality, medicine and connection to the land and environment.

Another successful communication method is to focus on youth during the school day. Children learn about the importance of physical activity and nutrition and can also be taught how to protect and promote brain health. Structured classroom discussions with peers about health promotion can help children learn how



to protect and improve their own brain health. They can also help teach them how to have meaningful interactions with people living with dementia and reduce stigma about the disease, especially considering many AI/AN children live in intergenerational households with Elders.

Close-knit communities may be more likely to notice early signs of dementia in their Elders. Sharing information can help communities engage in conversations about memory loss and thinking difficulties, reducing the stigma often associated with cognitive decline. Information can also focus on early warning signs and dispel myths about dementia as “normal aging.” The landscape of available, effective treatments for dementia is changing rapidly. Ongoing research is yielding new diagnostic techniques and tools and improved management strategies. The earlier diagnosis occurs, the sooner people living

with dementia and their caregivers can access and benefit from available services, care and social support. This keeps people living with dementia active and thriving within their communities for as long as possible. It is also important for policies and supporting community organizations to help protect people living with dementia from abuse, neglect and exploitation. People living with dementia are especially vulnerable because the disease may prevent them from recognizing the abuse or reporting it.^{47,72}

Additionally, caregivers need information about the important roles they have in caring for Elders with dementia, while also learning about ways they can take care of themselves by practicing self-care. This includes accessing respite care — a break from providing care so they can rest, travel, spend time with other family and friends, or engage in work or hobbies. Respite care can take place at home, in a health care

METHODS OF COMMUNICATION

Using various methods of communication will ensure that information is accessible to all. Conversations with Elders and their caregivers about vaccinations found that Elders get most of their information by word of mouth, followed by physical media, social media, broadcast media and internet research.⁷³



facility, at an adult day care center or in home- and community-based care services settings. Many tribes and urban Indian organizations have weekly Elder programs that provide a safe space for social connections among Elders, while also providing some needed respite time for caregivers.

It is important to remember that any successful educational or awareness effort requires participation from the intended audience during its development. For AI/AN peoples, it is essential to get input from Elders, trusted community members, leaders of tribal government and people with lived experience. Messages should be tailored to the specific culture and community and involve translating messages into traditional languages.

Starting conversations about brain health and dementia in the community can be hard. The questions below are adapted from the first *Healthy Brain Initiative, Road Map for Indian Country*. Many individuals found these questions helpful to get the conversation started in their communities.

- Do we have traditions about keeping ourselves healthy that include keeping our memories strong and maintaining our ability to learn and make decisions?
- Why is it important for us to stay healthy?
- There are many similarities in messages about diabetes prevention, heart health and brain health. Are we using what we know about diabetes or heart

disease to help us learn about dementia and promote brain health?

- What kinds of people and groups in our community are helping people living with dementia with day-to-day activities or transportation? How are these caregivers doing?
- Do people in our community know where to find information and services if a family member is experiencing memory loss?
- What types of information or training would help family and friends better support our Elders who need care?
- How might our cultural values, practices and beliefs help us support caregivers and people living with dementia?
- How could professionals who serve our community better support our Elders who have care needs?
- What groups in our community or in nearby communities could help us promote wellness across the life course?
- Who in our community supports caregivers and watches out for the safety and well-being of older adults with dementia?
- Without identifying individuals, how are people living with dementia doing in our community?
- What might we do as a next step? Who could help? When should we start?



W DOMAIN:

Build a Representative and Skilled Workforce

OUTCOME: Increase knowledge and skills of current and future workforce

OUTCOME: Reduce stigma and bias about cognitive decline

W-I Provide ongoing training to health care providers to support culturally centered and appropriate conversations about brain health and dementia.

W-II Provide training to community health and direct service workers who work in AI/AN communities about brain health and the ways dementia disproportionately impacts those they serve.



In our journey to combat Alzheimer's and dementia, tribal consultation is a cornerstone of our commitment to equity and inclusivity. By prioritizing early detection, reducing stigma, and addressing social determinants of health and lifestyle changes, we pave the way for a future where the reduction of chronic diseases intersects with the prevention of Alzheimer's and dementia.

LaRita Laktonen-Ward (Alutiiq), Leadership Committee



A representative and skilled workforce of health care providers is essential for brain health across the life course. Regardless of the health care delivery setting, this workforce needs to know how to support brain health, such as through the promotion of risk reduction activities and ensuring early detection of cognitive impairment. Equally important is the ability to do so in the context of the culture and customs of the AI/AN peoples they serve. This domain focuses on building the skills of the current workforce, which can increase the knowledge and confidence of health care professionals in discussing brain health and dementia

in a culturally centered way. The hope is that eventually this will reduce stigma in the workforce and, over time, lead to decreased stigma in the community, too.

Health care providers play a pivotal and influential role in promoting brain health and encouraging open and honest conversations about memory loss with their patients and families. To do so effectively, they need to be well versed in how their patients' history, traditions, cultures and practices influence their perceptions of dementia. AI/AN physicians are underrepresented in the workforce, meaning that many physicians serving

INDIAN HEALTH SERVICE/TRIBAL/URBAN HEALTH CARE SYSTEM

The infrastructure for care delivery varies considerably across tribal and urban communities. Many AI/AN people receive their health care through the federal government as a result of various treaties, laws, Supreme Court decisions and Executive Orders.⁷⁴ The Indian Health Service (IHS), established in 1955 within the U.S. Public Health Service, is responsible for providing health care services to citizens of federally recognized tribes.⁷⁵ In addition to the IHS, as a result of the Indian Self-Determination and Education Assistance Act and the Indian Health Care Improvement Act, AI/AN people may receive their health care through a tribal nation that has opted to receive funding from the IHS to operate all or part of their health system through compacting or contracting with IHS or an urban Indian organization.⁷⁶ Collectively, the three entities are the Indian Health Care System and are often referred to as the Indian Health Service/Tribal/Urban health care system, or I/T/U, and provide health services to over 2.5 million AI/AN people.⁷⁷

As part of the health care workforce, physicians, nurses, dentists and therapists provide patient care within the I/T/U system. Additionally, many tribes and urban Indian organizations rely heavily on community health representatives and others in similar roles as frontline public health workers who serve as trusted liaisons with the community.⁷⁸

AI/AN peoples are often not from the community.⁷⁹ Limited exposure to AI/AN peoples and their understanding of dementia requires cultural humility training so providers can better serve their patients.⁸⁰

A focus group of providers who serve Alaska Native communities recognized the need to obtain an early diagnosis, blend Western and traditional medicines, promote lifestyle and dietary changes, and foster training for caregivers. Providers who were Alaska Native themselves reported more emphasis on treating the unique person rather than only the disease.⁸¹ As the AI/AN older adult population grows, the need for culturally centered training and support services for dementia will continue to increase. It is important that providers understand and spend time with a community before they begin serving that community.⁸¹

A diagnosis of mild cognitive impairment or dementia early in the disease course is essential to access disease-modifying treatments when they have the most potential for clinical benefit.⁸² It can also motivate patients to engage in healthy behaviors for risk reduction to slow disease progression. Providers can begin assessing patients annually and, for those on Medicare, this assessment is reimbursed through the Medicare Annual Wellness Visit or general office visit codes. Regular assessments can help show changes over time, if they occur. If a diagnosis is made, sharing that diagnosis with the patient and their caregivers can lead to honest conversations to reduce stigma and support appropriate treatment and disease management. Providers should also be trained to record diagnoses of mild cognitive impairment and dementia in medical records to improve data quality



for AI/AN people. Asking patients to self-identify their race/ethnicity on medical forms, rather than making assumptions, will also improve the accuracy of public health data for planning and evaluating interventions (see M Domain, page 41).

Community health and direct service workers also provide care for AI/AN peoples. They can benefit from training about brain health, the ways dementia disproportionately affects the people they provide services to and how they can help recognize and treat people living with cognitive impairment and dementia. These workers can include certified nursing assistants, home health aides, para-professionals, long-term care staff, community health workers, community health representatives, Community Health Aide Program staff, public health nurses, Title VI directors and staff, and others who provide administrative support. Additionally, training courses can benefit staff working

in tribal public safety, emergency response and behavioral health/mental health agencies to improve their ability to recognize and meet the needs of people living with cognitive decline and dementia.

Training can be offered as new staff join, as well as annually or at regular intervals for existing staff. Training content should recognize the diversity of frontline workers and their role in providing valuable care to older adults and their caregivers. Training should also be sensitive to and honor cultural traditions of medicine and healing practices, especially for providers working in AI/AN communities who are not a member of the tribe themselves.

The current health care workforce already has shortages of qualified workers, which can limit access to care. The Advancing Brain Health Together chapter (page 49) discusses national strategies to train an expanded workforce.

INDIAN COUNTRY EXTENSION FOR COMMUNITY HEALTHCARE OUTCOMES (ECHO)

Indian Country ECHO, a program that provides no-cost training, technical assistance and capacity building services, is a valuable resource. Its teleECHO programs offer interactive online learning environments where clinicians and staff serving AI/AN patients can connect with peers, engage in presentations and be mentored by clinical experts from across Indian Country. A specific ECHO on dementia is available. Learn more about replicating the ECHO model at indiancountryecho.org.



M DOMAIN:

Measure, Evaluate and Use Data

OUTCOME: Increase data availability, quality and utilization

- M-I Support data sovereignty through local data collection to help plan, implement and evaluate programs and approaches for dementia and caregiving in AI/AN communities.
- M-II Encourage health care providers to assess for mild cognitive impairment and dementia, document in medical records and discuss findings with their patients.

