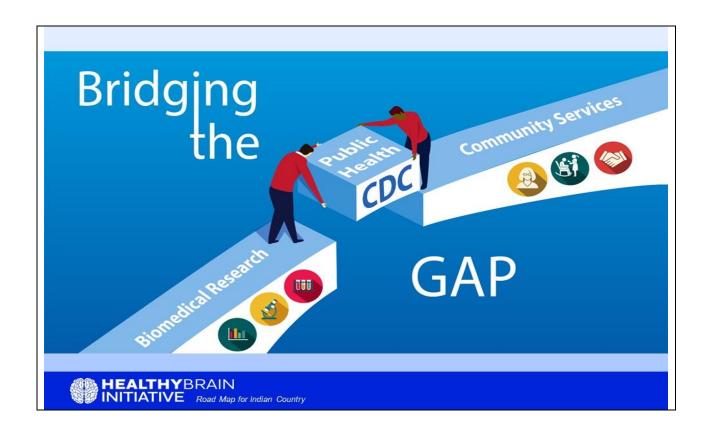
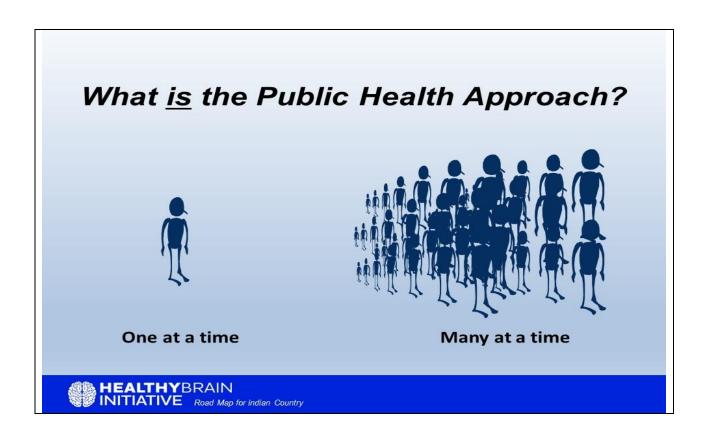


The Road Map for Indian Country

Starting Conversations about Dementia in Indian Country: A Public Health Road Map

July 29, 2019 National Alzheimer's Project Act Advisory Council Meeting







## **Speakers**

#### Blythe Winchester, MD, MPH, CMD

Certified Medical Director, Tsali Care Center Geriatrician, Cherokee Indian Hospital Chief Clinical Consultant, Geriatrics and Palliative Care, Indian Health Service

#### **Molly French**

Director of Public Health, Alzheimer's Association

#### Carolyn Angus-Hornbuckle

Director of Public Health Policy and Programs, National Indian Health Board **Bruce Finke, MD** 

Elder Health Consultant, Indian Health Service, Indian Health Services

#### Lisa McGuire, PhD

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



## National Alzheimer's Project Act

7/29/19

Blythe Winchester, MD, MPH, CMD
Eastern Band Cherokee
Geriatrician, Cherokee Indian Hospital
Certified Medical Director, Tsali Care Center
Chief Clinical Consultant, Geriatrics and
Palliative Care, Indian Health Service

## Objectives

- Provide a brief snapshot of Indian Country with a focus on diversity, culture, and traditions
- Overview of dementia and caregiving in Indian Country
- Examples/case studies from my clinical experience to illustrate the issue in Indian Country



## **AIAN Elders**

- The non-Hispanic American Indian and Native Alaskan older population was 231,482 in 2014, and is projected to grow to more than 630,000 by 2060
- Almost twice as many Al/ANs ages 50 and over are uninsured as are people of the same age in the US population
- Close to 22 percent of AI/ANs ages 50 and over receive care from the Indian Health Service (IHS)
- American Indians and Alaska Natives born today have a life expectancy that is 5.5 years less than the U.S. all races population (73.0 years to 78.5 years, respectively).



