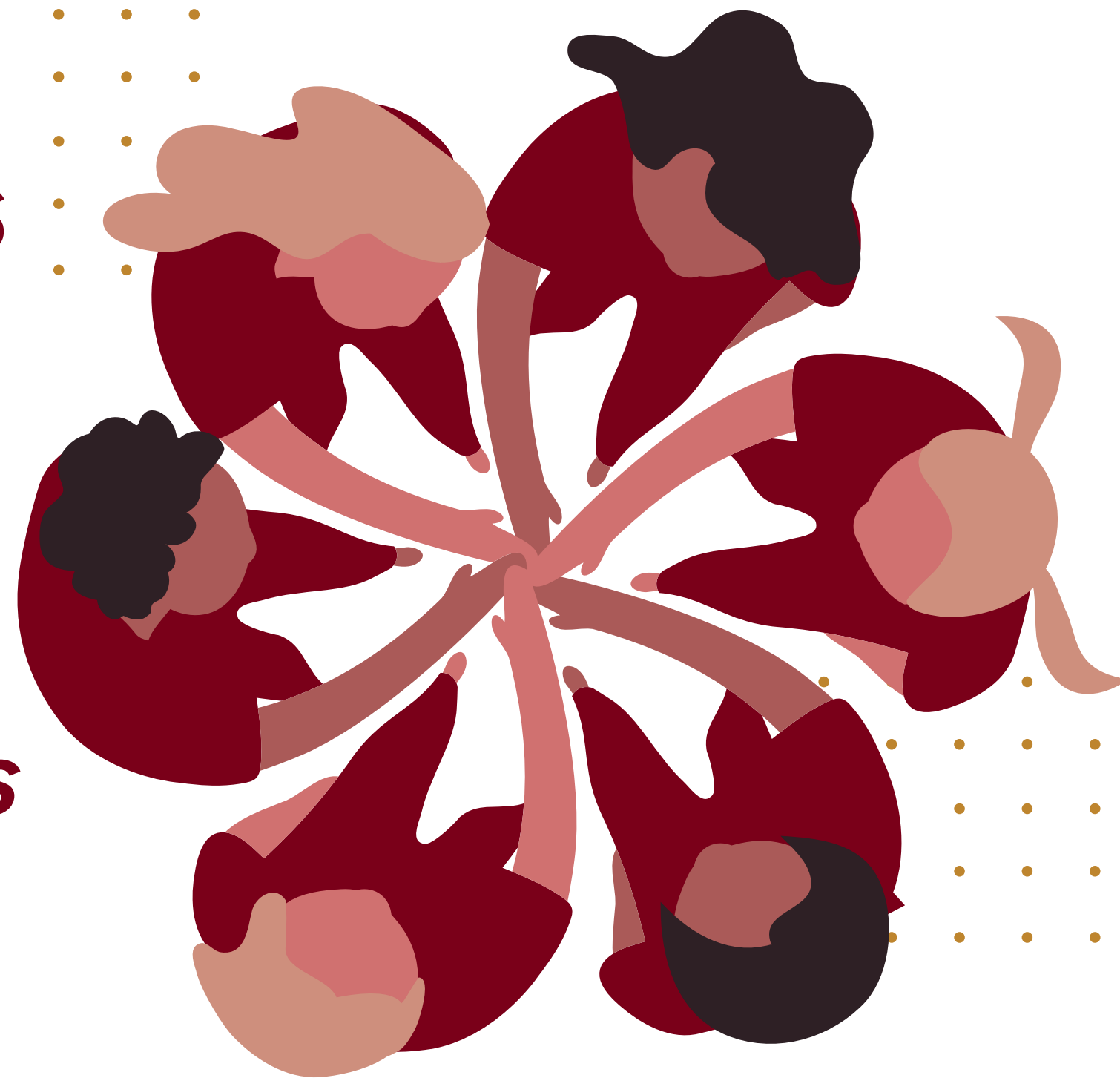


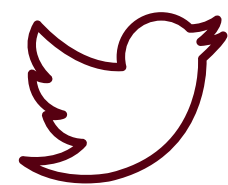
Part III: Public Health Considerations and Models for Cultural Adaptation in Dementia Caregiving

Focusing on Asian American/Pacific Islanders and Indigenous Caregivers



Follow the Conversation on Twitter!

