



INTERNATIONAL ASSOCIATION FOR
INDIGENOUS AGING

Tools for Tackling Alzheimer's and Dementia in Tribal Public Health: Honoring Sovereignty, Culture, Diversity, and Tradition

National Tribal Public Health Summit

April 28, 2021

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Pre Session Poll

Chat

Polls

Files

People

 **How would you rate your level of knowledge and experience with Alzheimer's and dementia?**

A. Novice – no previous experience or very limited knowledge

☐

B. Advanced beginner – some knowledge; but relies on rules, guidelines or outside resources to help

☐

C. Competent – 2-3 years experience, can independently plan and manage for care or programs

☐

D. Proficient – more advanced knowledge; holistic understanding of Alzheimer's and dementia

☐

E. Expert - extensive knowledge; confidence in work; easily understands complex cases & situations

☐

Welcome



Jolie Crowder
& Dave Baldrige (Cherokee)

Overview

Today is NOT: An in-depth or clinical overview of Alzheimer's disease or dementia

- 1** | **About IA²**
- 2** | **2-Person Breakout**
Intro, Expectation, & Context
- 3** | **About Dementia**
- 4** | **2-Person Breakout**
Reflection, Stigma & Awareness
- 5** | **IA² Healthy Brain Project & Other Tools**
- 6** | **2-Person Breakout**
Other Available Resource & What Do You Need?

About IA²

The International Association for Indigenous Aging, a 501(c)3 non-profit educational association, works to:

- Ensure the provision of appropriate and quality services and resources for indigenous elders
- Expand opportunities for elders' involvement in environmentalism, community participation, health maintenance, volunteerism/civic engagement, consumerism, senior enterprise
- Enhance the protection of the rights of elders including their freedom from abuse and neglect and their right to autonomy
- Educate the public, policymakers and practitioners about the status of indigenous elders
- Improve the status of older people worldwide, especially indigenous populations

www.iasquared.org

IA² Alzheimer's and Dementia Work

- 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 [set of materials](#) for American Indian and Alaska Native audiences on brain health for Association for State and Territorial Health Officials (ASTHO) with funding from CDC (flyers, posters, PSAs, videos, provider guide, articles)
- 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 and Absentee Shawnee Tribal Health Center on ACL Alzheimer's Disease Program Initiative (ADPI) grants as 3rd party evaluator
- Local work with Albuquerque Alzheimer's Association

2 Person Breakout - Introductions

- 5 minutes
- Name, tribal affiliation, & organization
- What do you want to experience in today's meeting? (Info, question answered, topic, takeaway)
- What is your experience with Alzheimer's Disease and dementia? What does it look like in your community?
- Come back and share in big group & 1 person post summary in chat



5 Minutes for Reflection

- Couple volunteers to share
- **Everyone:** Type brief summary in the chat to capture!