IHS updated April 2018 https://www.ihs.gov/newsroom/factsheets/disparities/ // ACLhttps://acl.gov/aging-and-disability-in-america/data-and-research/minority-

## Demographics/Epidemiology

- 5.2 million US residents AIAN, another 527,077 Native Hawaiian
- 2010- US Census estimated 37.1% AIAN and 26.7 % NHOPI (Native Hawaiians and other Pacific Islanders) were living alone
- 22% AIAN and NHPOI reported depressed mood much of the time in past year compared to 11.7% white elders
- Lower levels of cancer screening, esp for colorectal cancer
  - 2010 data: 49.5% AIAN were in compliance with colorectal cancer screening recs compared to 59.8% whites. 55.8% Native Hawaiians compared to 64.2%

US census bureau https://www.census.gov/

Patrick M. Lynch, Colorectal cancer screening in the American Indian/Alaska Native population: Progress and at least one new challenge, *Cancer*, **120**, 20, (3105-3107), (2014)

## Demographics/Epidemiology

- Al/ANs have the highest prevalence of CVD of any racial or ethnic group
- Al/ANs experience high rates of disability, especially compared to Whites
- Heart disease, cancer, unintentional injuries, and diabetes are leading causes of American Indian and Alaska Native deaths (2009-2011)
- 22 percent of American Indians and Alaska Natives live on reservations or other trust lands. 60 percent of American Indians and Alaska Natives live in metropolitan areas

R. Turner Goins, Margaret Moss, Dedra Buchwald, Jack M. Guralnik; Disability Among Older American Indians and Alaska Natives. An Analysis of the 2000 Census Public Use Microdata Sample, *The Gerontologist*, Volume 47, Issue 5, 1 October 2007, Pages 690 696, <a href="https://doi.org/10.1093/geront/47.5.690">https://doi.org/10.1093/geront/47.5.690</a>
IHS <a href="https://www.ihs.gov/newsroom/factsheets/disparities/">https://www.ihs.gov/newsroom/factsheets/disparities/</a>



## Cultural considerations

- Language
- Historical experience: The number of Native American children in the boarding schools reached a peak in the 1970s, with an estimated enrollment of 60,000 in 1973
- · Use of traditional indian medicine
- Framing and context for illness understanding



## Historical experiences of elders

1900-1920	1920-1940	1940-1960	1960-1980	1980-Present
Reservations	Citizenship	World War II Service	Vietnam War	Education of Professionals
"Vanishing America"	Adoption of Indian Children by Whites	Relocation by BIA to Urban Areas		Litigation
Forced Boarding Schools	Loss of Land by Allotment System	Forced Assimilation	Urbanization for Education & Jobs	Urban Pan- Indianism
Law Banned Spiritual Practices	Boarding Schools			Reservation Gaming

Source: Hendrix, L. in Yeo et al. (Eds.) 1998

## Caregiving

#### Cultural considerations:

- Framing
- Many more caregivers involved
- Matriarchy
- · Social situations at home
- Abuse





## Examples

- Little people, boogers- hallucinations or tradition?
- "that's just normal aging"- turnover and unfamiliar relationships in clinics
- Patients going to council members to seek additional assistance for dementia care



## Developing the New Road Map for Indian Country

Molly French, MS
Director of Public Health
Alzheimer's Association

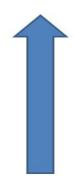


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## Take-Aways



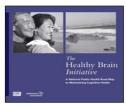
- 1. Rising interest
- 2. Solutions from within
- 3. Strengths-based strategies

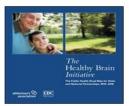


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## Healthy Brain Initiative (HBI) Road Maps

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







## **Need for 2 Road Maps**

A separate, parallel document for Indian Country that:

- Embraces the unique strengths, priorities, and practices of Indian Country
- Fits with existing health and public health foundations



State and Local HBI Road



HBI Road Map for Indian Country



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## **Building the Road Map**