Use **#CultureMattersinDementia**
to follow and keep the conversation
going!



@PHCOE_DC

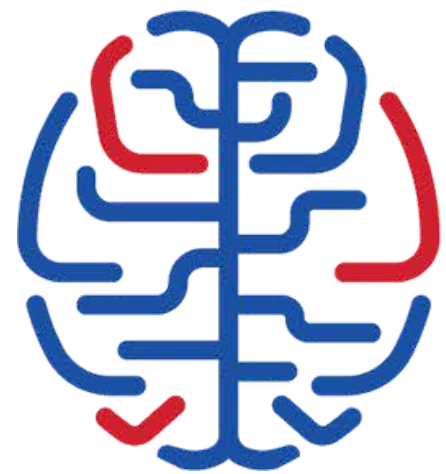


Presented by:



BOLD
PUBLIC HEALTH
CENTER OF EXCELLENCE
ON DEMENTIA
CAREGIVING

In collaboration with:



USAGAINSTALZHEIMER'S CENTER *for*
BRAIN HEALTH EQUITY

The Public Health Center of Excellence on Dementia Caregiving

Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...



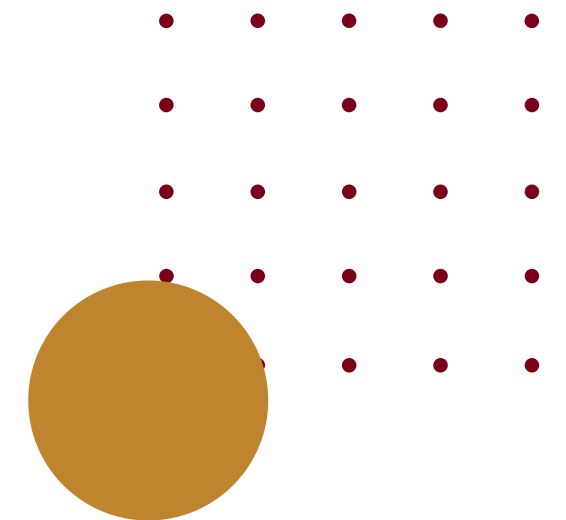
Improving access to evidence-based programs and best practices



Facilitating connections and collaboration among public health agencies and a wide range of service organizations



Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies



Welcoming our presenters...