OUTCOME: Increase data-informed decision making and action

- M-III Put data into action by sharing findings with AI/AN leaders, community members and organizations to help inform awareness efforts, resource needs, programs and policies.

Dementia IS a public health crisis for Native people due to its numbers and potential for reduction. American Indian and Alaska Native peoples will reap enormous benefits from applying recommendations in this new Road Map.

J. Neil Henderson (Oklahoma Choctaw), Leadership Committee

Tribes are sovereign nations, and their tribal governments are public health jurisdictions with the right to control the collection and use of their data.⁸³ This means that each tribal nation can collect, use and own their data for the benefit of the health and well-being of their community. This includes their public health data.

The actions in this domain emphasize the value of existing data sources and do not call for the creation of new data collection methods. Instead, the focus is on improving the quality of data and engaging the community in using findings to plan effective programs and policies.

In places where data are already available, adding questions or ensuring the completeness of the data can help to identify the needs and barriers communities are facing. One strategy is to include questions about brain health, memory loss and difficulties in thinking

when conducting community health needs assessments. These data can then be used to identify gaps, plan programs and evaluate outcomes. For example, the Elder Needs Assessment is a survey that can assist AI/AN communities in creating a record of the health and social needs of their Elders. The National Resource Center on Native American Aging, funded by the Administration for Community Living, provides free assistance in conducting this survey, analyzing results and using findings for planning, long-term care discussions and grant applications. Tribal ownership over the data is maintained to protect data sovereignty.⁸⁴

Medical records are another available source of data on cognitive health and dementia. When completed correctly and fully, these data help providers monitor their patients' health and can be aggregated to assess the larger community's health. Taking steps to improve

WHAT ARE PUBLIC HEALTH DATA?

Public health data are data about a population. They are a key tool of public health to help understand populations and communities better. Public health data include demographics, incidence and prevalence of diseases and health behaviors, health status, morbidity and mortality. Public health data can also include information on the indigenous and social determinants of health, such as involvement in traditional practices and access to health care. There are numerous ways to gather such data, including surveys, health records and vital statistics.

the completeness and accuracy of medical records can increase understanding of the impact of dementia on the AI/AN community. An ideal time to update medical records for AI/AN Elders over the age of 65 is the Welcome to Medicare or Annual Wellness Visit, a benefit available in the Medicare program. These visits are also an opportunity for health care providers to have discussions with patients and caregivers about brain health and dementia (see W Domain, page 37).

The quality and usefulness of any data will be improved when AI/AN respondents self-report as “American Indian or Alaska Native” on completed forms and documents. Starting with the 2000 Census, respondents are able to select more than one race, adding depth to the understanding of racial and ethnic composition in the population’s demographics.

A critical aspect of data collection and evaluation is sharing data and findings with the community. This

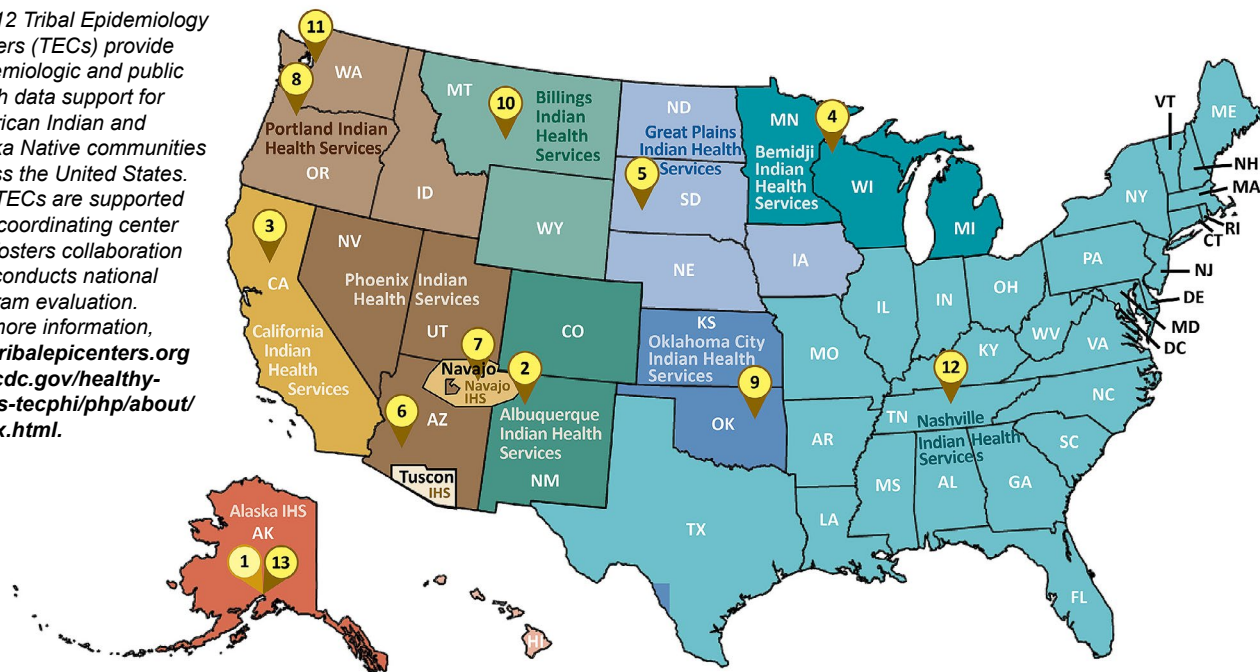
includes being transparent about what the findings mean and involving leaders, partners and the community in making decisions based on these findings. Sharing findings and being open about decision making helps build trust with the community, creates a sense of ownership and gives community partners information to change course when needed to improve outcomes.⁸⁵

Tribal Epidemiology Centers (TECs) are another valuable resource. TECs are public health authorities that work to “improve public health capacity and the availability of valid and reliable data in AI/AN populations.”⁸⁶ The twelve TECs are a valuable resource for the area Indian health boards, tribes and urban communities they serve as they can help manage public health information systems and investigate diseases of concern, among other services (see Figure 5, page 44).^{86,87}



Figure 5: Map of Tribal Epidemiology Centers

The 12 Tribal Epidemiology Centers (TECs) provide epidemiologic and public health data support for American Indian and Alaska Native communities across the United States. The TECs are supported by a coordinating center that fosters collaboration and conducts national program evaluation. For more information, see tribalepicenters.org and cdc.gov/healthy-tribes-tecphi/php/about/index.html.



PRINCIPLES OF DATA SOVEREIGNTY^{88,89,90}

Tribal data sovereignty emphasizes the inherent right of tribes to control the collection, ownership, and application of data related to their communities. Supporting tribal self-determination allows tribes to manage and govern their own data for public health purposes. Tribes can ensure data are used in culturally appropriate ways that address historical harms while respecting traditional knowledge systems. State and local health departments can honor sovereignty by developing equitable data sharing agreements that ensure tribes have the authority over how data are shared and used.

NATIONAL DATA SOURCES

The Behavioral Risk Factor Surveillance System (BRFSS) is a telephone (landline and cellular) survey conducted annually in all 50 states, the District of Columbia and participating U.S. territories to collect information on health-related behavioral risk factors, health care access and chronic conditions among noninstitutionalized U.S. adults aged 18 years or older. These data are collected at the state level and can be analyzed looking specifically at state residents that selected AI/AN as their racial identification. Several studies have used oversampling of AI/AN peoples to examine variations in health and health-related behaviors by IHS region and for some larger tribes.^{91,92} Two BRFSS modules that produce actionable data across the United States are the Cognitive Decline and Caregiver Modules. Data from these modules can be accessed through the Alzheimer's Disease and Healthy Aging Data Portal at cdc.gov/healthy-aging-data.

Healthy People 2030 (HP2030)⁹³ is the framework that sets the nation's disease prevention and health promotion objectives for the next decade. Three of these objectives focus on cognitive decline and dementia:⁹⁴

- DIA-01:** Increase the proportion of older adults with dementia, or their caregivers, who know they have it.
- DIA-02:** Reduce the proportion of preventable hospitalizations in older adults with dementia.
- DIA-03:** Increase the proportion of adults with subjective cognitive decline who have discussed their symptoms with a provider.

Chronic Disease Indicators (CDI) provides surveillance data to track chronic diseases and their risk factors at the national and state level. It compiles estimates from various data sources, including surveys, vital records and administrative data, using standardized definitions to allow comparisons at national and state levels. CDI includes the BRFSS Cognitive Decline and Caregiver Modules.⁹⁵

Population Level Analysis and Community Estimates (PLACES) generates modeled estimates of the prevalence of health conditions and behaviors at four levels: census tract, county, place and zip code. This allows local jurisdictions, regardless of population size and rurality, to better understand the burden and geographic distribution of health measures in their areas and assist in planning public health interventions.⁹⁶ While it does not currently include cognitive decline, it does include data on numerous risk factors.

The National Alzheimer's Coordinating Center (NACC) was established by the National Institute on Aging (NIA) to facilitate collaborative research and to record the cumulative enrollment of the NIA-funded Alzheimer's Disease Centers. Using data collected from these Centers across the United States, NACC has developed and maintains a large relational database of standardized clinical and neuropathological research data.⁹⁷

When using national datasets, it is important to look at the original sources of the data to understand if the data are applicable to a specific AI/AN community.⁹⁸



P DOMAIN:

Strengthen Policies and Relationships

OUTCOME: Increase community partnerships

P-I Build relationships within and outside of the health and public health sectors to strengthen sustained commitments to brain health and its physical, mental, emotional and spiritual impacts across the life course.

