FOUR PATHS TO ADDRESSING DEMENTIA IN TRIBAL COMMUNITIES

July 26, 2022
2:00 – 3:30 PM Eastern time

National Indian Health Board
Brain Health for Tribal Nations Project
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<thead>
<tr>
<th>Time</th>
<th>Presentation Title</th>
<th>Presenter(s)</th>
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<tbody>
<tr>
<td>2:00-2:10 PM</td>
<td><strong>Blessing</strong> - Carla Eben, Numaga Senior Services Title VI Director, Pyramid Lake Paiute</td>
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<td></td>
<td><strong>Welcome</strong> - Aaron Payment, EdD, Government Relations Director, NIHB</td>
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<td><strong>Overview</strong> - Karrie Joseph, MPH, Brain Health Project Director, NIHB</td>
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<td>2:10-2:25 PM</td>
<td>Mount Sanford Tribal Consortium - Jody Hatch, CHP-C, Deputy Health Director</td>
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<td>2:25-2:40 PM</td>
<td>Sokaogon Chippewa Community Health Clinic - Tawny Booth, Grants Manager</td>
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<td>2:40-2:55 PM</td>
<td>Aleut Community of St. Paul Island - Charlene Naulty, MS, Director, Department of Community Safety and Peace</td>
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<td>2:55-3:10 PM</td>
<td>Cheyenne and Arapahoe Tribes Department of Health - Derrell Cox, PhD, Tribal Epidemiologist</td>
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<td>3:10-3:20 PM</td>
<td>Q&amp;A</td>
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<td>3:20-3:30 PM</td>
<td>Resources for Tribes - NIHB</td>
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<tr>
<td>3:30 PM</td>
<td>Wrap-Up - Aaron Payment, EdD, Government Relations Director, NIHB</td>
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Mission Statement:

Established by the Tribes to advocate as the united voice of federally recognized American Indian and Alaska Native Tribes, NIHB seeks to reinforce Tribal sovereignty, strengthen Tribal health systems, secure resources, and build capacity to achieve the highest level of health and well-being for our People.
Mt. Sanford Tribal Consortium

Jody Hatch, CHP-C, Deputy Health Director

Mt. Sanford Tribal Consortium is a Tribal Health Organization that is located in the headwaters region of the Copper River in Southcentral Alaska. We operate a Community Health Aide primary care clinic, including Dental services, in Chistochina, an Athabascan village on the road system 236 miles from Anchorage. The nearest airstrip for medical evacuations is 50 miles away. Patients needing advanced care travel to Anchorage, 243 miles away by road.

MSTC is proud to provide frontline health care to our community and surrounding region here at home. We are a small, closely connected village of close to 100 full-time residents.
Our elders are our center.

Goal is to safely stay in their home, their village.

Our population is aging. Median age is 45 currently.

Identifying early signs and symptoms supports effective interventions

Timely interventions and treatment = better quality of life
Starting Point

Training for Mt. Sanford staff, clinic and grant personnel, interested community members.

- Health Aides have a longer visit time.
- We know our patients so can identify changes
- Training for clinic staff for early signs and symptoms.
- Cheesh’na Village Council President is a champion for our project.
What Worked Well:

- Training clinic staff
- Training Administrative staff
What Worked Well:

Health Aides use the Community Health Aide Manual for every visit, it contains our baseline scope of practice.

• There are now 26 CHAP programs across the state of Alaska run by Tribal Health Organizations (THOs). These programs range in size from a single village with one or two CHA/Ps to a region with about 50 villages and 200 CHA/Ps.

• Currently there are over 550 CHA/Ps providing care to more than 88,000 people in 180 Alaska Native communities.

Additional screening questions in intake process

akchap.org
What Worked Well:

Frequent Home visits for Elders

Better perspective on how they are managing daily activities, nutrition, and safety concerns in their home.
Better communication while in own home, not acutely ill.
What Didn’t Work as Expected:

Raising awareness and educating the community is an ongoing process and we will continue with the clinic staff trainings and meeting with families going forward.
In hindsight...
we should have had zoom meetings every month, instead of fewer. More consistent, and better odds of reaching everyone over time.
What’s ahead?

• We will continue to utilize our Health Aides as community champions for Brain Health and tailor our regional guidelines to our needs as our population ages. Early detection of changes is our goal.

1. Follow this Plan:
   1. See Memory Problems.
      1. Consider:
         1. If not already done this visit: Mini-Cog Assessment.
         2. Health and Habits, Changes and Concerns.
         4. Behavior Survey for Caregiver of the Person with Confusion.
   2. Talk to doctor about appointments for further evaluation and management.

