HEALTHYBRAIN INITIATIVE

Embracing Strengths in the Healthy Brain Initiative Road Map for American Indian and Alaska Native Peoples
Eight Questions for Community Action

The *Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples (Road Map)* is a comprehensive resource for public health action to improve brain health throughout life among American Indian and Alaska Native (AI/AN) communities.

Whether you're just getting started, or you are looking to advance and build upon existing work, this implementation guide is a resource to help you. This includes tribal public health professionals and tribal professionals with public health experience working in community and clinical health settings in tribes, nations, pueblos, bands, villages or urban Indian organizations. This guide expands on the eight planning questions of the Road Map (page 29) to help operationalize Road Map actions.

Key questions to select Road Map actions and focus planning:

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?

The following pages of the implementation guide walk through additional considerations for each of the eight questions. This guide is a resource to help uncover opportunities as you begin your work with the Road Map and guide local multi-sector partnerships to expand reach and impact through collaboration.

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DEFINING AND UNDERSTANDING YOUR COMMUNITY

Understanding the community, its characteristics, and the most pressing needs related to cognitive health, dementia, and Alzheimer's disease.

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?

Quick Tips for Success

Who makes up your community? Is it enrolled tribal citizens that live within a certain geographic boundary or perhaps you're an urban Indian organization that serves American Indian or Alaska Native (AI/AN) people from all 574 federally recognized tribes?

Helpful References — Road Map

- Importance of Family and Community (page 8)
- Engage Communities and Share Knowledge (pages 33-36)
- Eastern Band of Cherokee Indians *Supporting Elders Through Community and Culturally Centered Long-Term Care* (page 55)
- Great Lakes Inter-Tribal Council *Partnering for a Comprehensive Approach to Dementia Care* (page 56)
- Spirit Lake Senior Services Program *Using a Culturally Centered Approach to Discuss Brain Health* (page 61)
- Nonprofit Partnerships Driven by Caregiver Needs *Supporting Caregivers in Seneca Nation* (page 63)

Define community.

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.

Identify strengths and needs.

Utilizing community strengths and understanding the most urgent or common needs of your community related to cognitive health does not need to be a long and formal process. Simply having conversations and engaging with your community members is an easy and cost-effective way to gain a better understanding of their strengths, needs and stigmas associated with memory loss. These conversations can include everyone, including youth, to better understand their strengths and needs from a life-course perspective.

Many individuals found these questions on page 36 of the Road Map 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?

PLANNING AND PRIORITIZATION

Identifying relevant actions, determining priorities, and using data to guide decision-making and set a starting point.

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?

Quick Tips for Success
Start with known strengths, needs and gaps. What do you hear out in the community? Do your data or publicly available data back this up? Consider how these strengths, needs and gaps are unique to your community.

Helpful References — Road Map
- Dementia Facts (pages 12-17)
- Taking a Public Health Approach to Dementia (pages 18-26)
- Public Health Action Agenda (pages 27-48)
- Measure, Evaluate and Use Data (pages 41-45)
- State Health Departments *Partnerships to Support AI/AN Communities in Alaska and Washington State* (page 64)
- University Partnerships *Supporting Elder Health and Caregivers* (page 65)

Review existing plans to understand current public health priorities, programs and funding.
- Tribal/Community Health Needs Assessments
- Strategic plans related to health

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. In places where data are already available, adding questions or ensuring the completeness of

the data can help to identify the strengths, needs and barriers communities are facing. One strategy is to include questions about brain health, memory loss and difficulty in thinking.

Explore existing data.
- Elder Needs Assessment (National Resource Center on Native American Aging)
- Medical records
- Behavioral Risk Factor Surveillance System
- Alzheimer's Disease Facts and Figures
- Alzheimer's Disease and Healthy Aging Data Portal
- Cognitive Decline and Caregiver Infographics
- National Health and Nutrition Examination Survey (NHANES)
- Hospital records – outpatient and inpatient

- State and community profiles, reports and dashboards
- Disease registries and electronic medical records
- Mortality data from death certificates