Dementia As A Community Concern

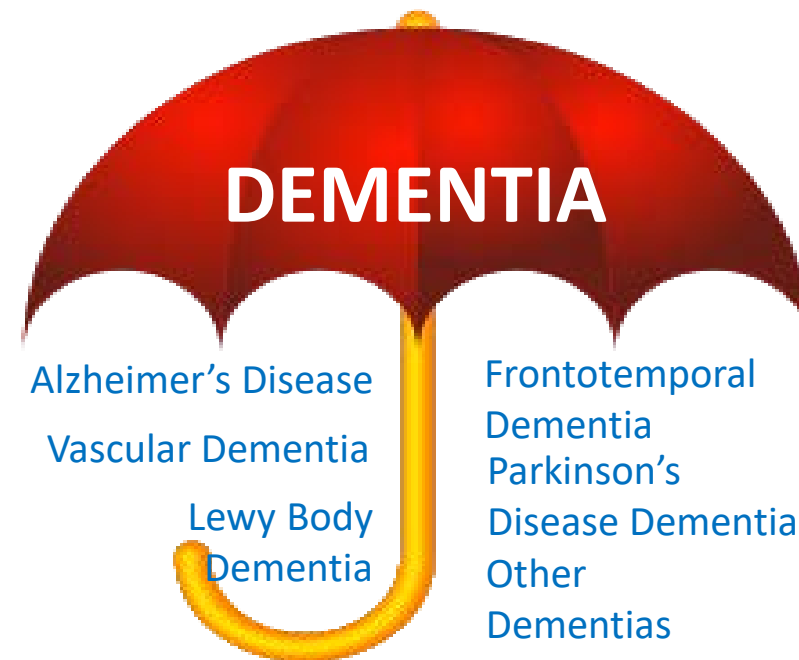


BUT

- 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

What is Dementia?

- Dementia - Changes in the brain resulting in loss of cognitive function that interferes with daily life
- Many types of dementia
 - Alzheimer's is the most common cause of dementia
 - Many (maybe majority) of cases have multiple causes



Alzheimer's in the US

- 6.2 million adults
- 1 in 9 adults age ≥ 65
- 1 in 3 adults age ≥ 85
- 2/3 are women
- 1 in 3 older adults dies with Alzheimer's or dementia
- 5th leading cause of death in US
- 2x more likely to get COVID-19 if a person has dementia



<https://www.alz.org/alzheimers-dementia/facts-figures>

<https://www.nia.nih.gov/news/dementia-increases-risk-and-severity-covid-19-study-finds>

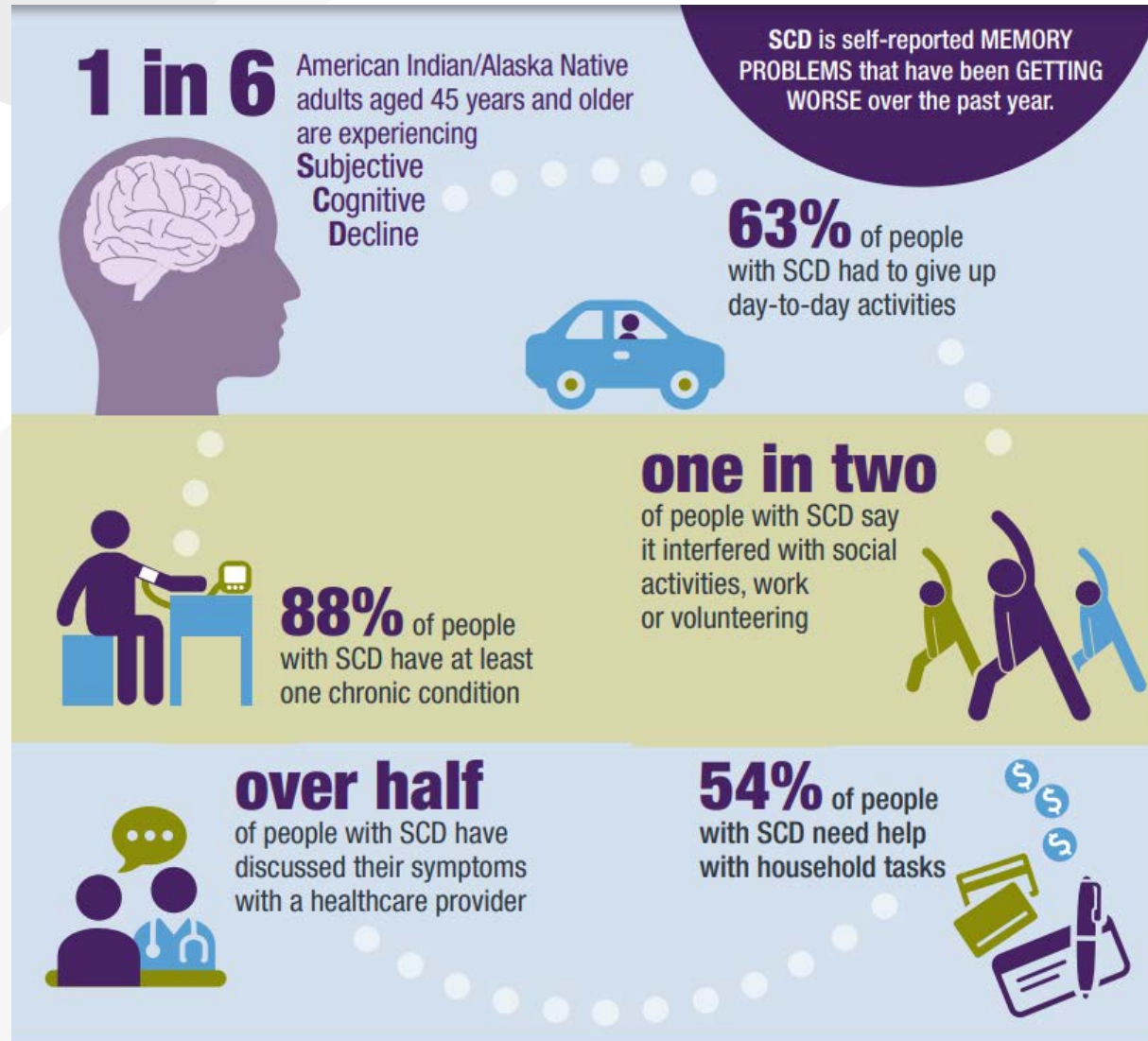
Dementia in American Indian and Alaska Native Peoples