Ocean Le

Senior Program Coordinator,
Diverse Elders Coalition



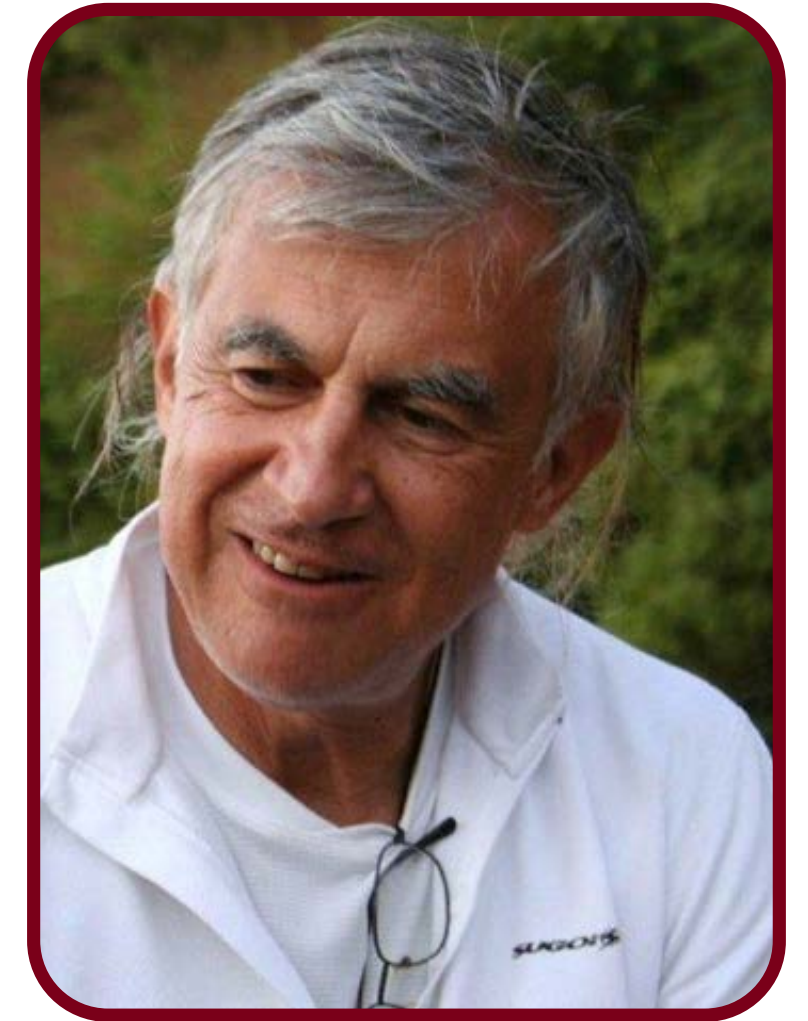
Haera Han, PhD

Professor; Associate Dean for
Community Programs and
Initiatives, Johns Hopkins
School of Nursing



**Jolie Crowder, PhD, MSN,
RN,CCN**

Senior Director, International
Association for Indigenous Aging



David Baldrige (Cherokee)

Board Member and Executive
Director, International Association
for Indigenous Aging



The Unique Realities of Indigenous & Asian American (AAPI) and Pacific Islander Dementia Caregivers

Ocean Le
Senior Program Coordinator



The Unique Realities of Indigenous & AAPI Dementia Caregivers

- Discrimination, negative experiences and neglect of diverse communities may lead to distrust of governmental institutions and service providers
 - Indigenous caregivers expressed distrust of the majority culture and government due to a history of poverty, displacement, and discrimination (Scharlach et al.)
- On average, American Indian and Alaska Native caregivers reported utilizing 1.62 services from providers (n=104)
- Indigenous dementia caregivers are less prepared for the caregiving role, negatively affecting their own health and the health and well-being of their aging loved ones



The Unique Realities of Indigenous & AAPI Dementia Caregivers

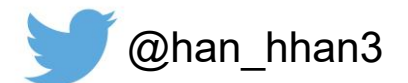
- Social and community support utilization in diverse communities is nuanced by the impact of cultural and linguistic barriers
- > 1/4 of Southeast Asian American caregivers reported some or great deal of difficulty with culture-related task
 - Overcoming language barriers, translating information, naturalization/immigration
- Diverse caregivers who reported some or great difficulties with cultural tasks had elevated levels of depression and 4 types of strain
 - Isolation, Work, Health Relationship strain



Cultural Adaptations in Dementia Caregiving—A Case of Korean Americans

Hae-Ra Han, PhD, MSN, RN, FAAN

Johns Hopkins University School of Nursing



Presenter Disclosures

Cultural Adaptations in Dementia Caregiving—A Case of Korean Americans

- 1. The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:**

No relationships to disclose

- 2. Sources of Funding:**

National Institute on Aging (P30AG048773; R01AG062649)

Asian Americans in the US

- Growing fast¹
 - Fastest growing racial/ethnic group from 2000 to 2019 (81% vs. 70%, 61%, and 20% for Hispanic, NHPI, and Black Americans, respectively)¹
- Diverse²
 - 20+ countries of origin² (China, India, Philippines, Vietnam, and Korea)
- Overrepresented by immigrants²
 - More than two thirds of Asian adults born in another country (71% vs. 17% of American adults)
 - Projected to become the largest immigrant group by 2055
 - Two thirds speak a language other than English at home