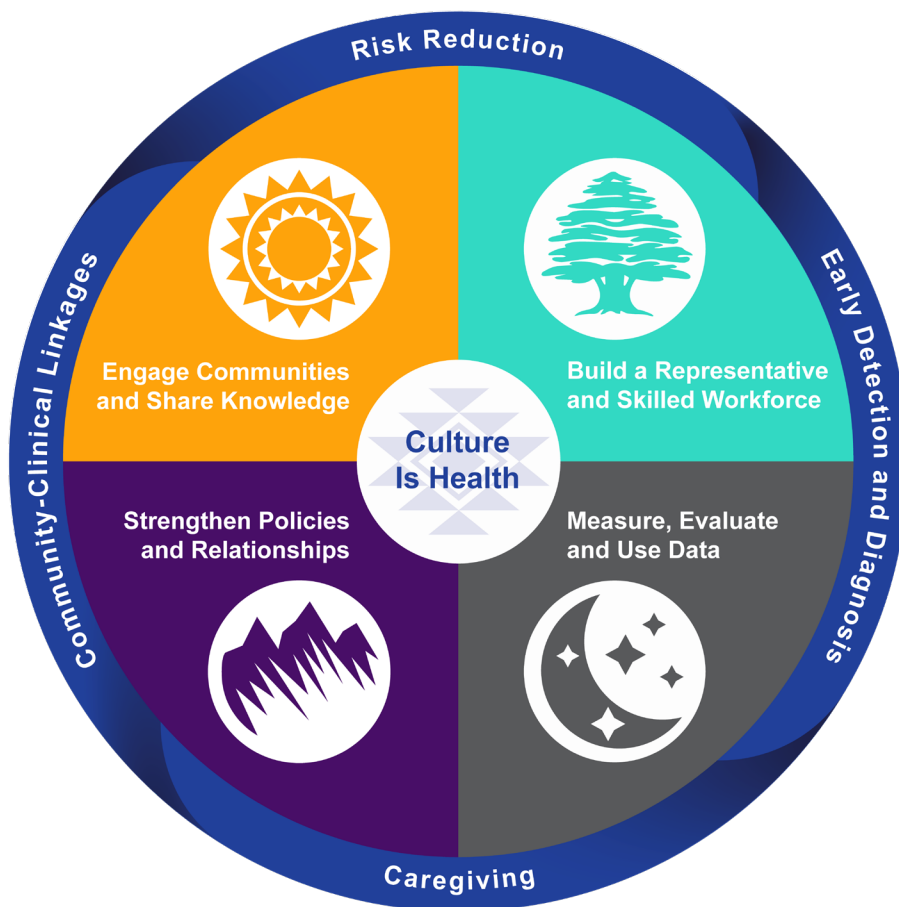**Identify community strengths, needs and gaps.**
- Conduct an environmental scan to identify other agencies or organizations working in this space to identify strengths and gaps.
- Conduct an internal organizational assessment of brain health, caregiving, dementia, healthy aging, and public health across all departments and programs. Identify areas for collaboration.

Select approaches and interventions.
Reviewing the framework of the Road Map can also help you prioritize actions. The domains are interrelated and have actions that build on one another. A single project may achieve multiple Road Map actions. For example, a project focused on early detection and diagnosis could:
- Provide ongoing training to health care providers to support culturally centered and appropriate conversations about brain health and dementia (W-I)

- 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 (W-II)
- Engage AI/AN communities to increase awareness and share knowledge about brain health across the life course (E-I)
- 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-II)
- Encourage health care providers to assess for mild cognitive impairment and dementia, document in medical records and discuss findings with their patients (M-II)
- Build on existing AI/AN chronic disease, aging and disability programs and policies to include brain health (P-IV)

Risk Reduction

Community-Clinical Linkages

Early Detection and Diagnosis

Engage Communities and Share Knowledge

Build a Representative and Skilled Workforce

Culture Is Health

Strengthen Policies and Relationships

Measure, Evaluate and Use Data

Caregiving

INTEGRATING BRAIN HEALTH FOR SUSTAINED IMPACT

Integrate brain health action into existing initiatives to grow capacity and ensure lasting impact.

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?

Quick Tips for Success

Brain health is an issue that spans initiatives. Consider how brain health fits with other topics or broad projects happening in your community — for potential collaboration, integration and potential funding to support these shared efforts.

Helpful References — Road Map

- Strengthen Policies and Relationships (pages 46-48)
- Cherokee Nation Health Services *Utilizing Patient Navigators to Support People Living with Dementia and Their Caregivers* (page 54)
- Great Lakes Inter-Tribal Council *Partnering for a Comprehensive Approach to Dementia Care* (page 56)
- Indian Health Council, Inc. *Integrating Cognitive Health into Existing Programs* (page 57)
- Oklahoma City Indian Clinic *Providing a Complete Care Pathway for People Living with Dementia and their Caregivers* (page 59)
- Pyramid Lake Paiute Tribe *Preventing Wandering Among Tribal Elders Living with Dementia* (page 60)
- Spirit Lake Senior Services Program *Using a Culturally Centered Approach to Discuss Brain Health* (page 61)
- Nonprofit Partnerships (pages 62-63)
- State Health Departments *Partnerships to Support AI/AN Communities in Alaska and Washington State* (page 64)
- University Partnerships *Supporting Elder Health and Caregivers* (page 65)

Communities are already doing great work, communicating about many issues, concerns and resources. Integration of brain health into existing messaging, programs, policies and data can accelerate impact and improve dissemination of messages internally and throughout the community. Many Road Map actions focus on this integration and collaboration with existing initiatives (E-II, P-I, P-IV).