Social:
1. Encourage elder to participate in social activities and community events. This helps elder feel a valued part of the community; passes on knowledge; decreases depression, isolation, and memory changes.
   1. Consider (if not already done this visit):

This is a part of an Elder visit from the Community Health Aide Manual. Each of these are options for screenings to follow for the Elder patient.
Contact Information

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Photography credit: Stacie Charley
Mole Lake Reservation, Crandon, WI
- 1,377 SCC Tribal Members
- The Sokaogon Chippewa Community Health Clinic (SCHC)
  - Primary and Urgent care
  - One of only three testing sites in a more than 30-mile radius
  - Main COVID-19 testing and vax provider.
- Serves Tribal members and non-members
- Rural
Background

- One clinical diagnosis for Dementia or Alzheimer’s
- 10 Elders participated in the Music and Memories program from 2014-2018 which consisted of
  - IPOD and notebook to track their progress.
  - Roadblocks:
    - getting Elders to be seen at a memory clinic in Rhinelander, WI
    - cultural beliefs
    - stigma of ADRD diagnoses
- SCHC wants to focus on early detection and diagnosis.
## Starting Point

<table>
<thead>
<tr>
<th>Educate and empower</th>
<th>Educate and empower Tribal/Community Members on the importance of early detection and treatment.</th>
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<tbody>
<tr>
<td>Work</td>
<td>Work with Tribal/Community members to understand brain health, early warning signs of dementia, and benefits of early detection and diagnosis for persons with dementia and their caregivers, and number</td>
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<tr>
<td>Provide</td>
<td>Provide information and tools to help older adults with dementia and their caregivers anticipate and respond to challenges that typically arise during the course of dementia.</td>
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What Worked Well:

• Held 2 Outreach Events – Health Fair on May 12th, 2022 and meet and greet with the new Elderly Director on June 2nd, 2022.

• Outreach/Event Materials. Target Goals to reach out to 20 Elders – at Health Fair we gave out materials, brochures, and books related to Dementia to 25 SCC Tribal Members.
What Worked Well:

- Do screening with providers to incorporate into their exams – We received Mini Mental State Examination from the providers that they completed on two SCC Tribal Elders and referrals were made to the Memory Clinic in Rhinelander, WI.

- Develop a brochure and mailings to community members – Brochure has been developed and in process of mailing out to the Tribal Community.

- Resource training for family and caregivers – Educational Resource Books for Caregiver guides for Dementia, Caring for a person with Memory Loss and Confusion were handed out to the Elderly caregivers and families.
What Worked Well:

Resources for Caregivers and Aging Planning

1. The Complete ElderCare Planner
2. Alzheimer’s Through the Stages: A Caregiver’s Guide
3. Who Will Take Care of Me When I’m Old?
4. How to Care for Aging Parents
What Worked Well:

Activity Books for the Elders
What Didn’t Work as Expected:

Medical Director will host events and speak with Elders. – Due to COVID-19 unable to see the Elders in their building per Tribal Council direction.

Work with Tribal law enforcement in training on signs and symptoms of dementia. To assist with potential wanderers within the community and silver alert if they go missing. – Unable to do this activity due to the vacancy of Law Enforcement Officer.

Challenges were definitely dealing with the COVID-19 Pandemic with multiple closures on Tribal Reservation and with quarantine protocols that were implemented with the Tribe’s ICS Team and Council.

Another challenge we encountered was the vacancy of the Elderly Director position.
In hindsight...

• If we were not dealing with the COVID-19 Pandemic, the vacancy of the Law Enforcement and Elderly Director position, ADRD stigma, the project would have worked perfectly!
What’s ahead?

• We hope to find additional funding to support ADRD

• We will continue to use the Mini Mental State Examination and refer to the Memory Clinic if needed.
Contact Information

Tawny Booth/Grants Manager
715-478-6418
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Aleut Community of St. Paul Island
Charlene Naulty, Txin Kaangux
Administrative Services Director

• 42.6 Square miles, in the Bering Sea
• 800 miles west of Anchorage, 300 miles north of the Aleutian Chain
• Population of 475, 83.96% Home to the largest Unangax population in the world
• 58 Seniors
• 19.95% of the population speak Unangam Tunuu (Aleut)
St. Paul Island
Background: Why We are Addressing ADRD