¹<https://pewrsr.ch/3tbjILO>

²<https://pewrsr.ch/3e3t4nF>

Korean Americans



- 5th largest (9% or 1.9 million) and one of the most rapidly increasing Asian sub-populations²
- Higher prevalence of dementia compared to general older adult population (20% vs 6-13%)^{3,4}
- Korean older adults heavily dependent on informal family-level caretaking^{5,6}
- Characterized under-resourced and underserved for dementia care⁴⁻⁶

²<https://pewrsr.ch/3e3t4nF>

³Alzheimer's Association. 2021 Alzheimer's disease facts and figures

⁴Lee HB et al. Aging Ment Health. 2014

⁵Han HR et al. J Adv Nurs. 2008

⁶Han HR et al. J Clin Trans Res. *In press*

What is the issue?

Korean Americans are less likely to utilize mental health services^{4,5,7}

- Issue #1 - Lack basic knowledge about the diagnosis, treatment, and cause of dementia
Result - Lack of follow-up treatment and care
- Issue #2 - Often treat dementia as part of the normal aging process and interpret it as insanity
Result - Feelings of shame and stigma
- Issue #3 - Lack adequate health providers who can provide culturally and linguistically appropriate dementia screening and care
Result – Lack of diagnosis and follow-up care

⁴Lee HB et al. Aging Ment Health. 2014

⁵Han HR et al. J Adv Nurs. 2008

⁷Sun F et al. J Gerontol B Psychol Sci Soc Sci. 2015

Objectives

1. To discuss our research endeavors to create a culturally relevant intervention program—PLAN—with goals to promote linkage to care for dementia evaluation and care planning while improving caregiver outcomes
2. To share key lessons learned from the PLAN intervention development processes



PLAN Study Team

Project PLAN: Dementia Literacy Education and Navigation for Korean Elders with Probable Dementia and Their Caregivers

PLAN Intervention

- Community health worker-led intervention
- Dementia literacy education (one session)
- Follow-up phone counseling with navigation assistance to promote linkage to medical service for dementia evaluation and care planning while improving caregiver outcomes

Main themes from pre-intervention inquiries: Key areas to address^{5,8}

- Linkage to care
 - Functional decline as a common reason for caregiving but had limited awareness and access to care
- Promotion of health literacy
 - High education ≠ High health literacy
 - “So the educational part is so over, way over their head. It’s just up there, you follow me? It just needs to be real basic, plain information”
- Community outreach and navigation assistance
 - Korean American caregivers facing double challenges of settling in a new country vs. filial piety—*Hyo*

⁵Han HR et al. J Adv Nurs. 2008

⁸Han HR et al. J Health Commun. 2014

Focus group meetings to develop and refine intervention materials





Main findings from pilot



- Community health worker successfully provided PLAN intervention that increased linkage to care and improved caregiver outcomes
- PLAN was high acceptable with 9.7 overall satisfaction on 1 to 10-point scale
- 100% of caregivers would recommend PLAN to others.
- 100% Korean American elders with probable dementia and caregiver dyads completed both baseline and follow-up.

Quotes from post-intervention interviews



- "I used to be very upset if my mother-in-law didn't remember things. Sometimes she couldn't even tell what year it was. This program [PLAN] made me realize that she was showing signs of dementia and **I began to accept that this may be a new normal for her.**" *(daughter-in-law)*
- "I think phone counseling was the best thing that this program [PLAN] offered... I wouldn't have taken my wife to the clinic if it wasn't for her call. I find it very **important that she [community health worker] called me on a regular basis, checking to see if I had any issues...**" *(husband)*
- "I sensed that she [Korean older adult with probable dementia] might have dementia for some time. I **wanted her to see a doctor but she couldn't because of her insurance problem...**" *(church friend)*

Lessons learned



- Caregiver trust in community health worker
- Community health worker knowledge and understanding of the topic
- Caregivers stated they appreciated the length of time allowed for questions and answers in the language they understood
- Navigation assistance provided by trained community health worker proved to be a key factor in obtaining the resources for dementia evaluation and care.

