



## NICOA Conference 2021

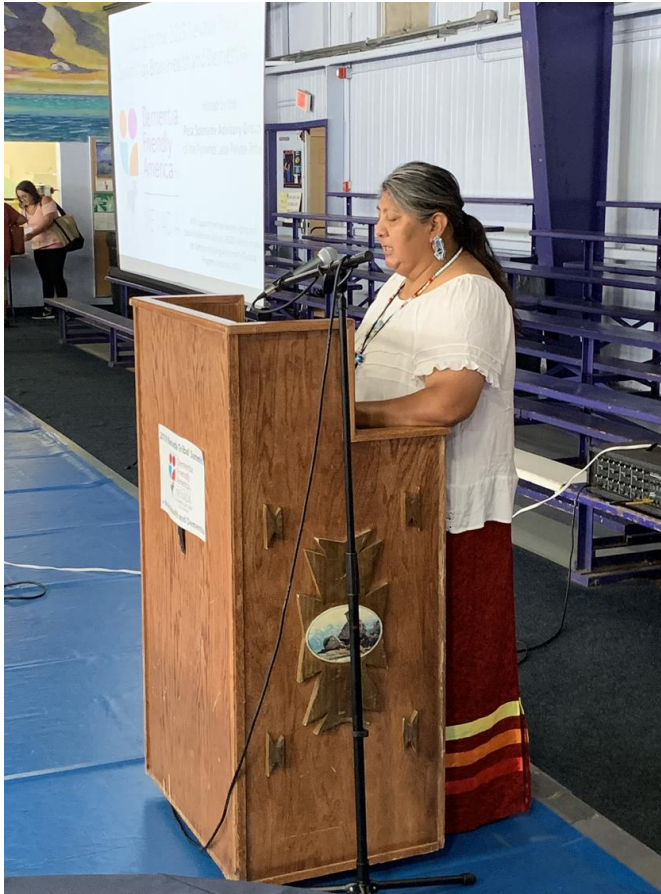
**Pesa Sooname:**  
Pyramid Lake Paiute  
Tribe's Brain Health  
and Dementia-  
Friendly Effort

**Carla Eben**, Numaga Senior Services Program, Pyramid Lake Paiute Tribe

**Jennifer Carson**, Dementia Engagement, Education and Research Program, School of Public Health,  
University of Nevada, Reno



“Pesa Sooname” is Northern Paiute for “**good thought**” and “**good think.**”  
We named our dementia-friendly group “Pesa Sooname” because we want to have good thoughts toward elders living with dementia and we want to protect our own good thinking.



**Carla Eben,**  
Director,  
Numaga Senior Services Program,  
Pyramid Lake Paiute Tribe





**Jennifer Carson,**  
Director,  
Dementia Engagement,  
Education and Research  
Program, School of  
Public Health, University  
of Nevada, Reno





Special thanks to our partner,  
**Casey Acklin,**  
Program Coordinator,  
Dementia Engagement, Education  
and Research Program, School of  
Public Health, University of Nevada,  
Reno



# *Participatory Action Research*

PAR is an approach to research that brings together researchers and community members to:

- identify issues that the community faces (setting the research agenda)
- empower community members to research and create solutions
- improve conditions within the community



*Research With*  
*vs.*  
*Research On*

September 2016, ADSD was awarded an Alzheimer's Disease Initiative – Specialized Supportive Services grant from the Administration for Community Living to launch...



... which aims to develop and promote communities that are **respectful, educated, supportive** and **inclusive** of persons living with dementia and their care partners.

This effort is currently also supported through funding from Nevada Division of Public and Behavioral Health (BOLD Public Health Program) and Nevada Aging and Disability Services Division (Older Americans Act)



- Community groups in seven (7) areas across the state aimed at transforming the culture of dementia and promoting brain health, enabling conversation and participation by all citizens, especially persons living with dementia.
  - 2017: Southern Nevada Urban, Winnemucca, Washoe County and Elko County
  - 2018: Pahrump and Pyramid Lake Paiute Tribe Reservation**
  - 2021: Douglas County









Each community group is encouraged to have representation from **persons living with dementia** and **family care partners**, plus representatives from at least **four (4)** different sectors or **tribal departments**.