OUTCOME: Increase policy action and implementation

P-II Engage AI/AN leaders to increase awareness about the indigenous and social determinants of

health associated with brain health, dementia and caregiving.

P-III Equip AI/AN leaders with policy options to improve brain health across the life course and reduce stigma about dementia.

OUTCOME: Increase integration with other chronic disease efforts

P-IV Build on existing AI/AN chronic disease, aging and disability programs and policies to include brain health.

The development of the HBI Road Map for AI/AN centered around who we are as AI/AN, how we need to protect our rights as political and racial entities while providing an attainable working document for professionals addressing brain health and dementia within our communities in the most efficient, effective ways of best practices.

Twila Martin Kekahbah (Turtle Mountain Band of Chippewa), Leadership Committee

This domain focuses on engaging and involving multiple groups, including tribal and urban leaders, Elders and other community partners, to support brain health across the life course. The public health function of convener, bringing together multiple groups from across communities, has been successfully used for decades to build relationships to address chronic diseases.

Building relationships within and outside of the health and public health sectors — such as faith-based communities, small businesses and schools — can be helpful in many ways. In the context of brain health, these relationships can strengthen efforts to address indigenous and social determinants of health⁹⁹ and improve equitable access to healthy and safe neighborhoods and environments. They can also provide access to community resources that encourage socialization, especially for people living alone, with disabilities or in areas with limited

transportation options. In addition, these relationships can increase awareness about the indigenous and social determinants of health in the community and the opportunities for integrating cultural practices to improve health.

Partnerships begin by listening and learning. Conversations with a community about dementia should include people living with dementia, their families and caregivers. In some cases, new coalitions or collaborations may need to be created. In others, existing coalitions could broaden their membership or expand their scope to address brain health, dementia and caregiving. Places to start include tribal-led coalitions, Tribal Epidemiology Centers, Area Indian Health Boards, Title VI programs, state Alzheimer's disease coalitions and Building Our Largest Dementia (BOLD) Infrastructure program coalitions. Strong relationships with state and community agencies can



BUILDING RELATIONSHIPS

When building relationships, it is important to include voices from different types of groups in the community. Consider these different categories of community groups when thinking about how to expand relationships:

- Caregivers and people living with dementia
- Government and public safety
- Groups focused on Elders or older adults
- Groups focused on improving health in the community
- Groups focused on youth and intergenerational programs
- Health care professionals
- Media
- Nonprofits supporting the community
- Professional associations
- Tribal colleges and universities

improve timely access to programs and provide critical links to valuable services. Recognizing community-clinical linkages between community-based programs and clinical services, and using them as a bridge for relationship building and connection, can have a pivotal impact.

Tribal and urban leaders and Elders can be helpful in identifying policy options that promote brain health across the life course and support the health and well-being of caregivers. Policy options might address funding gaps, gaps in existing policy, resource scarcity, insufficient infrastructure and Elder safety. One example of a policy opportunity is Health in All

Policies, a collaborative approach that integrates and articulates health considerations in policies across sectors to improve the health of all communities and peoples.¹⁰⁰ There are many opportunities for inclusion of dementia in a Health in All Policies approach, since policies related to dementia have only recently been included in public health initiatives. Educating tribal leaders and elected officials about healthy aging, dementia risk reduction and the impact of indigenous and social determinants of health on brain health can stimulate their understanding and motivate policy action. Sharing existing policies within and across communities with AI/AN leaders helps build on their collective experience and spark new ideas.



Advancing Brain Health Together

Improving the brain health of AI/AN peoples and improving the quality of life of AI/AN people with dementia and their caregivers requires strong commitment at all levels of public health. The actions presented in this Road Map focus on specific ways professionals conducting public health work with tribes and urban Indian organizations can improve outcomes for brain health, dementia and caregiving in their communities. In addition to this community-level focus, there is an important role for national organizations including federal, nonprofit and tribal-serving organizations to both accelerate and support this progress. Thinking about the role of national organizations in the context of the domains, the following paragraphs describe potential collaborative actions and activities.

E — Engage Communities and Share Knowledge

The actions in the E domain focus on increasing awareness about brain health, early detection and resources and support for people living with dementia and their caregivers. Federal and other national partners can accelerate this work by **developing national awareness campaigns to reduce stigma around memory loss for American Indian and Alaska Native peoples**. As seen with other national campaigns, like *Hear Her*,¹⁰¹ awareness efforts are most successful when there are options to tailor messaging for specific AI/AN communities. The E domain also includes actions that focus on AI/AN communities working with local schools. National organizations can support and build on this work by **partnering with state and national tribal education associations, federal agencies and nongovernmental organizations to include brain health and dementia in elementary, secondary and post-secondary school curricula**. Such curricula could inspire AI/AN youth to enter science, public health and health care related professions in addition to providing information on brain health and dementia.

W — Build a Representative and Skilled Workforce

Actions in the W domain focus on providers and other direct service workers working in AI/AN communities. National organizations can help increase the number of workers through educational and certification initiatives and by reaching providers while they are in training. They could partner with nursing and medical associations and providers, such as the Indians Into Medicine program or the Association of American Indian Physicians, **to include education on cultural humility and ways to approach early detection and care management of dementia in AI/AN communities**. Efforts can also be taken to **increase the number of AI/AN peoples pursuing medical and nursing education by partnering with tribal colleges**. National organizations can **train current and future public health professionals about AI/AN communities' strength-based approach to brain health and ways to integrate this information with other chronic disease prevention strategies**.

M — Measure, Evaluate and Use Data

Actions in the M domain focus on data collection and the use of that data to make informed public health decisions. Tribal data sovereignty is an important consideration when undertaking these actions. State, local and tribal governments may need more education about data issues. National organizations can play a role by **educating state and local health officials about tribal data sovereignty and appropriate ways to share and collaborate on the collection, analysis and use of data to benefit AI/AN communities.**

P — Strengthen Policies and Relationships

Actions in the P domain focus on the importance of educating tribal leadership about brain health and building cross-sector partnerships. At the national level, work can be done to **support direct funding to AI/AN communities to implement public health interventions focused on brain health.** National funding opportunities from a variety of federal agencies — such as the National Healthy Brain Initiative (CDC), Building Our Largest Dementia Infrastructure for Alzheimer’s Act (CDC), Geriatric Workforce Enhancement Program (HRSA), Alzheimer’s Disease Programs Initiative (ACL) and Alzheimer’s Disease Dementia Program (IHS) — have allowed for the acceleration of this work. The actions in this Road Map can be used to help guide those funding opportunities and create additional opportunities for both federal and nongovernmental funding organizations.

Working together, national, state, local and tribal entities can help shift perceptions of dementia, reduce stigma about cognitive decline, increase knowledge and skills of the workforce and improve early detection and diagnosis. Combining the strengths of AI/AN peoples and the tools of public health can make a difference in brain health across the life course.

FEDERAL RESOURCES TO SUPPORT USE OF THE ROAD MAP

Administration for Community Living/Alzheimer's Disease Programs Initiative (ADPI)

This program supports the development and delivery of home and community-based programs designed to support people living with Alzheimer's and other dementias and their caregivers. ADPI funds the creation and evaluation of culturally competent supports, services and education designed to improve the quality of life for affected people, including their caregivers.

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

The Title VI program provides essential funding to support nutrition, supportive services and caregiver support services for American Indian and Alaska Natives, including those living with dementia. Through this program, tribes and tribal organizations can develop culturally tailored services, such as specialized care and support systems, to address the unique needs of people living with dementia, ensuring they receive compassionate and effective care within their communities.

Centers for Disease Control and Prevention

More states, jurisdictions and tribes are creating, updating and implementing strategic plans that address brain health, cognitive impairment, dementia and caregiving. Their work has been accelerated with the passage of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (Public Law 155-406) in 2018. The BOLD Act supports public health efforts to strengthen systems, environments and policies that promote risk reduction, improve early