Experiences of research teams using stakeholder engagement

- Stakeholder engagement is an ongoing and iterative process

“I will say that the iterative process can actually be big advantage... I think that's an incentive at least for most of the individuals that I have worked with that they really appreciate how their ideas have taken shape and how their input has been utilized. I think that can make things take a little bit more time but ultimately it is beneficial.” (Participant 1; Investigator)

“We should be engaged in all stages of the research process.” (Participant 6; Community member)

- Mutual trust, respect, and transparency are central

“That does make a huge difference... when the community sees somebody there, not with their hands out but actually wanting to be there month in and month out so when you do come calling or knocking or you need support, you have the stakeholders that relationship built that you can go to the head, the leadership of the community and they know you and they trust you.” (Participant 8; Community member)

Food for thoughts

- Unmet needs of older immigrant populations in intervention development
 - Incorporating essential health literacy skills into the intervention program may be important to maximize the impact of the intervention.
 - Strategies to address limited digital literacy required
 - Health problems often intersect with social factors such as absence of a usual source of care, sustainable caregiver, and poverty⁹
 - Free or reimbursed transportation in combination with tailored services may improve patient outcomes in chronic care, particularly among older patients and women¹⁰

⁹Institute of Medicine. 2002

¹⁰Starbird LE et al. J Community Health. 2019



"If you want to go fast, go alone.
If you want to go far, go together."

-African proverb





INTERNATIONAL ASSOCIATION FOR
INDIGENOUS AGING

Alzheimer's and Dementia in in American Indian and Alaska Native Communities: Cultural Adaptation – Community Engagement Approach

10/06/2021

Project activities are supported by the CDC Foundation and a cooperative agreement from the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$348,711 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

Welcome



- Dr. Jolie Crowder, IA²
- Dave Baldrige (Cherokee), IA²

IA² Dementia Work Before BOLD & HBI Funding

- Consultant to Alzheimer's Association on work with Indian Country
- Listening Sessions & Focus Groups with Aging Services and Tribal Service Providers on Caregiving and Dementia
- Contribute to [Road Map for Indian Country](#)
- Develop suite of materials for American Indian and Alaska Native audiences on brain health w/ ASTHO with funding from CDC
- Road Trip to Promote Road Map for Indian Country to Public Health
- Convene National Stakeholder Meeting of Federal and Non-federal Partners to Discuss Plans/First Steps
- Training content for Title VI staff on ADRD
- Working with Great Lakes Intertribal Council (WI) and Absentee Shawnee Tribal Health Center (OK), and now ITCA (AZ) on ACL Alzheimer's Disease Program Initiative (ADPI) grants as 3rd party evaluator;
- Local work with Albuquerque Alzheimer's Association

CDC National Healthy Brain Initiative Award to IA²

Develop a national project that identifies and incorporates locally tailored, culturally relevant information resources to address disparities in the burden of Alzheimer's disease and related dementias (ADRD) among American Indian and Alaska Native (AI/AN) populations.

- Advance community engagement and help build capacity among tribes and tribal member-serving organizations in serving elders living with dementia
- Promote healthy cognitive aging strategies across the lifespan
- Foster dementia-capable tribal communities
- Promote activities from the [Road Map for Indian Country](#)

*Our approach to this work is built on our belief in **values that** promote tribal sovereignty over work in local communities, respect cultural traditions and knowledge while encouraging innovation, recognize the importance of mutually beneficial collaborations and partnerships, and acknowledge the rights of sovereign tribal nations to work in a way that honors their culture, diversity, and traditions.*

Project Activities - Advisory Group Members



Dementia in American Indian and Alaska Native Peoples

- 1 in 3 American Indians 65+ are projected to develop dementia
- & the number 65+ living with dementia is projected to grow more than 5 x



Mayeda, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & dementia : the journal of the Alzheimer's Association*, 12(3), 216–224. <https://doi.org/10.1016/j.jalz.2015.12.007>

Urban Migration

- >70% of today's population lives in urban areas
- If you move out of the tribal service area your options may be very limited



What's Unique About AI/ AN Populations?