- Facilitate and mobilize **community-driven change** utilizing the Dementia Friendly America model.
  - Phase 1: Convene** a community group
  - Phase 2: Assess** current strengths and gaps
  - Phase 3: Analyze** community needs and develop goals
  - Phase 4: Act** on your goals and identify ways to evaluate progress
- Each group initially received \$10,000 to support their work, and have since received smaller awards.

- Expand the reach of programs within the **Nevada Dementia Supports Toolbox.**
- In FY'15 (pre-DFNV), a total of 194 people living with dementia were reported to have received ADSD-supported services. In FY'19, service utilization increased to 1,924 people, representing an **892% overall increase.**

NEVADA DEMENTIA FRIENDLY - SUPPORT SERVICES	
<p>ALZHEIMER'S ASSOCIATION OF NORTHERN AND SOUTHERN NEVADA</p> <p> <b>alzheimer's association</b></p> <p>24/7 Helpline 1-800-272-3900 www.alz.org</p> <p><b>Person Living With Dementia Support Services</b></p> <ul style="list-style-type: none"> <li>• Early-Stage Engagement Activities</li> <li>• <b>Person Living With Dementia &amp; Caregiver Support Services</b></li> <li>• EPIC (Early-Stage Partners In Care)</li> <li>• Care Consultations</li> <li>• Education Workshops</li> <li>• Support Groups: Person Living With Dementia, Early Stage</li> <li>• <b>Caregiver Support Services</b></li> <li>• CarePRO (Care Partners Reaching Out)</li> <li>• Respite Voucher Services</li> <li>• Support Groups: Caregiver</li> <li>• <b>Other Support Services</b></li> <li>• Safety Net: Medic Alert/Safe Return, First Responder Trainings</li> </ul>	<p>CLEVELAND CLINIC LOU RUVO CENTER FOR BRAIN HEALTH</p> <p> <b>Cleveland Clinic</b></p> <p>www.keepmemoryalive.org/socialservices www.healthyliving.org</p> <p><b>Person Living With Dementia &amp; Caregiver Support Services</b></p> <ul style="list-style-type: none"> <li>• <b>Lunch and Learn</b>—Phone: 702-778-6702, email: louruvosocialserv@ccf.org</li> <li>• <b>Frontotemporal Disorders</b>—email: familyservicesNV@ccf.org</li> <li>• <b>Huntington's Disease</b>—Contact Donna, phone: 702-483-6035, email: municd@ccf.org</li> <li>• <b>Memory Loss for Caregivers</b>—Contact Donna, phone: 702-483-6035, email: municd@ccf.org</li> <li>• <b>Parkinson's Disease</b>—Contact Samuel, phone: 702-701-7929, email: hicksos@ccf.org</li> <li>• <b>Counseling Services</b>—email: familyservicesNV@ccf.org</li> <li>• <b>Lynne Ruffin-Smith Library</b>—Phone: 702-483-6033, email: louruvolib@ccf.org</li> <li>• <b>Art &amp; Education Offerings</b>—Phone: 702-778-6702, email: louruvosocialserv@ccf.org <ul style="list-style-type: none"> <li>-Art Explorations-Art Therapy</li> <li>-Conversations to Remember</li> <li>-The Learning Arts</li> <li>-Music Therapy-Respite</li> <li>-Healthier Living</li> <li>-Powerful Tools for Caregivers</li> </ul> </li> </ul>
<p><b>ACCESS TO HEALTHCARE NETWORK</b></p> <p> <b>access to healthcare</b></p> <p>www.accesstohealthcare.org/ 1-877-861-1893</p> <p>Provides services through Northern NV Aging and Disability Resource Centers (ADRCs)</p>	
<p><b>NEVADA SENIOR SERVICES</b></p> <p> <b>Nevada Senior Services, Inc.</b></p> <p>www.nevadaseniorservices.org</p> <p><b>Person Living With Dementia &amp; Caregiver Support Services</b></p> <ul style="list-style-type: none"> <li>• Adult Day Care: Las Vegas 702-648-3425, Henderson 702-368-2273</li> <li>• Nevada Care Connection Resource Center: 702-364-2273 or 844-850-5113</li> <li>• New Pathways Café (Early Memory Loss Program): 702-333-1538</li> <li>• Connections (Moderate Memory Loss Program): 702-333-1538</li> <li>• Respite Care &amp; Support Program: 702-333-1599</li> <li>• <b>Caregiver Support Services</b></li> <li>• Caregiver Support Groups: Las Vegas 702-648-3425, Henderson 702-368-2273</li> <li>• BRI (Benjamin Rose Institute on Aging) Care Consultation: 702-364-2273 or 844-850-5113</li> <li>• RCI (Rosalynn Carter Institute for Caregiving) REACH (Resources Enhancing Alzheimer's Caregiver Health): 702-364-2273 or 844-850-5113</li> <li>• Skills2Care: 702-364-2273 or 844-850-5113</li> <li>• Caring for You, Caring for Me: 702-364-2273 or 844-850-5113</li> </ul>	<p><b>NEVADA RURAL RESPITE SERVICES</b></p> <p> <b>RSVP</b></p> <p>www.nevadaruralrspv.org/ 775-687-4680 x123</p>
	<p><b>NEVADA AGING AND DISABILITY SERVICES DIVISION</b></p> <p> <b>http://adsd.nv.gov/</b></p> <p>Regional Centers provide Federal—Home &amp; Community Based Waivers, Counseling, Employment Services, Family &amp; Residential Support, &amp; Service Coordination for individuals throughout the lifespan.</p> <p>Provides support and services to children and adults with intellectual disabilities or related conditions.</p> <ul style="list-style-type: none"> <li>• <b>Desert Regional Center:</b> 1391 S. Jones Blvd., Las Vegas 702-486-6200 or 702-486-7850</li> <li>• <b>Rural Regional Center:</b> 1665 Old Hot Springs Rd., Ste. 157, Carson City 775-687-5162</li> <li>• <b>Sierra Regional Center:</b> 605 S. 21st St., Sparks 775-688-1930</li> <li>• <b>Elko:</b> 1825 Pinion Rd, Ste. A 775-753-4236</li> <li>• <b>Fallon:</b> 131 N. Maine St. 775-423-0347</li> <li>• <b>Silver Springs:</b> 3595 Highway 50 West, Ste. 3 775-577-4077</li> <li>• <b>Winnemucca:</b> 475 W. Haskell, Ste. 3 775-623-6593</li> </ul>



