## Indigenous Aging



## Advancing a community-based model to address dementia in tribal clinics

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## Partnerships for Native Health



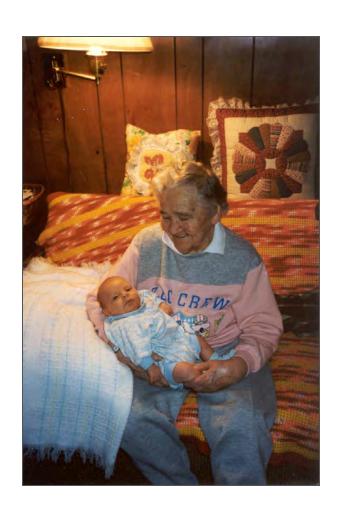
- Community-based action research, education and training
- Urban and reservation-based Al/AN populations across the lifespan
- Physical and mental health, chronic disease, elder health, healthcare needs
- ~ 160 partners: tribal colleges, AI/AN organizations, tribes (30 active partners)
- 75 projects funded since 2007



## Outreach, Research, and Education (ORE)



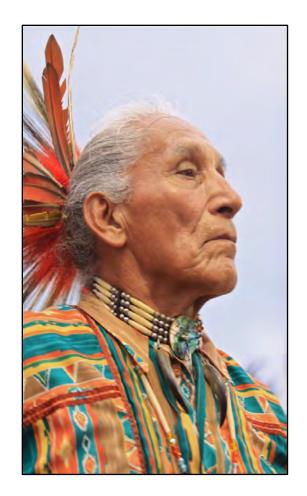
- Context
  - Dementia 101
  - American Indians/Alaska Natives (Al/ANs), cognitive impairment, and dementia
  - Washington State data
- Clinical Integration Efforts
  - Native outreach and education
  - Detection
  - Resources



### What is Dementia?



- Dementia is a decline in mental ability, including memory, that is severe enough to result in loss of independence in typical daily activities.
- Dementia is most common in older adults and has many known causes.
- Alzheimer's disease is the most common type of dementia in older adults.



### What is Alzheimer's Disease?

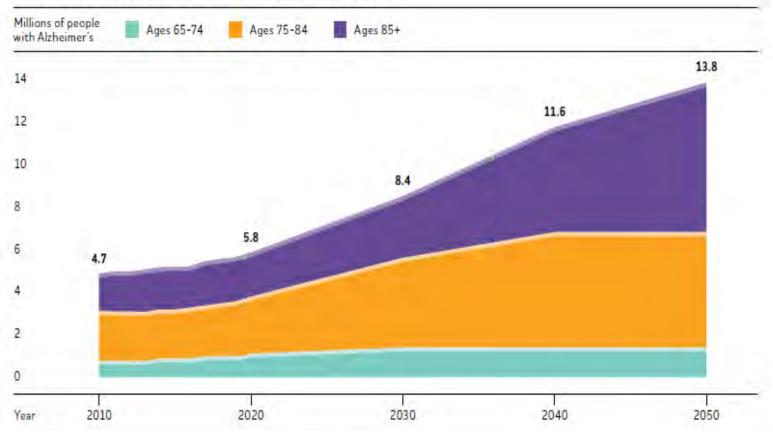


- When cognitive impairment is due to Alzheimer's disease, symptoms usually start gradually and progress slowly, over many years.
- In its early stages, memory loss is mild, but with latestage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment.
- There is no cure for Alzheimer's disease, but there are opportunities for early diagnosis and interventions which temporarily slow the worsening of dementia symptoms and improve quality of life.

## 2017 Facts and Figures



Projected Number of People Age 65 and Older (Total and by Age Group) in the U.S. Population with Alzheimer's Dementia, 2010 to 2050

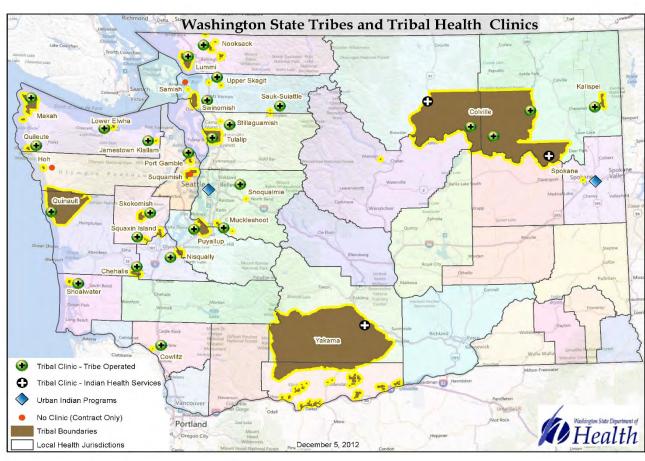


Alzheimer's Association 2017 Disease Facts and Figures <a href="http://www.alz.org/">http://www.alz.org/</a>