- 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
- 63% of Native American caregivers have faced discrimination navigating care for PLWD
- Native Americans report the least concern about developing Alzheimer's; they also believe they won't live long enough to get it



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>
<https://www.alz.org/media/Documents/alzheimers-facts-and-figures-special-report.pdf>

Memory Issues Don't Just Impact Older Adults



A Few More Facts

<https://www.alz.org/alzheimers-dementia/facts-figures>

- 70% of people with dementia live in community settings
- < 50% of people diagnosed with dementias, or their caregivers, aware of diagnosis
- ~ 50% of people with Subjective Cognitive Decline discussed memory concerns with health care provider
- 96% of Medicare beneficiaries with dementia have 1 or more additional chronic conditions
- About 24% of hospitalizations are preventable among older adults diagnosed with dementia
- About 1 in 3 caregivers for people with Alzheimer's report worsening health themselves

“While reliable prevalence or incidence data on Alzheimer’s disease or other types of dementia in the American Indian and Alaska Native population are not currently available, we do know that in every Tribal community there are individuals with dementia and caregivers struggling to support them.”

-- Bruce Finke, MD, Senior Advisor for Improvement and Innovation, Testimony to Special Committee on Aging

2 Person Breakout – Awareness & Stigma

- 10 minutes
- Reflection: Was there anything that surprised you? What more would you like to know/learn?
- Is there **stigma** related to talking about or diagnosing Alzheimer's Disease and dementia, and memory issues in your community? How can we talk about it in a more positive light? How can we engage families, elders and community in creating **awareness** about ADRD without them shutting down?
- Come back and share in big group & 1 person post summary in chat