## Dementia Community Needs Survey – **Dementia Attitude Scale (DAS)**

	N	DAS Overall Mean (%)	Subscale 1: Comfort	Subscale 2: Knowledge
<i>Possible Range:</i>		<b>20 - 140</b>	<b>12 - 84</b>	<b>8 - 56</b>
Elko County	163	102 (68%)	57 (63%)	46 (79%)
Humboldt County	119	101 (68%)	57 (63%)	45 (77%)
Washoe County	390	106 (72%)	60 (67%)	46 (79%)
Clark County	195	103 (69%)	60 (67%)	43 (73%)
<b>Pyramid Lake</b>	43	106 (72%)	60 (67%)	46 (79%)
Nye County	89	104 (70%)	60 (67%)	46 (79%)
Non-Participating County	67	112 (77%)	64 (72%)	48 (83%)
Statewide (Nevada)	<b>1066</b>	<b>105 (71%)</b>	<b>60 (67%)</b>	<b>45 (77%)</b>



## Dementia Community Needs Survey

**Pesa Sooname Advisory Group decided to address two gaps in Year 1:**

Key **strengths** reported:

- Family support
- Clinical services
- General community support

Key **gaps** reported:

- Lack of support groups
- **Lack of geriatric clinical services**
- Lack of community-based services for people living with dementia and family care partners
- **Lack of dementia education programs**



Pesa Soonomie's Year 1 Goal:

Provide **formal and informal dementia education** to families, elders, tribal departments, and neighboring tribes