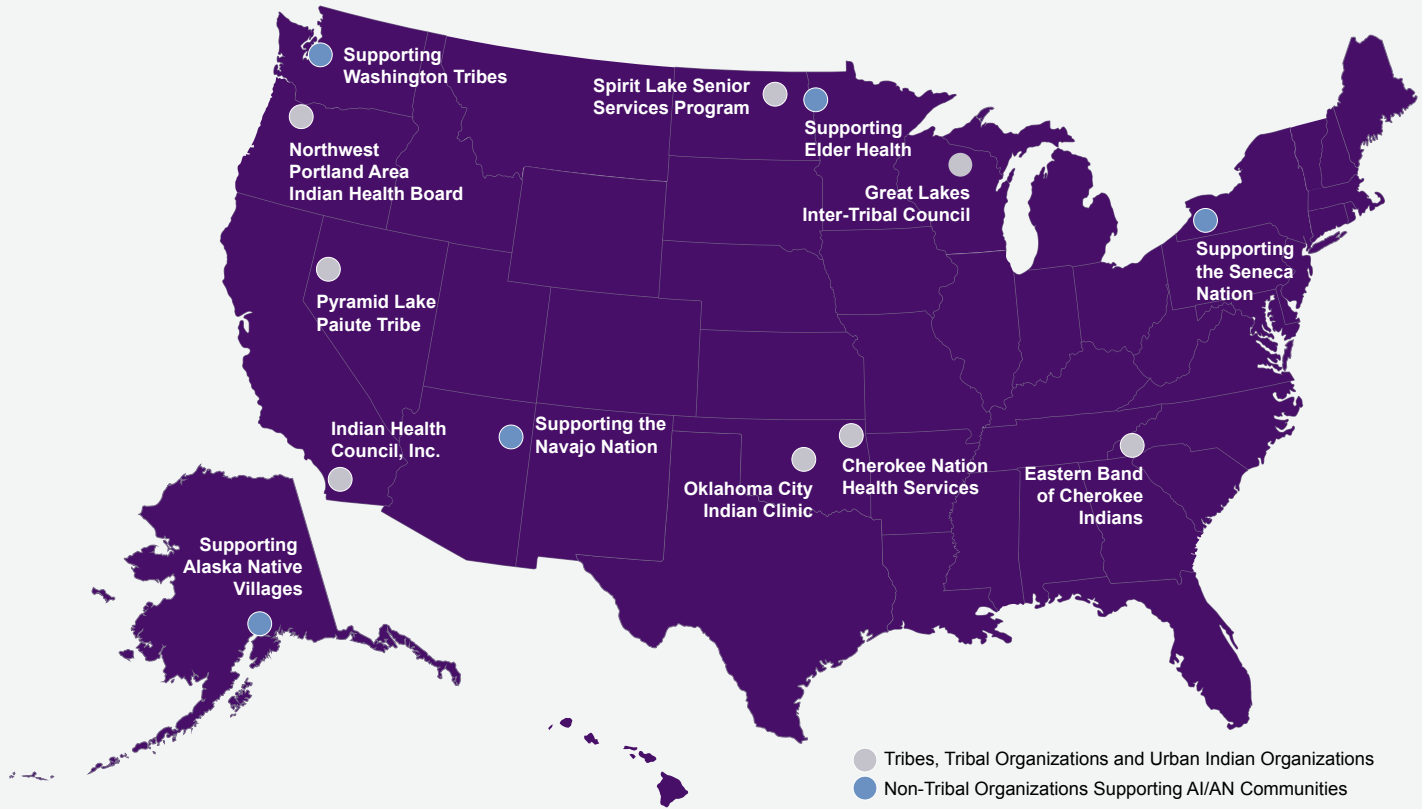
detection and diagnosis, prevent and manage comorbidities, avoid preventable hospitalizations and support dementia caregiving. This work is supported by resources such as this Road Map, which is funded by the CDC's National Healthy Brain Initiative program. Implementation of the Road Map is accelerated by the BOLD Act public health program recipients.

Health Resources and Services Administration/ Geriatrics Workforce Enhancement Program

The purpose of the Geriatrics Workforce Enhancement Program is to educate and train the health care and supportive care workforces to care for older adults by collaborating with community partners to maximize patient and family engagement, address care gaps and improve health outcomes for older adults. The Program integrates geriatrics with primary care and other appropriate specialties using the Age-Friendly Health Systems Framework.

Indian Health Service/Alzheimer's Disease and Dementia Program

This program offers funding for the development of care and services for people living with dementia and their caregivers and for initiatives in workforce development and training. In addition, IHS funding to support diabetes prevention and treatment, health promotion and disease prevention, and fall and injury prevention are directly applicable to efforts to preserve brain health and prevent injury in those living with cognitive impairment and dementia. Many other IHS programs are integrating cognitive impairment issues into the services they provide.



Communities in Action

These stories highlight a sampling of recent efforts by and with AI/AN communities to implement Road Map actions. The map shows the location of the communities and the icons at the beginning of each story indicate the corresponding domains of the Road Map.

Cherokee Nation Health Services

Utilizing Patient Navigators to Support People Living with Dementia and Their Caregivers

Domains:



Cherokee Nation Health Services (CNHS), a department of the Cherokee Nation, is committed to providing patient-centered care to all its citizens, especially those living with dementia and their caregivers. Navigating health care can be challenging for this population, so CNHS has expanded its Patient Experience Team with the help of Indian Health Service (IHS) funds through the “Addressing Dementia in Indian Country” grant. A key aspect of this program is the addition of a full-time Patient Navigator who focuses solely on dementia patients or others with cognitive decline and their caregivers, as well as anyone with questions regarding dementia.

The Patient Navigator works closely with patients and their caregivers, forming meaningful relationships to better understand and address their unique needs. Recognizing that everyone’s needs are different, the Patient Navigator meets with the patients on-site, virtually or by phone or email. This role includes helping patients navigate clinical care, working with providers and collaborating with other tribal departments such as Human Services, which oversees senior nutrition programs, and the

Housing Authority, to connect patients with resources for in-home care. Additionally, the Navigator partners with external organizations, including the Alzheimer’s Association and the Program of All-Inclusive Care for the Elderly (PACE), to provide access to respite care and other essential services.

This expanded service also includes efforts to raise awareness about dementia within the Cherokee community. The Patient Navigator plays a key role in community outreach, facilitating caregiver support groups and developing educational programs that aim to reduce stigma and provide insight into living with memory loss. Support groups, held monthly within the Cherokee Nation, offer a more accessible option for citizens to receive help. The grant has also allowed the development of a media campaign to promote early recognition of, and intervention on, dementia, as well as financial aid for transportation and durable medical equipment for qualifying patients. By fostering partnerships, increasing resources and providing personalized assistance, CNHS is significantly enhancing care for individuals living with dementia and their families.



Eastern Band of Cherokee Indians

Supporting Elders Through Community and Culturally Centered Long-Term Care

Domains:



Aging in place is often the preference for American Indian and Alaska Native Elders, yet it is not always feasible. The Eastern Band of Cherokee Indians recognized the need for culturally centered long-term care and established the Tsali Care Center as part of the Cherokee Indian Hospital Authority. Originally a 72-bed facility, it has transformed into a state-of-the-art 120-bed center in Cherokee, North Carolina, providing skilled nursing, assisted living and a dedicated memory care unit.

Guided by extensive community input through listening sessions, the new 135,000-square-foot center reflects the community's needs and preferences, incorporating natural lighting, cultural artwork and spaces fostering family connections. This community-driven approach, supported by tribal leadership through regular health board meetings, ensures that every decision honors Cherokee values, including the “sense of place.” Cultural traditions and respect for Elders remain central.

The Tsali Care Center's memory care unit exemplifies its commitment to residents living with dementia. With

private rooms and amenities like a Snoezelen room — designed to promote relaxation and reduce anxiety — the facility offers a nurturing, stigma-free environment that preserves dignity and independence through everyday activities such as cooking and laundry. This innovative approach addresses the complex needs of memory care patients while fostering an atmosphere of safety and familiarity.

To tackle workforce challenges in rural health care, the Tsali Care Center collaborated with universities and colleges to create health care career pathways, including Certified Nursing Assistants. In-house training programs allow existing staff to advance their careers while staying employed, demonstrating a commitment to staff development and retention.

Through strategic investments in community engagement, tribal leadership collaboration and workforce innovation, the Tsali Care Center sets a benchmark for compassionate, culturally centered Elder care.



Great Lakes Inter-Tribal Council

Partnering for a Comprehensive Approach to Dementia Care

Domains:



The Great Lakes Inter-Tribal Council (GLITC), serving 12 tribes in Wisconsin and Michigan, has developed culturally responsive dementia resources for tribal communities. A series of educational videos, created through informal discussions with tribal Elders, reflects the community's values and voices. These videos resonate with Elders and their caregivers as they incorporate traditional wisdom and storytelling, with one notable animated video that explains the journey through dementia. The Great Lakes Elders Association meetings were pivotal in shaping these resources, providing a forum for Elders to share their experiences. The videos, widely approved and used in tribal staff and caregiver trainings, are featured alongside the Savvy Caregiver in Indian Country program.

GLITC also adapted Wisconsin's dementia training for tribes and created the 80-page Tribal Dementia Care Specialists Toolkit. Released in May, the toolkit offers guidance on cultural practices like smudging, a ceremony used to cleanse and purify people and places, and provides tools for engaging with Elders in a culturally respectful way. It helps Tribal Dementia

Care Specialists address the unique needs of their communities and ensures continuity of care during staff transitions.

Regular meetings between GLITC staff and Tribal Dementia Care Specialists focus on supporting caregivers and people living with dementia. These efforts have reduced the stigma around dementia, encouraging more open conversations. The growing need for trained specialists is recognized, and GLITC is working on a Care Partner Guide to assist caregivers in navigating dementia care.

GLITC has also extended education into schools, offering sessions on brain health and promoting intergenerational learning. In June 2024, Elders discussed the role of cultural practices in maintaining mental, physical, emotional and spiritual balance. Insights from this discussion will be incorporated into a medicine wheel that will be shared with the community to promote ongoing brain health.

GLITC Videos can be found at glitc.org/programs/aging-disability/resources/.

Indian Health Council, Inc.

Integrating Cognitive Health into Existing Programs

Domains:



The Indian Health Council, Inc. (IHC) is addressing the cognitive health needs of its communities by leveraging funding from the Indian Health Service's Special Diabetes Program for Indians and dementia resources. IHC serves nine federally recognized tribes in San Diego's North County, covering 1,500 square miles. To support these communities, IHC hired a Cognitive Health and Wellness Nurse whose focus is assessing cognitive health and screening for dementia.

