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

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What is Dementia?

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

Healthy Brain Initiative (HBI)

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

**HBI Road Maps**

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

National Indian Health Board
International Association for Indigenous Aging
Administration for Community Living
Alzheimer’s Association
Association of State and Territorial Health Officials
Centers for Disease Control and Prevention
Centers for Medicare & Medicaid Services
Healthy Brain Research Network
Indian Health Service
National Institute on Aging

And many more.......Thank You!
Road Map Intent

Conversation starter
Prompt local planning
Encourage:
• Public health strategies
• Work across and between generations for the good of all
Road Map Strategies

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

https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html
Educate & Empower Communities

• Educate your community about:
  – Brain health
  – Talking to a doctor about memory problems

• Increase use of programs and services that support health and wellbeing

• Help families plan for the future

• Encourage your leaders to support public health approaches to dementia
Public Health Programs and Resources: Examples

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

Healthy Heart, Healthy Brain Messaging (available at http://www.astho.org/Healthy-Aging/Healthy-Heart-Healthy-Brain)
alz.org/PublicHealth/IndianCountry
Wyoming Center on Aging

10 Early Signs of Unnatural Memory Changes

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

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

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

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

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Collect & Use Data

• Get data about how dementia and caregiving affects your community

• Use quality measures to improve care for people living with dementia
SUBJECTIVE COGNITIVE DECLINE AMONG AMERICAN INDIAN/ALASKA NATIVE ADULTS

1 in 6 American Indian/Alaska Native adults aged 45 years and older are experiencing Subjective Cognitive Decline

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

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

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

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

54% of people with SCD need help with household tasks

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

CAREGIVING AMONG AMERICAN INDIAN/ALASKA NATIVE ADULTS


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

1 in 4 American Indian/Alaska Native adults are caregivers

WHO ARE CAREGIVERS?

56% are women

16% are 65 years old or older

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

7% of caregivers are providing care to someone with dementia

CAREGIVING CAN BE

LENGTHY
Half have provided care for at least two years

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

HOW DO CAREGIVERS HELP?

Over 80% manage household tasks

Over 50% assist with personal care

FUTURE CAREGIVERS

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

cdc.gov/aging

Data for Action
New Infographic
National Indian Council on Aging adapted the Savvy Caregiver model for use in Indian Country.
Strengthen the Workforce

• Train people who provide health care or other services about
  – Brain health
  – Alzheimer’s and dementia
  – Caregiving

• Give professionals information to share with patients (or clients)
alz.org/Public-Health-Curriculum

Free curriculum to help educate public health staff and students

A Public Health Approach to Alzheimer's and Other Dementias
An introductory curriculum to increase awareness of the impact of Alzheimer's and other dementias.
Examples and Tools to Get Started

Michael Splaine
Alzheimer’s Association
Pyramid Lake Paiute Tribe

Become “dementia-capable”
- Enhance awareness of dementia
- Educate & involve community members
- Increase peer support
- Expand supports, services for caregivers
St. Regis Mohawk Nation

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

- Native American Outreach program
- Increase community knowledge and awareness of Alzheimer’s and caregiving strategies
In the Road Map....

10 WARNING SIGNS OF ALZHEIMER'S

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

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

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

4. Confusion with time or place: having trouble understanding an event that is happening now, or losing track of dates

5. Trouble understanding visual images and spatial relations: having more difficulty with balance or judging distance, tripping over objects or bumping into things at home, or spilling or dropping things

6. New problems with words in speaking or writing: having trouble following or joining in a conversation or struggling to find the right word when talking

7. Misplacing things and losing the ability to retrace steps: placing car keys in the dryer or not being able to retrace steps to something

8. Decreased or poor judgment: being taken in by a scam, not managing money well, paying no attention to hygiene, or having trouble of a pet

9. Withdrawal from work or social activities

10. Changes in mood, personality, or behavior: becoming distant or out of touch with reality

Glossary

Alzheimer’s disease: an irreversible, progressive brain disorder that slowly destroys memory and thinking and, eventually, the ability to carry out the most basic activities of daily living. Alzheimer’s eventually develops slowly and can progress to severe enough symptoms that an individual may have trouble eating or drinking or controlling the movement of the body. Additional symptoms include:

- Changes in personality or behavior
- Trouble remembering recent events
- Difficulty performing familiar tasks
- Problems with language
- Disorientation
- Problems with judgment
- Changes in mood or personality
- Changes in activity levels
- Problems with reasoning or problem-solving

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

- American Indian/Alaska Native
- Non-American Indian/Alaska Native
In the Road Map....

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

Listening and learning are the first steps toward developing a holistic response to Alzheimer’s and other dementias. The Healthy Brain Initiative’s Road Map for Indian Country encourages AI/AN leaders to start a conversation within their communities to learn how dementia affects all generations. Dementia affects not only people living with the condition, but also their families, community members who are caregivers, and even future generations if memory loss associated with Alzheimer’s weakens cultural traditions and heritage.

- An initial community gathering to discuss dementia.
- Again, without identifying individuals, who in our community is helping people living with dementia with day-to-day living or getting places? How are these caregivers faring?
- Do we have traditions about keeping ourselves healthy that include keeping strong our memories, ability to learn, and make decisions?
- Do our diabetes or heart disease efforts help us learn about dementia and the brain?
- What kinds of information or training would help family and friends better support our fragile older adults?

Choose Road Map Strategies and Make a Plan

After learning about dementia’s impact on the community, the next step is to plan how to build a better future for all. Asking the following questions during the planning process can make it easier to choose which strategies to use and help identify additional interested partners.

1. Which Road Map actions best fit your tribal community’s priorities and capabilities?
2. What data and other information can be used to identify a starting place?
3. How can the identified actions best be integrated into existing initiatives? Are new initiatives needed?
4. Who are potential partners? Could any current partnerships be leveraged to implement actions?
5. What are possible funding sources, and how can they be secured?
6. How will implementation and impact be evaluated? How will progress be shared?
alz.org/PublicHealth/IndianCountry

Find:
- Road Map for Indian Country
- Tools & examples to help you use it
- Data
- More info about key issues
Healthy Heart, Healthy Brain

- Posters
- Flyer
- Provider guide
- Radio announcements
- 5-7 minute videos
- Articles in *Indian Country Today*
Discussion: What do we mean by a public health approach? Gretchen Dobervich
Alzheimer’s disease a Public Health Issue

The burden is large
5.8 Million Americans are living with Alzheimer’s disease
16 million Family caregivers provided 18.5 billion hours of unpaid care in 2018

The impact is major
More Americans die of Alzheimer’s disease than breast + prostrate cancer
Alzheimer’s disease will cost the US $290 billion in 2019

There are ways to intervene
Early diagnosis and treatment
Caregiver education and supports
Developing Alzheimer’s inclusive communities

https://www.alz.org/alzheimers-dementia/facts-figures
Alzheimer’s Disease a Public Health Approach

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

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

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

NDSU AMERICAN INDIAN PUBLIC HEALTH RESOURCE CENTER
For More Information

Centers for Disease Control and Prevention (CDC)
Alzheimer’s Disease and Healthy Aging Program
cdc.gov/aging

Alzheimer’s Association
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