Input gathered from:

- Regional tribal health boards and members
- Tribal health leaders
- Tribal aging service leaders
- Tribal government officials
- Other experts



HBI Road Map for Indian Country

HEALTHYBRAIN
INITIATIVE Road Map for Indian Country

## Advice & Expertise & Collaboration

Indian Health Service
International Association for Indigenous Aging (IA²)
National Indian Health Board (NIHB)
Alzheimer's Association
Centers for Disease Control and Prevention
Association of State and Territorial Health Officials
Healthy Brain Research Network
Administration for Community Living
Centers for Medicare & Medicaid Services
National Institute on Aging

And many more.......Thank You!



Alzheimer's Association & IA2

## **Listening and Learning**

### 2 Virtual Listening Sessions

- Tribal Health Directors
  - 12 Regions, 500+ invitations
- Tribal Senior Program (Title VI) Directors
  - Invitations through Admin. for Comm. Living

## 40+ tribal leaders and experts offered written suggestions and comments



### **Themes**

- Knowledge, awareness of dementia varies
- Complex, changing context

#### Recommendations

- Involve tribal leadership in planning
- Local leaders know best ways to reach and serve their members





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### St. Regis Mohawk Nation

Networking & finding examples

- 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



#### Alzheimer's Association & NIHB

## **Listening and Learning**

## Virtual Input Session on Graphic Design

· Motifs, photos, layout, etc.

## Invited written suggestions and comments



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### 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

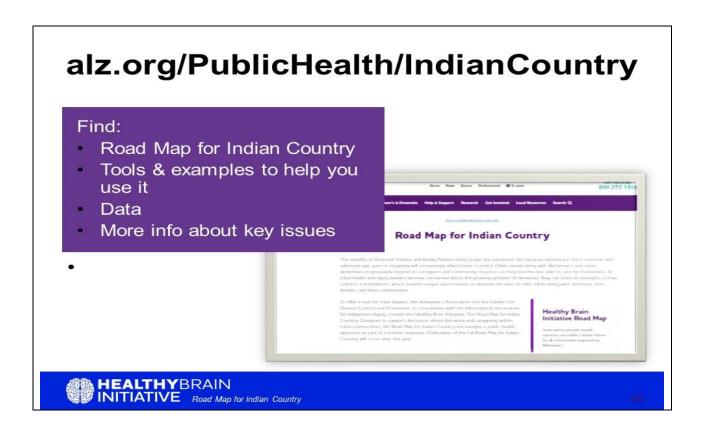
- Educate and empower community members
- Collect and use data
- Strengthen the workforce











### **Conclusions**



- 1. Rising interest
- 2. Solutions from within
- 3. Strengths-based strategies



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#### Prevalence and Incidence of Dementia in American Indians and Alaska Natives

"Reliable data on the prevalence or incidence of dementia among populations who identify themselves as American Indian or Alaska Native in the United States are nonexistent."

"...only a few researchers have attempted to study cognitive status among small samples of American Indian elders, none of which provided prevalence or incidence estimates"

- Mehta and Yeo Epub 2016

Systematic review of dementia prevalence and incidence in United States race/ethnic populations. Mehta KM, Yeo GW. Alzheimers Dement. 2017 Jan; 13(1):72-83. Epub 2016 Sep 4.

#### Kaiser Permanente Northern California Dementia Incidence Rates 2000-2013

- KNPC members enrolled and 60 years and older as of 1/1/96
- KNPC seniors (65 years and older) are similar to general population of seniors in Northern CA: hx chronic conditions, lifestyle factors, and patterns of racial inequality (CHIS data)
- No dementia diagnosis as of 1/1/2000
- Incident cases between 1/1/2000 and 12/31/2013.

Not a population-based study Self-identified AI/AN

Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimers Dement. 2016 Mar;12(3):216-24.. Epub 2016 Feb 11.