Goal: Provide **formal and informal dementia education**

*Free dementia education opportunity*

## **Dementia: An Introduction from a Social/Relational Perspective**

*Presented by:*

**Jennifer Carson, PhD**

Research Assistant Professor  
Community Health Sciences



University of Nevada, Reno

- Consider the common myths and misunderstandings of dementia
- Understand dementia from both biomedical and social/relational perspectives
- Explore society's understanding of dementia and the impact of stigma
- Hear firsthand accounts about the experience of living with dementia
- View so-called 'behaviors' as communication of identity, preferences and/or unmet needs
- Practice positive and empathic communication strategies
- Identify ways to support the well-being of people living with dementia
- Discuss regional and statewide resources for education, care and support

*When:*

**Wednesday, April 18, 2018  
1:00 – 3:00 PM**

*Where:*

**PLPT Tribal Chambers  
208 Capitol Hill  
Nixon, NV**

*For more information contact:*

**Carla Eben**

Senior Services Director  
Numaga Program  
775-574-1064  
ceben@plpt.nsn.us

**16  
participants**



*A program of the UNR Dementia Engagement, Education and Research Program*



- Welcoming, small-group session; not a formal training
- Approximately 60 – 90 minutes
- Facilitated by a Dementia Friends Champion or a pair of Champions
- Covers the five (now 6) key messages about dementia through activities and discussion
- Dementia Friends are asked to commit to a dementia-friendly action

**June 2018: Trained 12 Dementia Friends and 4 Dementia Friends Champions**



Goal: Provide **formal and informal dementia education**

PESA SOONAME ADVISORY GROUP  
(DEMENTIA FRIENDLY PYRAMID LAKE)  
PRESENTS:

A FREE EDUCATION SESSION ON  
**DEMENTIA**

**Wednesday, November 28<sup>th</sup>**  
**Noon to 4 pm**  
**PYRAMID LAKE PAIUTE TRIBE  
TRIBAL CHAMBERS**

**ANAKAREN LAMAS**  
• *Overview of Dementia - Alzheimer's Association*


**DENISE HUND**  
• *Effective and Empathic Communication - Alzheimer's Association*

**JENNIFER CARSON, PHD**  
• *Responding to Un-Met Needs ("Responsive Behaviors") - Dementia Engagement, Education and Research Program, UNR*

**KELLEY MCMILLAN, PHD**  
• *Local Resources for Persons Living with Dementia and Family Care Partners - Sanford Center for Aging, School of Medicine, UNR*

~Lunch Provided~

Funded by the Nevada Aging and Disabilities Division-Dementia Friendly Nevada, the PLPT Senior Services Program, Title VI Older Native Americans, and Caregivers Grants