A significant challenge is overcoming the distrust in health care systems due to generational trauma, making it hard to encourage cognitive health assessments. Structural issues, such as an electronic health record not including the designation of a health care representative noted in the chart, can limit family members' ability to discuss cognitive health with the medical team. Despite these hurdles, the nurse collaborates with other health care providers, including diabetes teams who already have strong community relationships, to encourage cognitive screenings. Through home visits with Community Health Representatives, early signs of possible cognitive decline are detected more effectively.

In the clinic, the nurse uses the Saint Louis University Mental Status test and similar tools during Medicare Annual Wellness Visits for all patients and the Mini-Cog® for patients at risk of dementia but without a formal diagnosis. Weekly case management meetings and educational outreach to families help build trust and raise awareness of cognitive health. The nurse's work is supported by participation in ECHO sessions, outreach events and specialized training such as the Indian Health Geriatric Nurse Fellowship Program.

Despite limited neurology specialists, staffing shortages and the large geographic area, IHC's collaboration between its Special Diabetes Program and the Cognitive Health and Wellness Nurse is helping break down barriers to dementia care. Looking forward, IHC plans to use a mobile clinic van to bring assessments by health care professionals to patients' homes, along with Elder safety checks and face-to-face education. In addition to attending tribal council and Elder meetings in their community, IHC plans joint meetings with the Indian Health Service, the Veterans Administration, the Alzheimer's Association and other organizations to continue building partnerships.



Northwest Portland Area Indian Health Board

The Northwest Tribal Elders Project Building Our Largest Dementia (BOLD) Infrastructure

Domain:



The Northwest Tribal Elders Project works with the Northwest tribes to ensure that Pacific Northwest tribal Elders receive satisfactory health and wellness services and resources. The project is currently funded through a cooperative agreement from the Centers for Disease Control and Prevention that focuses on capacity building, program and policy development; mobilizing partnerships; providing health education and promotion; and training and technical assistance to member tribes in areas that will enhance community development and health equity.

The goals of this project are to:

- Strengthen and foster growth of the dementia workforce at the tribal community level.
- Support Northwest tribes to promote Alzheimer's disease and related dementias risk reduction, early detection and caregiver support strategies.
- Implement clinical and community-based prevention programs.
- Provide training and technical assistance.
- Provide ongoing education and learning opportunities for individuals needing care, caregivers and clinical providers.

As part of this work, they have hosted two annual summits bringing together youth, Elders, caregivers, community health representatives, adult protection and public safety workers, social workers, clinical providers, nonprofit partners and tribal leaders to discuss brain health and dementia. The goal of creating this space was to come together and share resources to support community-based programs for brain health and dementia, hear from Elders and Northwest tribes on collaborating to better address community health needs, hear from leading national Indigenous brain health researchers, and organize the Northwest Brain Health Coalition for health advocacy. Key themes discussed were risk reduction, early detection and caregiver support. Through this gathering, they are building a regional network to address gaps in knowledge and awareness to prevent and address dementia within their tribal communities.

Over 100 people have attended the 2-day summit each year. At the summit, important questions were raised by Elders, including: "How are we preparing our tribal communities and workforce to recognize and respond to the growing population of Elders living longer and who may experience the signs and symptoms of dementias?". The community stories, strengths and learnings from the summits will continue to guide the work of the Northwest Tribal Elders project in the coming years.

Oklahoma City Indian Clinic

Providing a Complete Care Pathway for People Living with Dementia and their Caregivers

Domains:



Oklahoma City Indian Clinic is launching a pilot program to integrate dementia care — traditionally managed by neurology specialists — into primary care. Led by a clinical nurse manager working with an internal medicine physician, pharmacist and social services manager, the program focuses on education, support, holistic care and medication management.

Education is a key element, with classes offered in partnership with the Alzheimer's Association. Topics include *Healthy Living for Your Brain and Body*, *Understanding Alzheimer's and Dementia* and *Ten Warning Signs of Alzheimer's*. These aim to raise awareness and provide steps for risk reduction. As the program grows, additional classes will cover the middle and late stages of dementia, financial planning and caregiving strategies.

Support is provided through two concurrent support groups — one for caregivers and another for people living with dementia. Caregivers receive emotional support while those living with dementia participate in monitored activities such as painting and music,

offering respite for caregivers and meaningful engagement for patients.

The clinic also promotes holistic care with activities that support brain health. These include cooking classes for healthy eating, physical activities such as Moccasin Movers (a movement class for Elders), Tai Chi and dancing. These fun, community-based activities aim to reduce cognitive decline through healthy lifestyle choices.

Medication management is integral to the program. Donepezil and Memantine are often prescribed, with the clinical team closely monitoring patient responses and adjusting dosages as needed. Follow-ups occur at 30, 90 and 180 days, with annual reviews once a stable dosage is reached.

The Oklahoma City Indian Clinic's dementia care program is looking to expand to address broader needs, including a medically tailored meal program, and ultimately to become a national model for integrating dementia care into primary care settings.



Pyramid Lake Paiute Tribe

Preventing Wandering Among Tribal Elders Living with Dementia

Domains:



In 2022, the Pyramid Lake Paiute Tribe (PLPT) partnered with the International Association for Indigenous Aging (IA²) on a dementia wandering prevention project funded by the federal Department of Justice's Kevin and Avonte Program. Originally focused on autism, the grant was expanded to address dementia-related wandering. PLPT has had a strong relationship with IA² through prior collaborations, including Dementia Friends Training.

The Tribal Elder Safety Net Project, the first tribal-based initiative funded by the Department of Justice, aims to prevent wandering among tribal Elders with Alzheimer's disease and related dementias (ARD). The project focuses on creating a comprehensive wandering search and rescue strategy for the PLPT reservation in Northern Nevada and developing a guide to assist other tribes nationwide.

IA² and the Pyramid Lake Numaga Senior Center designed person-centered, culturally appropriate wandering prevention activities. The pilot project includes developing educational materials,

conducting a training series, creating missing person protocols, building an Elder profile database and holding a mock search operation. The target audience includes Elders with ARD, their caregivers, tribal police and first responders.

IA² trained tribal staff from various departments, including social services, police and EMS, on how to handle missing Elder situations. During a training exercise, participants practiced a simulated search for a missing Elder, complete with environmental scans, distribution of flyers and ground searches. The exercise provided valuable insights into how such searches could be adapted for different tribal settings, considering geography and other factors.

The project will continue with further training, interviews with emergency responders, the creation of a toolkit and an Elder profile template. There is potential to expand to include children with autism, as many grandparents in the community are raising grandchildren with autism.

Spirit Lake Senior Services Program

Using a Culturally Centered Approach to Discuss Brain Health

Domain:

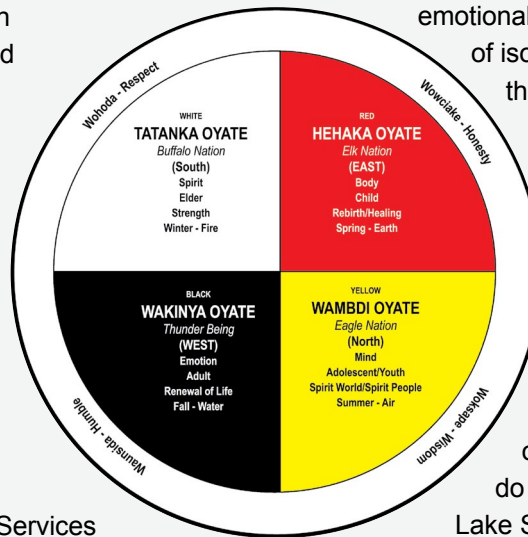


The Spirit Lake Tribe, located in North Dakota, through its Spirit Lake Senior Services Program, has developed a culturally grounded approach to discussing brain health and dementia using the medicine wheel. This medicine wheel serves as a tool to engage tribal Elders in conversations about dementia and cognitive health, drawing on the holistic balance that the medicine wheel represents. Each quadrant of the wheel (body, mind, emotion and spirit) addresses a key area of well-being, helping the Elders better understand how each aspect of their lives can influence brain health and dementia risk.

When discussing risk reduction strategies, the Spirit Lake Senior Services Program uses the medicine wheel to focus on practical actions for each quadrant. For the body, they emphasize the importance of a healthy diet, regular physical activity and the avoidance of commercial tobacco use, all of which can reduce the risk of

dementia. For the mind, Elders are encouraged to stay mentally active by learning new things and engaging in activities that challenge their cognitive abilities. The emotion quadrant highlights the significance of staying connected with friends and family, promoting emotional well-being and reducing feelings of isolation. Finally, in the spirit quadrant, the wheel fosters conversations about maintaining spiritual well-being through cultural practices, which helps promote balance and purpose, contributing to overall brain health.

Since using the medicine wheel as a teaching tool, community members and Elders are more open to talking about dementia and do not seem as scared. The Spirit Lake Senior Services Program also uses this medicine wheel for Elder abuse and other chronic diseases, as the framework is similar. This approach helps Elders feel more connected to their traditions while providing them with effective strategies for dementia risk reduction.



Nonprofit Partnerships to Address Alzheimer's Disease and Dementia

Supporting the Vast Navajo Nation Through Videos and Radio Broadcasts

Domain:



Meeting the needs of Navajo Elders with Alzheimer's and related dementias requires a multifaceted, community-driven approach rooted in trust, collaboration and accessibility. Two key projects exemplify this strategy.