## Alzheimer's in Washington State



- 100,000 cases in Washington
  - 40% increase expected by 2025
- Third highest incidence rate in the US
- Third leading cause of death
- 9<sup>th</sup> cause of death among Al/AN in Washington State 2006-2010.



Alzheimer's Association. 2017 Alzheimer's Disease Facts and Figures. Alzheimer's & Dementia 2015;11(3)332+ Washington State Death Certificates, 2006-2010 corrected for misclassified AI/AN race, NWPAIHB.

### Alzheimer's Disease and Al/ANs



- The number of AI/ANs age 65 and older is growing fast.
- The US Census Bureau estimated that in 2012, 266,000 AI/ANs were aged 65 and older
- According to projections, the population of Native elders in this age range will almost quadruple by 2050, to 996,000.
- Many experts believe that Alzheimer's disease is underdiagnosed in our communities.

#### Al/AN Dementia Risk: What do we know?



#### Two recent studies of Alzheimer's disease:

- Mayeda et al. Alzheimer's & Dementia (2016)
  - AI/ANs and African Americans have the highest incidence of dementia among all racial and ethnic groups.
- Chen and Panegyres. Journal of Alzheimer's Disease (2016)
  - AI/ANs and Native Hawaiians have twice the risk of early-onset dementia (before age 65) relative to Whites (lowest risk group).

## P4NH - Community-based Model



Start with Questions

Inventory of services
Local workgroups (AA)
Dementia action collaborative

Develop Partnerships Tribally operated clinics
Urban Indian Health Organizations

Design
Outreach &
Research

Clinic and community level education
Pilot study – Attitudes brain donation and
Alzheimer's related research

### **Start with Questions**

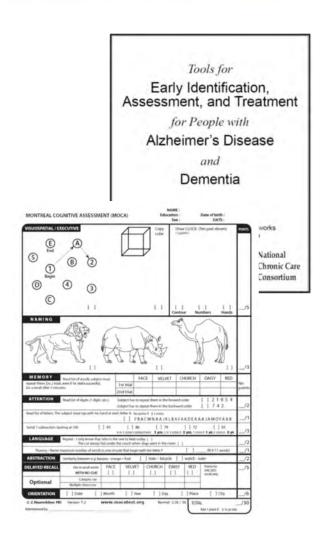


- Administered Alzheimer's Disease Knowledge Scale (ADKS) at 3 pow wows in 2016/2017
  - N=419 self identified AI/AN participated
  - 77% of respondents have heard of Alzheimer's disease
  - 37% have immediate family member with trouble thinking or memory loss
  - If personally diagnosed, 61% would agree or strongly agree to donate a blood sample to help researchers find causes and treatments for the condition

## Partnership with Tribal Clinics



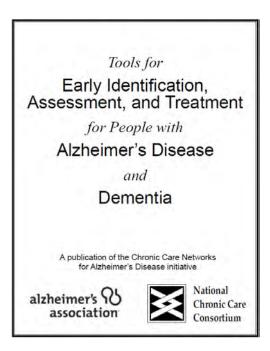
- Fewer than 50% of cases of dementia are diagnosed in a clinical setting.
- 45 minute presentation for tribal clinics in Wash. State
  - Improves knowledge of disease
  - Overview diagnosis criteria and screeners
  - Treatment & Prevention
  - Research at ADRC



### Clinic-based Evaluation



- Interview and history
- Physical and neurologic exam
- Cognitive assessment
- Depression screening
- Functional status
- Medical history review
- Medication review
- Laboratory tests
- Brain imaging
- Repeat evaluation in 6-12 months if cause unclear