- Well almost >>>
- Tribal sovereignty is the biggest differentiator
- Federal Trust Responsibility
- Complex and unique health care system



Dementia As A Community Concern



BUT

- Most tribal communities are aware and concerned about the growing problem; know someone
- Few have programming or resources in place to help people with dementia and their caregivers
- Few IHS or other health programs are in place to address dementia care and awareness



***Bruce Finke, MD, Senior Advisor
for Improvement and Innovation,
Indian Health Service***



Community Engagement

Multiple approaches

- Authentic partnerships
- Community based participatory engagement
- Indigenous principles of evaluation



Examples of Adaptation for American Indian and Alaska Native Communities

Dementia Friends

- Focus: increase awareness and reduce stigma around Alzheimer's and dementia
- Provided the opportunity to revise and recommend culturally-specific changes
- Started with 10-page workbook
- 10-person workgroup including multiple tribes - lower 48 + Alaska
- Three 4 hr working sessions (~ 120 man hours)
- Shared recommendations with national advisory group -> another 10 hours of revisions
- Pilot with AI/AN people
- Revise



Dementia Friends

- Changes in language
- Plain language / 5th grade reading level (still need work)
- Change imagery from Venn diagram to river imagery
- Inclusion of historical acknowledgements
- Focus on resiliency
- Incorporate culturally specific examples of healthy living
- Re-frame away from tragedy narrative – what we can't do, besides feel helpless and hopeless
 - Re-wrote the river story which was already a step up from the bookcase story
- Move from generic to specific references
- Focus examples on community vs personal care

SAVVY Caregiver for Indian Country

Lessons Learned



- ▶ Overall, the Indian Country version worked well.
- ▶ Original: teacher and classroom style
- ▶ Indian Country:
 - ▶ Not in a classroom
 - ▶ Not taught like a class
 - ▶ Informal
 - ▶ In homes on the couch
 - ▶ Multiple lessons per visit

10 Warning Signs

10 Warning Signs of Alzheimer's



HEALTHYBRAIN INITIATIVE
Road Map for Indian Country

Memory often changes as people grow older. Some people notice changes in themselves before anyone else does. For other people, friends and family are the first to see changes in memory, behavior, or abilities. Memory loss that disrupts daily life is not a typical part of aging. People with one or more of these 10 warning signs should see a doctor to find the cause. Early diagnosis gives them a chance to seek treatment and plan for the future.

- 1 Memory loss that disrupts daily life:** forgetting events, repeating yourself or relying on more aids to help you remember (like sticky notes or reminders).
- 2 Challenges in planning or solving problems:** having trouble paying bills or cooking recipes you have used for years.
- 3 Difficulty completing familiar tasks at home, at work, or at leisure:** having problems with cooking, driving places, using a cell phone, or shopping.
- 4 Confusion with time or place:** having trouble understanding an event that is happening later, or losing track of dates.
- 5 Trouble understanding visual images and spatial relations:** having more difficulty with balance or judging distance, tripping over things at home, or spilling or dropping things more often.
- 6 New problems with words in speaking or writing:** having trouble following or joining a conversation or struggling to find a word you are looking for (saying "that thing on your wrist that tells time" instead of "watch").
- 7 Misplacing things and losing the ability to retrace steps:** placing car keys in the washer or dryer or not being able to retrace steps to find something.
- 8 Decreased or poor judgment:** being a victim of a scam, not managing money well, paying less attention to hygiene, or having trouble taking care of a pet.
- 9 Withdrawal from work or social activities:** not wanting to go to church or other activities as you usually do, not being able to follow football games or keep up with what's happening.
- 10 Changes in mood and personality:** getting easily upset in common situations or being fearful or suspicious.