The So' Tsoh Foundation, working with caregivers for over a decade, recently focused on end-stage Alzheimer's care. With a grant from Duet, Partners in Health and Aging and collaboration with professionals and caregivers across the Navajo Nation, the Foundation translated educational videos into the Diné language, ensuring cultural relevance. These videos, featuring Diné narration and English subtitles, debuted at a caregiver summit and were praised for their cultural sensitivity and use of Navajo humor. The videos provide not only practical advice but also a sense of cultural representation, helping caregivers connect emotionally and practically. The Foundation continues to offer in-person and virtual support to ensure accessibility for all caregivers.

The second project, led by the Alzheimer's Association Utah Chapter, addresses the challenges of supporting dementia care in Utah's remote Navajo communities. Due to the vast geography of Grand County and limited internet access, the chapter relies on radio to reach Elders. Culturally relevant Public Service Announcements in Diné are broadcast on local radio stations, which are more accessible for many than the internet. The Alzheimer's Association works closely with local translators to ensure accuracy and cultural appropriateness of the translations.

Both projects highlight the importance of deep community engagement, culturally sensitive approaches and adaptability. The ongoing efforts of the So' Tsoh Foundation and the Alzheimer's Association Utah Chapter reflect the need for sustained, flexible solutions to support Navajo Elders living with dementia that address their unique challenges and foster a sense of cultural connection.

Nonprofit Partnerships Driven by Caregiver Needs

Supporting Caregivers in Seneca Nation

Domains:



The Alzheimer's Association Western New York Chapter has been collaborating with the Seneca Nation Area Office for Aging (AOA), a program of the Seneca Nation of Indians dedicated to providing services and support for Elders and caregivers. This partnership has made significant strides in promoting brain health and supporting caregivers within the Seneca Nation community.

The collaboration began with a request from the Seneca Nation to assist a caregiver struggling with the emotional and mental burdens of caregiving. In response, the Alzheimer's Association introduced education programs for AOA staff to help them understand caregiver needs and feel more confident supporting caregivers in their community.

The success of these initial efforts inspired a broader initiative, including community forums focused on the unique needs of Elders and their caregivers. Co-hosted by the Alzheimer's Association and the Seneca Nation AOA, these forums provided an opportunity for community members to share their

experiences and concerns related to brain health, dementia, and caregiving challenges. The forums were well-received, drawing dozens of participants and emphasizing the need for further programming on dementia and the importance of early detection.

As a result, the Alzheimer's Association Western New York Chapter developed an ongoing series of educational programs tailored specifically to the Seneca Nation. These programs focus on early detection, the diagnostic process, and caregiver support. Many participants have expressed relief in understanding dementia as a progressive brain disease rather than a normal part of aging. This growing awareness has fostered stronger trust within the community, encouraging Elders and caregivers to engage more actively in learning about brain health.

This partnership has also enhanced collaboration with the Seneca Nation's health system. Together, the two are working to implement dementia screenings and advance quality improvement efforts to better meet the community's unique needs.



State Health Departments

Partnerships to Support AI/AN Communities in Alaska and Washington State

Domains:



State departments of social and health services in Alaska and Washington state are collaborating with American Indian and Alaska Native (AI/AN) communities to address Alzheimer's disease and related dementias (ADRD) through culturally centered strategies. These partnerships ensure that AI/AN needs are incorporated into statewide dementia care plans, promoting equitable access to resources and support.

In Washington, the Department of Social and Health Services worked closely with tribal communities to develop the 2023–2028 Washington State Plan to Address Alzheimer's Disease and Other Dementias. Tribal Liaisons helped integrate recommendations specific to AI/AN populations, such as providing culturally relevant support for AI/AN caregivers and building a dementia-capable workforce within tribal health care systems. Tribal listening sessions and partnerships with leaders ensured that Washington's dementia strategy reflects AI/AN cultural strengths.

Similarly, Alaska's Department of Health has launched initiatives focusing on education, risk reduction and infrastructure building to address ADRD among Alaska Natives. A brain health curriculum for schoolchildren teaches dementia prevention and cognitive health, incorporating culturally relevant content. The Department also promotes brain-healthy behaviors through a media campaign in Alaska Native languages, including Yup'ik and Iñupiaq.

Both states are improving data collection on ADRD in AI/AN communities. Alaska is conducting a landscape assessment to identify data gaps, particularly for rural populations, while Washington integrates tribal perspectives into its data strategies through the Dementia Action Collaborative.

These efforts demonstrate the importance of state-tribal collaboration in developing dementia care programs tailored to the unique cultural and health needs of AI/AN communities. By working with tribes, both states are creating more inclusive and effective dementia care strategies that honor tribal traditions.

University Partnerships

Supporting Elder Health and Caregivers

Domains:



The University of North Dakota's National Resource Center for Native American Aging (NRCNAA), a resource center funded by the Administration for Community Living, focuses on addressing the unique needs of Native Elders through education, training and technical assistance. The Center assists in developing community-based solutions to improve the quality of life and the delivery of supportive services to the Native aging population. The Native Elder Caregiver Curriculum, which is available virtually or in person on request, is a culturally tailored training designed to equip caregivers with the skills needed to care for Native Elders. This curriculum focuses on the physical, emotional and cultural needs of Elders, including managing chronic conditions, dementia care and end-of-life issues. The program emphasizes traditional values and caregiving practices, helping both family and professional caregivers deliver respectful, holistic care that honors Native customs.

In response to the growing need for Elder care in tribal communities, the NRCNAA's Resource Center on Native Aging and Disability is designed to help tribal communities and organizations build self-sustaining supportive programs for Native Elders and adults with disabilities.

Additionally, NRCNAA offers Wise Elders Living Longer (WELL) Balanced training, which is designed to help Elders prevent falls, manage chronic conditions, engage in social activity and increase their level of physical exercise. The WELL-Balanced strategies use exercise, education and social interaction to help Elders improve balance and mobility, reducing the risk of falls — a critical concern for aging populations. The training helps Elders remain active and independent in their own homes as long as possible.

By providing these tailored programs, NRCNAA addresses the urgent need for qualified caregivers in Native communities. Their comprehensive training equips caregivers with knowledge and tools to improve the quality of care for Native Elders, ensuring culturally appropriate support that respects traditional practices. Through these initiatives, NRCNAA is building a stronger workforce that is well-prepared to meet the challenges of aging in Native communities, helping Elders live healthier, safer lives with dignity.

More information about the NRCNAA, their resources and trainings can be found at nrcnaa.org/.

Glossary

Key terms in the Road Map are defined below. Each definition reflects the term's specific use and intent within the Road Map and may differ in other contexts.

Alzheimer's disease is an irreversible, progressive brain disorder caused by damage to neurons in the brain. It is the most common cause of dementia. Early symptoms include difficulty with memory and thinking. As the disease progresses, symptoms include impaired communication and judgment, confusion, behavior changes and challenges with basic bodily functions. Symptoms usually develop slowly and worsen over time, becoming severe enough to interfere with daily tasks. Alzheimer's disease is fatal.

Alzheimer's disease and other dementias include Alzheimer's disease as well as vascular contributions to cognitive impairment and dementia (VCID), Lewy body dementia (LBD), frontotemporal dementia (FTD), Parkinson's disease, hippocampal sclerosis, mixed etiology dementias (MED) and many other less common diseases, disorders and conditions that can result in dementia. This term is sometimes referenced as ADRD (Alzheimer's disease and related dementias) in scientific publications.

Brain health is a concept that involves making the most of the brain's capacity and helping to reduce

some risks that occur with aging. Brain health refers to the ability to draw on the strengths of the brain to remember, learn, play, concentrate, understand and maintain a clear, active mind.

Caregivers provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis. The recipients of care can live either in the community or institutional settings, range from children to older adults and have chronic illnesses or disabling conditions. Because of their partnership with people living with dementia in making joint decisions to enhance their care and quality of life, caregivers can also be referred to as "care partners" or "carers." Because caregiving is a common part of AI/AN family culture, the term caregiver is not often used. Many tribal nations do not have a specific word for caregiving, using community, family or Elder helper instead. Whenever caregiver (or caregivers) is used in this Road Map, it means the unpaid person (or group of people) caring for a person living with dementia. This can be a direct family member, friend or relative and is often more than one person.

Caregiving for people living with dementia is unpaid help provided by spouses, partners, adult children, other relatives and friends to people living with dementia. Caregivers for people living with

dementia often assist with activities of daily living such as personal care, household management, medication and health care management and coordination of financial matters.

Cognitive decline is changes in memory, thinking and/or reasoning that are worsening over time. Some decline is a natural part of aging (“age-related cognitive decline”), but cognitive decline and dementia caused by Alzheimer’s or another condition is not a normal part of aging.

Cognitive functioning is a combination of mental processes that includes the ability to learn new things, intuition, judgment, language and remembering.

Cognitive health is present when cognitive functioning is working well and making the most of the brain’s ability to remember, learn, play, concentrate and maintain a clear, active mind.

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

Comorbidities refer to when a person has more than one disease or condition at the same time. Conditions described as comorbidities are often chronic or long-term conditions. Other names to describe

comorbid conditions are coexisting or co-occurring conditions and sometimes multimorbidity or multiple chronic conditions.

Community-clinical linkages are connections between community and clinical sectors that aim to improve health within a community. They are an effective, evidence-based approach to preventing and managing diseases such as Alzheimer’s and other dementias.

Dementia is a general term for a particular group of symptoms, including difficulties with memory, language and skills that are severe enough to interfere with daily life. Alzheimer’s disease is the most common cause of dementia. Other causes include vascular contributions to cognitive impairment and dementia (VCID), Lewy body dementia (LBD), frontotemporal dementia (FTD), Parkinson’s disease, hippocampal sclerosis, mixed etiology dementias (MED) and many other less common diseases, disorders and conditions that can result in dementia.