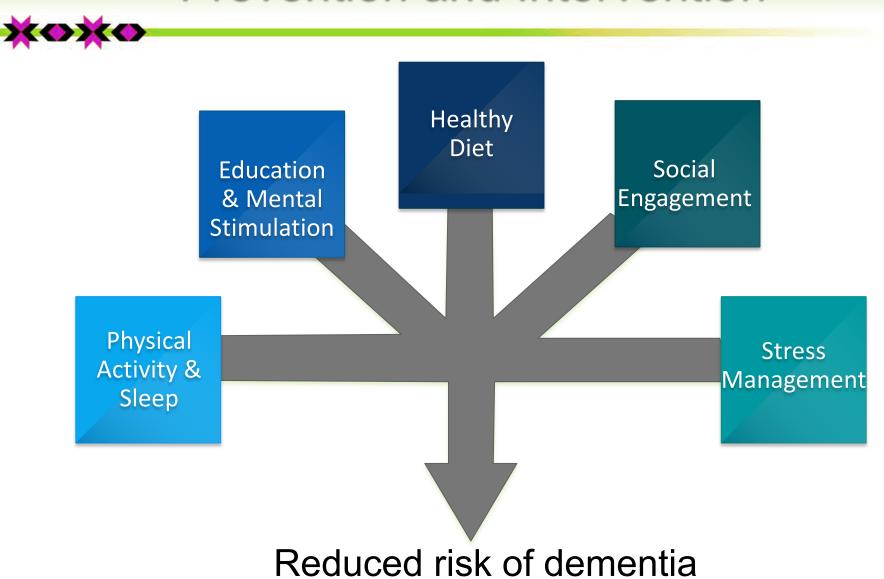
## Partnership Activities – Elder's Groups



- Improve patient and family knowledge
  - Digital story
  - Review the signs and symptoms of dementia
  - Discuss implications and distribute educational materials
  - Engage in dialogue with community members



#### Prevention and Intervention



Baumgart, Matthew, et al. *Alzheimer's & Dementia* (2015) Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective.

## Partnership Activities



- Distribute educational materials in clinic waiting rooms
- Distribute materials at health fairs and powwows
- Mail fact sheet to priority audiences
- Resource sharing
- Capacity building



Alzheimer's Association Information and resources to help elders and their families learn about dementia through a 24/7 helpline, care consultation, education, early stage programs, caregiver resources. and an online library. Online: http://www.alz.org/ 24/7 Helpline: 1-866-403-3073

King County Caregiver Support Network The King County Caregiver Support Network helps caregivers find support groups, counseling, training, and other resources to better care for their loved ones with Alzheimer's disease. Online: http://www.kccaregiver.org/

Alzheimer's Café Alzheimer's Cafes are available in various cities in King and Snohomish Counties for people with Alzheimer's disease and their caregivers to meet and talk Online: http://www.fulllifecare.org/alzcafes/ contact us. Our contact information appears

#### **Natives Care**

Understanding Alzheimer's Disease and Dementia



Partnerships for Native Health Online: http://www.p4nh.org/research/ Phone: 206-708-8629 (toll free)

University of Washington Alzheimer's Disease Research Center

Phone: 206-764-2069 or 1-800-317-5382



Alzheimer's Disease Research Center University of Washington

## Partnership Activities – Provider Training



- Dementia in Primary Care: Practical Tools.
   Real World Advice.
  - 3 hour workshop for primary care to better manage dementia
  - Is it dementia?
  - How do the types of dementia differ?
  - Retiring sagely from driving
  - Managing behavioral problems

### Other Research Activities



- "Alzheimer's Disease Research Study for American Indians and Alaska Natives" is a pilot study that was funded to:
  - Develop and deliver a presentation on Alzheimer's disease research
  - Administer pre- and post-presentation surveys
  - Conduct focus groups with AI/ANs on the impact of the presentation

# Research Activities at University of Washington



- Al/ANs are under-enrolled in clinical research and population-based studies.
- The University of Washington Alzheimer's Disease Research Center is a site for clinical trials and studies of potential treatments, prevention strategies, and new diagnostic approaches for Alzheimer's disease and related neurodegenerative conditions.
- http://depts.washington.edu/mbwc/research/clinica l-trials

# Research Opportunities at University of Washington



- Examples of intervention/treatment studies
  - EMERGE; CONNECT: placebo-controlled drug trials for people with early-stage Alzheimer's disease
  - A4: placebo-controlled drug trial for symptomfree older adults
  - Estia: computer games for older people with depression

## Research Opportunities at University of Washington



- Examples of observational studies
  - Alzheimer's Disease Research Center Clinical Core: natural history study to learn about cognitive aging over time in people with and without memory loss
  - IDEAS: Medicare-funded study to learn whether brain scans for detection of amyloids are useful
  - Neuroimaging and function studies to learn how changes in walking are associated with cognitive function in older people

### **Contacts**



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