### Kaiser Permanente Northern California Dementia Incidence Rates 2000-2013

Incidence among self-identified American Indians and Alaska Natives is second only to incidence among African-Americans

Race / Ethnicity	Age-adjusted Incidence Rate/1000 person-years (95% CI)	Hazard Ratio
African-American	26.60 (25.83-27.37)	1.73 - 1.65
American Indian / Alaska Native	22.18 (20.85-23.52)	1.32 - 1.43
Latino	19.59 (18.97–20.20)	1.24 – 1.29
Pacific Islander	19.63 (14.51–24.75)	1.23 – 1.28
White	19.35 (19.16–19.54)	1.22 – 1.25
Asian-American	15.24 (14.73-15.74)	1.00 (reference)

Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimers Dement. 2016 Mar;12(3):216-24.. Epub 2016 Feb 11.

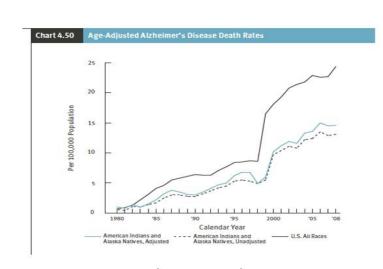
## Prevalence of Dementia in First Nations of Alberta 1998-2009

- Aggregate data from Alberta Health and Wellness
- Physician-treated dementia
- Age-adjusted Prevalence

First Nations: 7.5/1000 (95% CI: 6.6-8.5) Non First Nations: 5.6 (95% CI: 5.5-5.6)

Disproportionately younger and male in First Nations

The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. Jacklin KM, et al. Can J Public Health. 2012 Nov 8;104(1):e39-44.



Trends in Indian Health 2014

https://www.ihs.gov/dps/publications/trends2014/

#### Population-based risk factors

	Ratio: Al/AN to U.S. All Races
Diabetes	2.5
Unintentional injury	2.5
Nephritis, nephrotic syndrome	1.5
Chronic liver disease and cirrhosis	4.8
Cerebrovascular Diseases (stroke)	1.0
Hypertensive disease	1.0
Alzheimer's disease	0.7

https://www.ihs.gov/newsroom/factsheets/disparities/

## Response to ADRD - The Indian Health System NOT COMPREHENSIVE

- Tribal Health Programs and Systems
- Urban Indian Health Programs
- Indian Health Service Direct Services
- Tribal Epidemiology Centers (TECs)
- Regional and National Health Boards and Tribal Organizations
- Native non-profit organizations (e.g. National Indian Council on Aging)
- Non-profit sector health services and consulting organizations
- Private sector health services and consulting organizations
- University-based health services research and programs

- IHS Area Programs
- IHS Headquarters Programs
- CDC AI/AN focused staff and programs
- CMS Tribal and Intergovernmental Affairs
- SAHMSA mental health and substance abuse
- HRSA workforce development and Urban Indian Health and Tribal Health Programs (FQHCs and Health Center lookalikes)
- AoA/ACL linking to community-based program

#### **ADRD - Focus Areas for IHS**

- Awareness in the community
  - Timely recognition
  - Demand for services
  - Community-based services with linkages to health services
- Workforce competency in recognition, diagnosis, management
  - Increase knowledge and confidence
  - Content includes cultural competencies
- System competence to meet the needs of individuals with dementia.
  - Evidence-based caregiver support based in REACH
  - Targeted care management, integrated into primary care
- Reduction of risk factors for dementia
  - Management of DM, HTN, CVD, Substance Use Disorders, Injury Prevention
- Measurement to guide improvement in Care and Services
  - NAPA Plan Measurement
- Availability of LTSS

## HEALTHY BRAIN INITIATIVE

STRENGTHENING THE PUBLIC HEALTH RESPONSE TO ALZHEIMER'S DISEASE AND DEMENTIA LISA C. MCGUIRE, PHD



## HBI Road Map for Indian Country

- Tailored for tribal health leaders
- Learn, plan, and start responding to Alzheimer's and other dementias