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

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



HEALTHYBRAIN INITIATIVE
Road Map for Indian Country

alzheimer's association
cdc.gov/aging

alz.org/publichealth/indiancountry

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10 EARLY SIGNS OF ABNORMAL MEMORY CHANGES



WyCOA
Wyoming Center on Aging

UNIVERSITY OF WYOMING

10 Warning Signs of Abnormal Memory Changes or Dementia

Everyone slows down as they get older, both in body and mind. But big changes that make it hard to get through the day are not a normal part of aging. Some people notice changes in themselves. Sometimes, friends and family are the first to see changes in memory, behavior, or abilities. If you have one or more of these 10 warning signs, see a doctor to find the cause.

- 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 New trouble planning or solving problems:** having a hard time paying bills or cooking recipes you have used for years.
- 3 Difficulty with familiar tasks at home, at work, or at leisure:** having problems with cooking, driving places, using a cell phone, or shopping.
- 4 Confusion with time or place:** having trouble understanding an event that is happening later, or losing track of dates.
- 5 Trouble understanding visual information:** having more difficulty with balance or judging distance, tripping over things at home, or spilling or dropping things more often.
- 6 New problems with words in speaking or writing:** having trouble following or joining a conversation or struggling to find a word you are looking for (saying "that thing on your wrist that tells time" instead of "watch").
- 7 Misplacing things and losing the ability to retrace steps to find them:** placing car keys in the washer or dryer or not being able to retrace steps to find something.
- 8 More slips in judgement or acting impulsively:** being a victim of a scam, not managing money well, paying less attention to hygiene, or having trouble taking care of a pet.
- 9 Withdrawing from work or social activities:** not wanting to go to church, cultural events, other activities as usual, not being able to follow radio shows or sports games or keep up with what's happening.
- 10 Changes in mood and personality:** getting easily upset in every day situations or being fearful or suspicious.



American Indian and Alaska Native elders have a higher risk of dementia & younger Indian and Native people report more memory problems at a younger age

Big changes in memory, thinking, and ability that make it hard to get through the day are not a normal part of aging.

People with one or more of these 10 warning signs should see a doctor to find the cause.

Other health problems may also cause these same symptoms and may be treated.

Early diagnosis gives you a chance to seek treatment and plan for your future.



www.AIAnBrainHealth.org
www.cdc.gov/aging
www.alz.org/publichealth/indiancountry



Adapted from resources from the Alzheimer's Association & University of Wyoming. UoW materials created in collaboration with Eastern Shoshone and Northern Arapaho tribal members. Funding support provided by the CDC Foundation to the International Association for Indigenous Aging.

Questions to Consider for Materials Adaption

Eight Dimensions of the Ecological Validity Model

| Dimensions | Adaptation hypotheses |
|------------|---|
| Language | - Language should be simplified to match literacy level of providers and study populations - Created/ translated as needed and identified by the priority population |
| Persons | - Material's graphics should depict individuals from populations - Case examples should be adapted to reflect common problems and stressors, reactions, and coping strategies among the population, as well as institutions and individuals providing care and services - Consider culturally appropriate interaction between providers and beneficiaries (e.g., physical contact, ways of addressing each other). |
| Metaphors | - Identify sayings and metaphors relevant to resource topic - Identify somatic expressions of important concepts, e.g., dementia or stress - Common sayings or storytelling are adapted into resource if appropriate |
| Content | - Identify common and culturally appropriate social support and leisure activities - Consider culturally appropriate ways of discussing sensitive topics (e.g., domestic violence, dementia, depression) - Intervention/ provided activities are understood and are appropriate in the cultural context - Incorporates cultural values such as familism, community, respect for elders |
| Concepts | - Key concepts (e.g., dementia, caregiving, intervention, etc.) and titles are correctly interpreted by the population - Technical terms (e.g., dementia, depression, withdrawal, social isolation) match literacy level |
| Goals | - Intervention/ action goal(s) match social and cultural values |
| Methods | - Intervention/ resource delivered in a format that is acceptable to populations (e.g., including family, appropriate location, time between sessions) - Instruments are validated with target population and revised by volunteers for comprehension |
| Context | - Address common barriers to participation (e.g., child-care, transportation, caregiving requirements, financial situation) - Address barriers for providers (e.g., knowledge, time, accessibility of services and supports locally) - Consider any issues unique to the population's context (e.g., family separation, community as family, substance use issues, location/access to care) - Conduct intervention sessions in culturally appropriate locations - Identify culturally and context appropriate referral pathways |

Once the communication materials to be adapted have been identified, review the three elements below for *each material*. This will help the team identify specific components that may need to be modified. The team may use qualitative research techniques like small focus group discussions or in-depth interviews with audience members, and/or insights derived from program staff experience to define adaptation needs.