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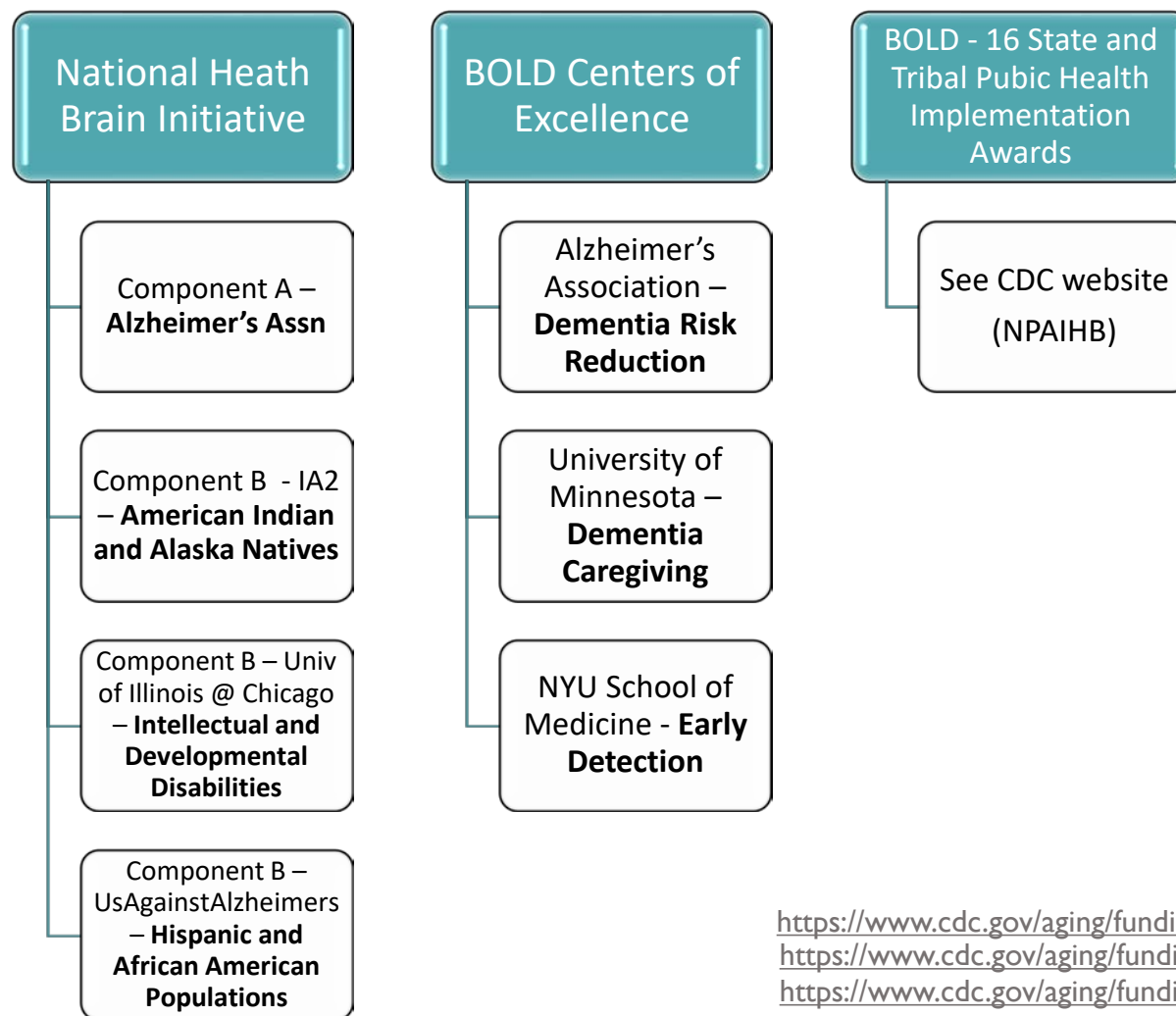
CDC Funded Alzheimer's & Dementia Programs



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



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



<https://www.cdc.gov/aging/funding/hbi/index.html>
<https://www.cdc.gov/aging/funding/php/index.html>
<https://www.cdc.gov/aging/funding/phc/index.html>

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



What We Are Working On

Activity	How to Access
Looking for ADRD resources for AIAN audiences (flyers, posters, guides, training, people, projects), please share	https://www.surveymonkey.com/r/advisorygroupassetrequest Email: jolie@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 select resources (flyer, poster, provider guide)	http://iasquared.org/wordpress2/2021/02/18/ia2-now-offers-print-on-demand-for-brain-health-resources/
Starting project website redesign – resource library	Stay tuned to e-news and website
In-person training at NICOA Conference in Reno, NV Aug 1-6 th – Savvy Caregiver	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