Integrate brain health into existing initiatives for lasting work.

- Learn about existing or growing work in areas with relevance to brain health, caregiving and dementia. Consider initiatives in other chronic diseases, falls prevention, disability, equity, aging, labor benefits such as paid family leave and workforce development. Some examples of existing initiatives that provide opportunities to support brain health include the Title VI Elder Services and the Special Diabetes Programs for Indians. Annual wellness exams also provide a great opportunity to share information and resources on brain health.
- Include brain health, dementia and caregiving as a consideration when developing organizational and community-wide strategic plans, such as for the community health assessment and health improvement process.
- Ensure brain health and related topics are a part of all staff onboarding to build knowledge.

Consider a wide range of potential partners.

- 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

Seek traditional and new sources of funding.
- When seeking funding to sustain or grow your work, think about funds that are available specifically for dementia or related topics, such as caregiving, aging or disability.
- When looking to apply for new funding, look for additional opportunities from nonprofits and foundations. There are multiple opportunities for federal funding for different departments within state and local government. Understand how your department or organization is funded and what additional opportunities may be available.

EVALUATING AND SHARING IMPACT

Evaluating, understanding and sharing progress, impact and results helps communities move forward, identify areas of success and opportunities for improvement and change.

8 How will implementation and impact be evaluated? How will progress be shared with the community and local leaders?

Quick Tips for Success

Achieving lasting impact by aligning to the collective outcomes of the Road Map. These outcomes offer meaningful measures to track progress and assess impact.

Reach out to a tribal epidemiology center, the International Association for Indigenous Aging, or the public health team at the Alzheimer's Association for support in creating evaluation questions. The 12 Tribal Epidemiology Centers (TECs) provide epidemiologic and public health data support for American Indian and Alaska Native communities across the United States.

Helpful References — Road Map
Measure, Evaluate, and Utilize Data (pages 41-45)
Northwest Portland Area Indian Health Board *The Northwest Tribal Elders Project Building Our Largest Dementia (BOLD) Infrastructure* (page 58)

Support data sovereignty.
Tribal data sovereignty is an important consideration when discussing data. 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.

Ensure evaluation is included from the start.

- Incorporate evaluation early into each project, starting with planning efforts.
- Standardize evaluation metrics and measures where possible to understand the impact of the broader initiative, compare with other programs, and scale successful initiatives to increase impact.
- Use the Road Map outcomes as a starting point when designing evaluation processes.

Disseminate findings broadly to drive action.

- Share with leadership, staff, policymakers, community partners, local media and others with a shared interest.
- Tailor findings to resonate with diverse populations within the community.
- Sharing challenges or remaining gaps can both inform future approaches as well as bring attention to needs not easily addressed through a given initiative.
- Share your findings with peers through professional conferences, publications and national membership organizations, including:
  - » Alzheimer's Association
  - » American Public Health Association
  - » International Association for Indigenous Aging
  - » National Council of Urban Indian Health
  - » National Indian Council on Aging
  - » National Indian Health Board
- Use findings to inform strategic program planning efforts, such as health planning, workforce, transportation and emergency preparedness.
- Use evaluation data to drive program changes and implementation efforts in your health systems, community-based organizations and broader community.
- Make data-informed recommendations for regulations and policies relevant to brain health, dementia and caregiving

STAY CONNECTED

This guide is a starting point. Progress on brain health, dementia and caregiving will take a multisector, all hands approach. As you move forward with your work, stay connected with the latest resources, support and linkages to the broader community working to make change in this field.

Alzheimer's Association – Public Health
- Website: Public Health (alz.org/publichealth)
- Newsletter: Alzheimer's Public Health News
- Email: publichealth@alz.org

International Association for Indigenous Aging
- Website: Brain Health (iasquared.org/brain-health)
- Newsletter: American Indian & Alaska Native Resource Center for Brain Health E-news
- Email: admin@iasquared.org

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Road Map Series

AMERICAN INDIAN
and **ALASKA NATIVE**
RESOURCE CENTER FOR BRAIN HEALTH