Disease prevention levels are opportunities for public health intervention that include primary (e.g., dementia risk reduction), secondary (e.g., early detection and diagnosis; linkages to treatment, care and services) and tertiary prevention (e.g., prevention and

management of comorbidities leading to preventable hospitalizations and poor health outcomes; caregiving for people living with dementia).

Early detection and diagnosis (secondary prevention) aims to identify diseases in the earliest stages, before the onset of more severe symptoms. Public health plays a unique role in building relationships between communities and health systems to assure equitable access for all people to diagnostic services.

Essential Public Health Services describe the 10 public health activities that all communities should undertake. The framework was first developed in 1994 by the Core Public Health Functions Steering Committee, which included representatives from U.S. Public Health Service agencies and other major public health organizations. The latest update to the framework occurred in 2020.

Health promotion is the process of enabling people to increase control over, and to improve, their health. It moves beyond a focus on individual behavior towards a wide range of social and environmental interventions.

Healthy aging is the process by which older adults retain their health and independence, while avoiding

disease and injury. For older adults with chronic diseases and other diseases or syndromes, this includes helping them effectively manage their diseases and avoid complications.

Healthy behaviors are practices that can prevent or reduce the likelihood of a disease or a chronic disease such as not smoking commercial tobacco, maintaining a healthy body weight, being physically active, not drinking alcohol or drinking in moderation and getting sufficient sleep.

Health disparities are preventable differences in the burden of disease, injury, violence or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.

Health equity is the assurance of optimal health for all people.

Indigenous Determinants of Health are the conditions specific and unique to indigenous communities that affect health and well-being.

Lewy body disease is one cause of dementia. It is associated with abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia can result. This is called Lewy body dementia.

Mental health includes emotional, psychological and social well-being. It affects how we think, feel and act. It also helps determine how we handle stress, relate to others and make choices. Mental health is important at every stage of life, from childhood and adolescence through adulthood.

Mild cognitive impairment (MCI) is a medical condition typified by an early stage of memory loss or other type of cognitive ability loss (such as language or visual/spatial perception) in individuals who otherwise maintain their ability to independently perform most activities of daily living. MCI is a part of the continuum of cognitive decline; it can be caused by brain diseases but also can be due to hormonal or nutritional imbalances.

Modifiable risk factors are the lifestyle and behaviors that can reduce or increase a person's chances of developing a disease.

Primary care providers are health practitioners who can diagnose, treat and prevent many conditions and illnesses affecting physical and mental health. In addition to providing preventive health care services, they can manage long-term care for chronic diseases such as diabetes and hypertension.

Provider includes any individual who promotes, protects and improves the health of individuals and communities. This includes health care providers, community health workers, first responders, paid caregivers and others who provide care or services to people living with dementia and/or their caregivers.

Public health approach focuses on improving the health of entire populations across the lifespan, including dementia risk reduction, early detection and diagnosis, prevention and management of comorbidities leading to preventable hospitalizations, community-clinical linkages, referral to services and caregiving for persons with dementia. It also includes building coordinated systems that bind together jurisdiction efforts for dementia and caregiving.

Public health data are information about the population. They are a key tool of public health to help understand populations and communities better. Public health data include demographics, prevalence of diseases and health behaviors, health status, morbidity and mortality.

Respite care is a break from providing care so caregivers can rest, travel, spend time with other family and friends, or engage in work or hobbies. Respite care can take place at home, in a health

care facility, at an adult day care center or in home and community-based care services settings.

Risk reduction (primary prevention) strives to intervene before health effects occur through measures such as vaccinations, altering health risk behaviors (e.g., poor eating habits, lack of exercise) and banning substances known to be associated with a disease or health condition (e.g., asbestos, lead and mercury). Modifiable risk factors are the lifestyle choices and behaviors that can be changed to reduce a person's chances of developing a disease.

Social determinants of health are the conditions in places where people are born, live, learn, work and play. These conditions can have a profound effect on a person's health, including their risk for Alzheimer's disease and other dementias.

Sovereignty refers to the rights of tribal governments to ensure healing, health, welfare and safety of their people and ancestral lands. The practice of sovereignty includes governance practices, both current and traditional, that support wellness for individuals, families, communities and the environment around us.

Stigma is a negative social attitude and social disapproval that can lead unfairly to discrimination against an identifiable group of people, a place or a nation. It is associated with a lack of knowledge, a need to blame someone, fears about disease and death and gossip that spreads rumors and myths.

Subjective cognitive decline is the self-reported experience of worsening or more frequent difficulties in thinking and memory in the past year. It is an early sign of possible cognitive impairment and can be an indicator of future risk of Alzheimer's disease and other dementias.

Systemic inequities are systems, laws, written or unwritten policies and entrenched practices and beliefs that produce, condone and perpetuate widespread unfair treatment and oppression of a specific group of people, with adverse health consequences.

Tertiary prevention includes managing disease after diagnosis to minimize disease progression and negative health and quality of life effects. It also encompasses prevention of complications, support for caregivers and management of comorbidities.



Appendices

APPENDIX A: DEVELOPING THE ROAD MAP

A key feature of the Healthy Brain Initiative Road Map Series is the development process that engages multiple sectors and groups that will use the Road Map to identify priorities, inform strategy and support sustainable implementation and impact. For this Road Map, four methods were used to engage, elicit input and foster collaboration from tribal leaders and communities.

Leadership Committee Meetings: In October 2023, the Alzheimer’s Association and Centers for Disease Control and Prevention (CDC) invited 19 experts and tribal leaders to join the Leadership Committee. The committee convened virtually in November 2023 to inform the open input period (see below) and again in person in March 2024 to review the feedback and provide input on draft actions for the Road Map. The meetings provided an opportunity to share actions being taken to address brain health in tribal and urban communities and opportunities for the future. Committee members discussed a broad spectrum of significant dementia concerns and the role of public health in addressing these concerns. In-depth topics included national efforts that shape health care and data access, the role of caregivers and community members, workforce training needs and the importance and significance of the graphics and images used in the Road Map. The Leadership Committee reviewed two drafts of the full document and met again in August 2024 to provide feedback on the draft and proposed layout. A list of the Leadership Committee members is provided in Appendix B.

Federal Liaisons: In October 2023, a group of nine individuals representing different federal agencies were invited to participate as Federal Liaisons to the Road Map development process. This group attended Leadership Committee meetings and reviewed the draft actions and two drafts of the Road Map. The Federal Liaisons are listed in Appendix B.

Listening Sessions and Open Input Period: To inform the development of this edition of the Road Map, the Alzheimer’s Association invited feedback from tribal and non-tribal public health organizations and individuals. The Association received input from 207 individuals through an online feedback form and virtual listening sessions hosted by Leadership Committee members. This feedback guided the development and initial direction of the document as well as the content for the March 2024 Leadership Committee meeting. The results were shared fully with the Leadership Committee and Federal Liaisons, and a summary was posted on the Association’s website.

Review: This Road Map underwent five rounds of review. It was first reviewed by individuals at the Alzheimer’s Association and CDC, followed by two rounds of review by the Leadership Committee, Federal Liaisons and additional experts. The draft was then reviewed again by the Association and CDC. Finally, the document was reviewed as part of the CDC approval and clearance process. Additionally, the layout and images used in the Road Map were reviewed by the Leadership Committee, Federal Liaisons, the Association and CDC.

APPENDIX B: LEADERSHIP COMMITTEE AND FEDERAL LIAISONS

LEADERSHIP COMMITTEE

Co-Chairs

Carl V. Hill, PhD, MPH

Chief Diversity, Equity and Inclusion Officer
Alzheimer's Association

Lisa C. McGuire, PhD, FAPA, FGSA

Lead Health Scientist, Division of Population Health
Centers for Disease Control and Prevention

Members

Collette Adamsen, PhD, MPA (Turtle Mountain Band
of Chippewa)

Research Assistant Professor
Director, National Resource Center on
Native American Aging
University of North Dakota

Ronny Bell, PhD, MS (Lumbee)

Fred Eshelman Distinguished Professor
Chair, Division of Pharmaceutical Outcomes and Policy
University of North Carolina at Chapel Hill

Bill Benson

President/Executive Director
International Association of Indigenous Aging

Catherine Carrico, PhD

Clinical Associate Professor
Associate Director, Center on Aging
University of Wyoming

Ryan Eagle (Mandan, Hidatsa, Arikara Nation)

Public Health Research Project Manager
American Indian Public Health Resource Center

Abigail Echo-Hawk, MA (Pawnee)

Executive Vice President
Director, Urban Indian Health Institute
Seattle Indian Health Board

Bruce Finke, MD

Elder Health Consultant
Indian Health Service

Will Funmaker, MBA, MLT (ASCP)^{CM} (Ho-Chunk Nation)

Director, Great Lakes Inter-Tribal Epidemiology Center
Executive Director, Great Lakes Area Tribal Health Board

R. Turner Goins, PhD

Ambassador Jeanette Hyde Distinguished Professor
Western Carolina University

R. Kim Hartwig, MD (Nez Perce/Diné/Cowichan)

Medical Director
Nimiipuu Health

J. Neil Henderson, PhD (Oklahoma Choctaw)

Professor Emeritus
University of Minnesota Medical School

Cynthia LaCounte (Turtle Mountain Band of Chippewa)