Words (written and spoken): Text, Narratives, Captions

- Determine whether the language and terms used are appropriate to the audience's literacy level/ reading levels.
- Review text, narratives and captions for content accuracy, quantity of information and clear presentation of concepts, including whether they are presented in logical order.
- Determine whether wording is used appropriately and if it addresses the audience's behavioral and socio-cultural barriers to change.
- Examine culture-specific statements and local idioms used; consider whether they are in the preferred language of the audience and used in the right context.
- Determine whether text complements visuals used (and not compete with it).
- Find out if the messages and the people communicating the messages are relevant, credible and attractive to the audience.

Visuals: Photographs, Cartons, Drawings, Images, Graphics

- Decide whether the visuals illustrate important points, are understood and will not confuse the audience.
- Determine whether the people and places in the visuals represent the audience and their culture realistically, and will be familiar attractive and acceptable.

Format: Style, Size and Type of Materials, Sequence of Events

- Decide whether the existing format—print, audio, audio-visual or interactive (like mobile and social media)—is likely to be effective in reaching the audience.
- Determine whether the design of the material is inviting, visually appealing and easy to follow, including fonts, typefaces and colors used.
- Decide whether the size and format of printed materials are appropriate and convenient for their intended use (often field tests are required to know this).

Modifications may be minor, such as including a more culturally relevant image on a poster or brochure. Other times, a material may require more extensive modifications to make it relevant to the audience or setting, such as developing a "new" interpersonal counseling activity guide by compiling activities from several different guides.

Closing Thoughts on How to Work with Elders

- Approach directly and personally
- ASK how and where they get info and services
- Important to engage with people who have direct contact with elders and caregivers
- Informal and formal leader(s) within elder population
- Need to understand systems within the tribe – social service, health care
- Understand historical challenges for the community
- Focus on strengths and assets in approaches

Resources on Cultural Adaptation

- [Health Equity Guiding Principles for Inclusive Communication by CDC Including Preferred Terms](#)
- [Audience Check-in for Cultural Adaptation of Materials by CDC](#)
- [Culture Matters in Communicating the Global Response to COVID-19](#)
- [A Toolkit for Applying the Cultural Enhancement Model](#)
- [A Guide to Choosing and Adapting Culturally and Linguistically Competent Health Promotion Materials](#)
- [Resource library of resources by Georgetown University National Center for Cultural Competence](#)



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

www.AIANBrainHealth.org

What We Are Working On

| Activity | How to Access |
|---|---|
| Looking for ADRD resources for and by AIAN audiences (flyers, posters, guides, training, people, projects), please share | Email: jolie@iasquared.org or MaryAnn@iasquared.org |
| Need feedback on new info resources you need NOW! | Email: jolie@iasquared.org |
| Monthly e-news for ADRD for and by American Indian and Alaska Natives | Sign up now: http://eepurl.com/hfDI6n |
| Print-on-demand \$250 stipends for tribes for select resources (flyer, poster, provider guide) | https://www.surveymonkey.com/r/2021PrintRequest |
| NEW – website and resource library | www.AIAnBrainHealth.org |
| NEW – “Dementia Friends” adaptation for AI/AN communities | https://iasquared.org/dementia-friends/ |
| Savvy Caregiver for Indian Country Training – 2 Next Year | Stay tuned to e-news and website |
| VA Training Referral - Addressing Behavioral Challenges of Dementia (ABCD) training program for I/T/U public health and aging staff; other resources | Email: jolie@iasquared.org |





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Q&A

Please use the Q&A feature to submit your questions!



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