## Road Map Strategies

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

https://www.cdc.gov/aging/healthybrain/Indiancountry-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

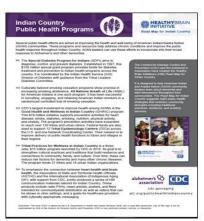




## New Materials to Educate & Empower Communities











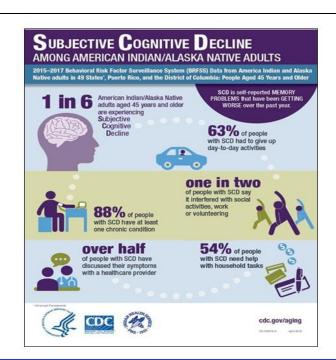
## Collect & Use Data



- Get data about how dementia and caregiving affects your community
- Use quality measures to improve care for people living with dementia









#### Data for Action

https://www.cdc.gov/aging/data/infographic/2017/american-Indian-alaska-native-cognitive-decline.html









#### Data for Action

https://www.cdc.gov/aging/data/infograp hic/2017/american-indian-adultscaregiving.html



## Strengthen the Workforce

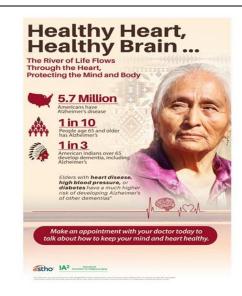
- Train people who provide health care or other services about
  - Brain health
  - Alzheimer's and dementia
  - Caregiving
- Give professionals information to share with patients (or clients)





# Series of Communication Materials

- Poster and flyers for clinics and health fairs
- Radio public service announcements
- Micro-videos for clinics
- Provider guide about heart and brain health
- Newspaper articles for the Indian Country Today Media Network



http://www.astho.org/Healthy-Aging/Healthy-Heart-Healthy-Brain/



## New Continuing Education ACPM Course: Brain Health

American College of Preventive Medicine

Section 1

 Descriptions & Risk Factors

Section 2

 Risk Reduction & Management I

Section 3

 Risk Reduction & Management II

Section 4

• Resources & References

#### Learning Outcomes:

- Explain-review brain health terminology
- Define and describe risk factors associated with age related cognitive decline, mild cognitive impairment, and dementia
- Summarize lifestyle medicine management strategies, including hypertension management, that may decrease risk

#### **Continuing Education:**

1.0 CME/MOC education activity is available through ACPM's learning platform

#### Cost:

Learners can create a free login account and take the course at no cost

https://www.acpm.org/page/brainhealthcourse



### New Brain Health Resources



American College of Preventive Medicine physicians dedicated to prevention

For your convenience, ACPM provides this collection of resources for physicians, health care professionals, and their patient populations. Materials include those developed by ACPM, its partners, and leading advocates of brain health.

#### RESEARCH

- Emerging research
- Epidemiological information

#### PROVIDER TOOLS

- · Best practices and guidelines
- Screening and diagnostic tools
- Risk factor treatment strategies
- Evidence-based community programs
- Referral strategies
- Insurance coverage
- Provider reimbursement

#### PATIENT MATERIALS

Patient handouts

**Brain Health Resources** 





## Additional CDC Public Health Programs and Resources

- Good Health and Wellness in Indian Country
- Tribal Epidemiology Centers
- Tribal Practices for Wellness in Indian Country
- Healthy Heart, Healthy Brain Messaging





## Next Steps....Highlights



- Continue to support States, Territories, and Tribes with data for action and to implement New Road Maps
  - Integrate brain health messaging in to chronic disease messaging
  - Action Institutes to stimulate strategic changes in policy, systems, and environments





What's this?

**Email Address** 

address:

Newsletter Subscription Select "Healthy Aging"

Submit



cdc.gov/aging





### 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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alzheimer's 8