Current Webpage Info and Resources

- <http://iasquared.org/wordpress2/what-we-do/current-projects/healthy-brain-initiative/>

Healthy Brain Initiative

National Healthy Brain Initiative



The 5-year U.S. Centers for Disease Control and Prevention (CDC) funded project establishes IA² as a national hub for Alzheimer's disease and related dementias (ADRD) information resources serving Indian country. IA² will provide training, technical assistance, and resources for tribes, tribal leadership, healthcare and public health staff at Urban Indian Health Centers and organizations, and tribal elder services advocates across the country. Activities are designed to advance community engagement and help build capacity among tribes and tribal member-serving organizations, promote health cognitive aging strategies across the lifespan, and foster dementia-capable tribal communities.

Recent Posts

New Resource – COVID & Brain Health Protection Flyer

New Resource – Planning Guide for Road Map for Indian Country

Community Health Workers Assist with Early Detection of Dementia and Cognitive Impairment

IA² Now Offers Print on Demand for Brain Health Resources

NEW Healthy Brain Initiative for Indian Country Resource: IA² is now offering print on demand flyers and posters from the IA² / ASTHO and National Council for Urban Indian Health (NCUIH) suite of materials developed with funding from the Healthy Brain Initiative sponsored by Centers for Disease Control and Prevention. Printed materials are sent directly to tribal offices or urban Indian health centers.

[Click here](#) to see the suite available brain health resources for health care providers and American Indian and Alaska Native peoples or learn more.

Print requests are limited to \$250 in materials per tribe or urban Indian center.

To see items available to print, costs per item (to build your budget), or to place your order [click here](#).



Other Available Resources for Native American Elders, Caregivers, and Healthcare Providers

Savvy Caregiver in Indian Country Training Materials

Alzheimer's Association Indian Country Resources

National Indian Health Board Resources

Urban Indian Health Resources

Centers for Disease Control and Prevention Healthy Brain Initiative

Indian Country Training Materials

Designed for trainers working with American Indian and Alaska Native elders for an elder with memory loss and thinking problems. These materials are one of the main themes of the Savvy Caregiver in Indian Country Trainer's Guide, which helps caregivers to know the stage of dementia corresponding to their abilities. Knowing how to determine the stage allows the caregiver to select tasks that fit the elder's changing abilities.

New Resources from Others / Keep An Eye Out

Activity	How to Access
Participate! IHS \$5 million/ 2 year funding for ADRD – Area listening sessions in May	https://www.ihs.gov/dccs/consultationandconference/
Apply! ACL Alzheimer’s Disease Program Initiative (ADPI) Tribal Grants – ~ May	https://www.grants.gov/custom/viewOppDetails.jsp?oppld=332306#
Take Action! New Resource - NCUIH & Alzheimer’s Assn Planning Guide for Road Map for Indian Country	http://iasquared.org/wordpress2/2021/04/22/new-resource-planning-guide-for-road-map-for-indian-country/
Learn More! NIHB Resources - Brain Health Action Institute & Training Module	NIHB staff available to share
Special Support! Intellectual and Developmental Disabilities and Dementia: Resources and webinar series start next week	<ul style="list-style-type: none"> • https://www.healthmattersprogram.org/hbi-pwidd/ • https://www.healthmattersprogram.org/2021-healthy-brain-webinar-series-for-people-with-idd/

2 Person Breakout – Other Resources & Your Needs

- 10 minutes
- Are there other resources (training, resources, people, programs, etc.) are out there for **Native communities** we are missing – tribal, state, national?
- What **information resources**, training or other help do you need? What do you need to get started or do more?
- Come back and share in big group & 1 person post summary in chat



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Additional Information



IA² Healthy Brain Initiative – Project Staff



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