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

Members (continued)

LaRita Laktonen-Ward, MPH (Alutiiq)

Assistant Director, Alaska Native Epidemiology Center
Alaska Native Tribal Health Consortium

Jessica Lewandowski, MBA (Cherokee Nation)

Patient Experience Manager
Cherokee Nation Health Services

Jordan P. Lewis, PhD, MSW, CPG (Aleut and Sugpiaq,
Native Village of Naknek)

Director of Research/Research Professor
Center for One Health Research
University of Alaska Fairbanks

Twila Martin Kekahbah, MEd (Turtle Mountain Band
of Chippewa)

Independent Contractor
TMK

Julianna Reece, MD, MPH, MBA (Diné/Navajo)

Director, Healthy Tribes Program
Centers for Disease Control and Prevention

Billie Tohee, MLS, LL.M (Otoe-Missouria)

Executive Director
National Indian Council on Aging

Chandra Wilson, MSW (Modoc/Klamath/Yahooskin)

Project Director
Northwest Portland Area Indian Health Board

FEDERAL LIAISONS

Ellen Blackwell, MSW

Senior Advisor
Centers for Medicare & Medicaid Services

Sarah Fontaine, PhD

Health Science Program Manager
Department of Defense

Melinda Kelley, PhD

Associate Director for Scientific Strategy, Innovation,
and Management
National Institutes of Health

Helen Lamont, PhD

Director, Division of Disability and Aging Policy
Office of the Assistant Secretary for Planning and Evaluation

Yen Lin, MPH

Healthy Aging Lead and Public Health Advisor
Office of Disease Prevention and Health Promotion

Shari M. Ling, MD

Deputy Chief Medical Officer
Centers for Medicare & Medicaid Services

Erin Long, MSW

Team Lead, Alzheimer's Disease Programs Initiative
Administration for Community Living

Rochelle Rollins, PhD, MPH

Senior Policy Advisor
Office of Minority Health

Joan Weiss, PhD, RN, CRNP, FAAN

Deputy Director, Division of Medicine and Dentistry
Health Resources & Services Administration

APPENDIX C: STAFF, CONSULTANTS AND SPECIAL THANKS

STAFF

Kelly Bishop, MA, MCHES®, FASHA

Tribal Team Lead, Program Services and Innovation Branch
Centers for Disease Control and Prevention

Kelsey Donnellan, MPH

Director of Dementia and Alzheimer's Disease Projects
International Association for Indigenous Aging

Breana Dorame (Gabrielino-Tongva)

Tribal Public Health and Aging Senior Associate
International Association for Indigenous Aging

Alisha Etheredge, MS, MPH

Lead, Alzheimer's Disease Program Team
Centers for Disease Control and Prevention

Mary E. Hall, MPH

Health Scientist, Healthy Tribes Program
Centers for Disease Control and Prevention

Eva Jackson, MPH

Associate Director, Healthy Brain Initiative
Alzheimer's Association

Romy Mohelsky, MPH, CPH

Epidemiologist, Healthy Tribes Program
Centers for Disease Control and Prevention

Shelby Roberts, MPH

Senior Director, Public Health
Alzheimer's Association

Juan Rodríguez

Specialist, Healthy Brain Initiative
Alzheimer's Association

Hannah Rowland

Fellow
Centers for Disease Control and Prevention

John Shean, MPH

Director, Healthy Brain Initiative
Alzheimer's Association

Katie Spears, MPH

Fellow
Oak Ridge Institute for Science and Education

M. Candace Spradley

Office of Human Resources
Centers for Disease Control and Prevention

Edie Yau

Senior Director, Diversity, Equity & Inclusion Engagement
Alzheimer's Association

CONSULTANTS

John Avila

Graphic Design Consultant
Avila Creative, Inc.

Susan D. Baker, MPH

Writing Consultant

April Hale (Diné/Navajo)

Design and Communications Consultant
A.Hale PR, Inc.

Peter Hoey

Illustrator
Rapp Art

Jamie Ishcomer-Aazami, MPH, MSW (Choctaw Nation
of Oklahoma)

Writing Consultant
Ishcomer Consulting

Vicki Lasky, MSED

Graphic Design Consultant
VRL Design, LLC

Mike Splaine

Consultant
Splaine Consulting

Valerie Tsosie (Diné/Navajo)

Facilitator
So' Tsoh Foundation

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April Hale, A.Hale PR, Inc., Navajo Nation

Jordan P. Lewis, PhD, MSW, CPG, Aleut and Sugpiaq, Native Village of Naknek

Michelle Reed, Lac du Flambeau Ojibwe

















Mississippi Band of Choctaw Indians























Osage News, Osage Nation

Nickolaus Lewis, Lummi Nation

APPENDIX D: ACTION AGENDA ACROSS THE LIFE COURSE

The Road Map actions vary in the extent they relate to three points of prevention (primary, secondary and tertiary) and for caregivers. This table shows the intended impact of each action across the life course.

Action	Description	Primary	Secondary	Tertiary	Caregiving
E Domain: Engage Communities and Share Knowledge					
E-I	Engage AI/AN communities to increase awareness and share knowledge about brain health across the life course.				
E-II	Work with local school systems to add brain health and dementia awareness content to learning plans.				
E-III	Provide information on how to recognize signs of dementia and increase awareness of services, care, and social support for people living with dementia and their caregivers.				
E-IV	Ensure caregivers have information about their important roles and how to support their own health and well-being.				
W Domain: Build a Representative and Skilled Workforce					
W-I	Provide ongoing training to health care providers to support culturally centered and appropriate conversations about brain health and dementia.				
W-II	Provide training to community health and direct service workers who work in AI/AN communities about brain health and the ways dementia disproportionately impacts those they serve.				

Action	Description	Primary	Secondary	Tertiary	Caregiving
M Domain: Measure, Evaluate and Use Data					
M-I	Support data sovereignty through local data collection to help plan, implement and evaluate programs and approaches for dementia and caregiving in AI/AN communities.				
M-II	Encourage health care providers to assess for mild cognitive impairment and dementia, document in medical records and discuss findings with their patients.				
M-III	Put data into action by sharing findings with AI/AN leaders, community members and organizations to help inform awareness efforts, resource needs, programs and policies.				
P Domain: Strengthen Policies and Partnerships					
P-I	Build relationships within and outside of the health and public health sectors to strengthen sustained commitments to brain health and its physical, mental, emotional and spiritual impacts across the life course.				
P-II	Engage AI/AN leaders to increase awareness about the indigenous and social determinants of health associated with brain health, dementia and caregiving.				
P-III	Equip AI/AN leaders with policy options to improve brain health across the life course and reduce stigma about dementia.				
P-IV	Build on existing AI/AN chronic disease, aging and disability programs and policies to include brain health.				

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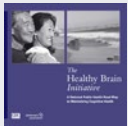
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OVERVIEW OF THE HEALTHY BRAIN INITIATIVE ROAD MAP SERIES

In 2005, Congress appropriated funds for the Centers for Disease Control and Prevention (CDC) to focus on brain health and dementia for the first time. This action led to the Healthy Brain Initiative and the longstanding collaboration between the Alzheimer's Association and CDC to advance understanding of and support for cognitive decline as a central part of public health practice. Since that time, Healthy Brain Initiative partners have worked together to implement public health strategies that promote brain health, address dementia and better support caregivers. The Healthy Brain Initiative Road Map Series guides this effort.



The first Road Map — *National Public Health Road Map to Maintaining Cognitive Health* — was released by the Alzheimer's Association and CDC in 2007. It was the first framework for viewing cognitive health and dementia as a public health issue. It outlined 44 actions to address dementia at the national level and laid the foundation for the public health community more broadly to engage on the issue.



The second Road Map was *The Public Health Road Map for State and National Partnerships, 2013–2018*. This guidebook expanded the role that state and local public health departments and partners could play by offering 35 actions to promote cognitive functioning, address cognitive impairment and dementia, and help meet the needs of caregivers.



The third Road Map — *State and Local Public Health Partnerships to Address Dementia, The 2018–2023 Road Map* — continued to chart a course for state and local public health departments and their partners. This Road Map prepared communities to act quickly and strategically by stimulating changes in policies, systems and environments. Alignment of the Road Map's 25 actions with the Essential Public Health Services ensured that initiatives to address Alzheimer's could be incorporated easily and efficiently into existing public health efforts.



The *Healthy Brain Initiative, Road Map for Indian Country*, published in 2019, was the first public health guide focused on dementia in American Indian and Alaska Native communities. This Road Map offered eight broad public health strategies designed to support discussion about dementia and caregiving within tribal communities and to encourage a public health approach as part of a larger holistic response.



The current edition of the Road Map — *Healthy Brain Initiative: State and Local Road Map for Public Health, 2023–2027* — guides public health professionals through an updated set of expert-developed actions toward a vision that everyone deserves a life with the healthiest brain possible. This fourth edition of the state and local Road Map builds on the successes to date, advances equity by fully integrating brain health and caregiving into state and local public health practice, and addresses social determinants of health across the life course.

The Healthy Brain Initiative and the development and dissemination of the Healthy Brain Initiative Road Map Series is supported by the Centers for Disease Control and Prevention and the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$14,229,665 with 100% funding 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.



The Alzheimer's Association is a worldwide voluntary health organization dedicated to Alzheimer's care, support and research. Our mission is to lead the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. Our vision is a world without Alzheimer's and all other dementia®. Visit **alz.org** or call 800.272.3900.



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