<table>
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<tr>
<th>Increase in</th>
<th>Increase in Alzheimer’s Disease and Related Dementias (ADRD) diagnoses and symptoms</th>
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<tr>
<td>Lack</td>
<td>Lack of programs for people living with ADRD</td>
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<tr>
<td>Need</td>
<td>Need to clarify referral process and services</td>
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<td>Need</td>
<td>Need education in the community on warning signs, diagnosis and treatment options</td>
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<td>Need</td>
<td>Need to address the contributing factors such as untreated depression, obstructive sleep apnea, and vitamin B12 deficiency</td>
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Starting Point

- Educate and Empower
- Strengthen Workforce
- Partnership
  - Aleut community of St. Paul Island Tribal Government Department of Healing and Wellness and Southcentral Foundation, our local Tribal Health Organization
Starting Point

• Identifying the people who could be held to TASC.
  • T - who owns the task?
  • A – Do they have the authority to be held accountable?
  • S – do we agree that they are set up for success? Time, resources, clarity...
  • C – do we have a checklist of what needs to happen to accomplish the task?

• Identify asks and needs of the community

• Identify needs of programmatic talent force
What Worked Well:

Regular meetings every two weeks with project talent force to find out what was being done and what still needed to be done

Develop materials to present to the community at 3 local Health Fairs with weekly meals that support brain health

Identified training and getting talent force enrolled
What Worked Well:

During this award we were able to strengthen the relationship between the two agencies on St. Paul who have the responsibility to care for aging elders.

We were able to meet directly with the experts who are delivering the services vs administrative staff.

We looked at all the options available in AK as well as what services are available in the community and develop specific resources.
Product Development
What Did Not Work Well

- Ongoing technology issues
  - Broadband
  - GCI Outages
  - System issues

- Competing Priorities

- Maternity Leave
In hindsight...

- Add stakeholders to the development team
- Agree to continue to meet
- Develop a process to share information easier across agencies
- Invite more caregivers to the training given to talent force
What’s ahead?

- We will work on finishing an easy to access video for the community.
- Training more caregivers.
- Continued community level education on prevention and early detection.
Contact Information

• Charlene Naulty, Txin Kaangux Administrative Director
  • cjniaulty@aleut.com

• April Kushin, Healing and Wellness Director
  • amkushin@aleut.com

• Heather Goecke, Administrator, Medical Services Division
  • hgoecke@southcentralfoundation.com
Cheyenne and Arapaho Tribes
Department of Health

Brain Health Mini-Grant Project Coordinator:
Derrell Cox, PhD dcox@cheyenneandarapaho-nsn.gov

~13,000 enrolled citizens
Background

• As with most American Indian Tribes, the Cheyenne and Arapaho Tribes (CAT) highly value our elders for their wisdom, stories, and histories.

• We viewed this grant as an opportunity to:
  • Enhance knowledge; and,
  • Improve awareness.
Starting Point

• We chose all three components of the Brain Health grant:
  • Component 1: Educate and Empower
  • Component 2: Collect and Use Data
  • Component 3: Strengthen the Workforce

• We partnered with our EMS, CHRs, Elder Care and RESpECT Programs

• Before this grant, limited knowledge about Alzheimer’s Disease and the dementias
What Worked Well:

• 2 large annual elder outreach events, Elder’s Conference and Elder’s Day Out.
• Distributed information to over 250 elders
• Present information to >300 elders, families
What Worked Well:

- PSAs to 8,000 community members
- Trained frontline healthcare staff
What Worked Well:

- Home visits with elders
- Distributed more than 1,000 informational questionnaires to elders
What Didn’t Work as Expected:

- Informational questionnaires to our 2,240 elders with SASEs
- Systematic home visits with all elders
In hindsight...

• Affected elder advocacy worked very well

Photo Credit: 2021, Rosemary Stephens
What’s ahead?

• Continued Education
• Incorporated educational questionnaire into our standard assessments—ongoing results ahead
• Referrals to clinicians and social support services
• Data gathering analysis, and guidance for future efforts
• New grants and research opportunities
Contact Information

• Derrell Cox, PhD, dcox@cheyenneandarapaho-nsn.gov
• Gloria Bellymule-Zuniga, gbellymule-zuniga@cheyenneandarapaho-nsn.gov
Resources

NIHB Brain Health for Tribal Nations website: https://nihb.org/brain-health/

National Council on Urban Indian Health (NCUIH) https://ncuih.org/wisdomkeeper/

International Association for Indigenous Aging (IA2) https://nihb.org/brain-health/

CDC Alzheimer’s Disease and Healthy Aging website https://www.cdc.gov/aging/index.html

Alzheimer’s Association https://www.alz.org/
Thank you!

Karrie Joseph
kjoseph@nihb.org