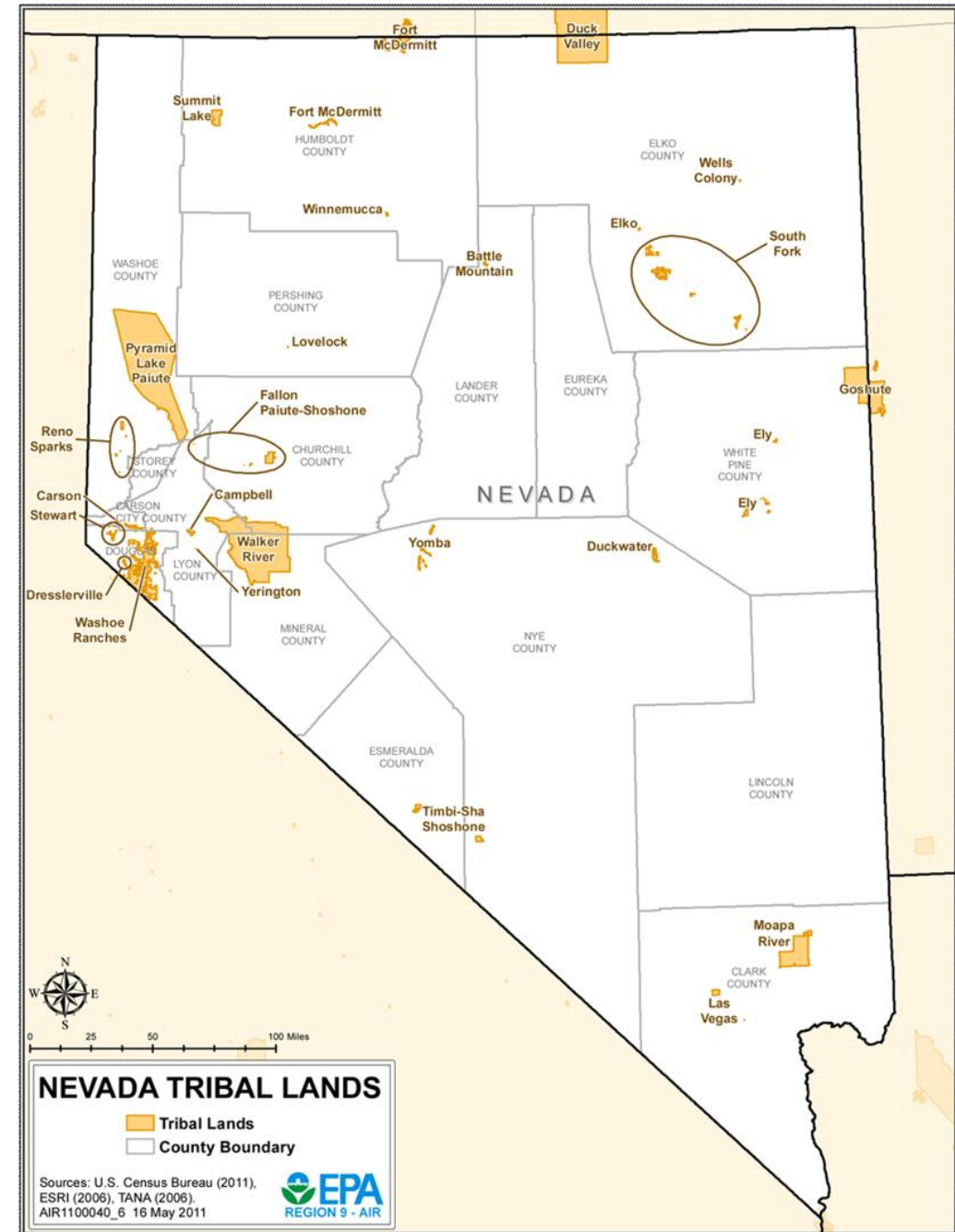
Dementia  
Friendly  
America™  
NEVADA  
PYRAMID LAKE

**15**  
**participants**

# Carla's dream!

## Nevada Tribal Summit on Brain Health and Dementia

Nixon, NV  
August 22, 2019



# The 2019 Nevada Tribal Summit on Brain Health & Dementia

Thursday, August 22, 2019 | 9:00 AM - 4:00 PM

Nixon Tribal Gymnasium

301 Highway 447, Nixon, NV 89424

**For all Nevada tribes, and their community partners.**

9:00 - 9:30 AM	Summit Opening and welcome
9:30 - 10:30 AM	<b>Mike Splaine:</b> Overview and development of the Road Map for Indian Country
10:30 - 10:45 AM	Break
10:45 - 11:45 AM	<b>Dave Baldrige (Cherokee):</b> Customization and implementation of the Road Map for Indian Country
11:45 AM - 12:00 PM	Opportunity for reflections and comments
12:00 - 1:00 PM	Lunch
1:00 - 1:45 PM	Wisdom circles regarding brain health and dementia
1:45 - 2:00 PM	Break
2:00 - 2:15 PM	Gentle yoga and movement
2:15 - 2:45 PM	<b>Dr. Peter Reed:</b> The Sanford Center for Aging's Comprehensive Geriatric Assessment Clinic
2:45 - 3:45 PM	<b>Dr. J. Neil Henderson (Oklahoma Choctaw):</b> Dementia and Diabetes among Native people
3:45 - 4:00 PM	Cultural closing and remarks

For more information and to register, visit:

[DementiaFriendlyNevada.org/TribalSummit](https://DementiaFriendlyNevada.org/TribalSummit)

Hosted by the Pyramid Lake Paiute Tribe's Pesa Soaname Advisory Group:

A member of Dementia Friendly Nevada



**Carla Eben, Pyramid Lake Paiute Tribe,  
Numaga Senior Services Director**

Telephone: (775) 574-1064

Email: [ceben@plpt.nsn.us](mailto:ceben@plpt.nsn.us)

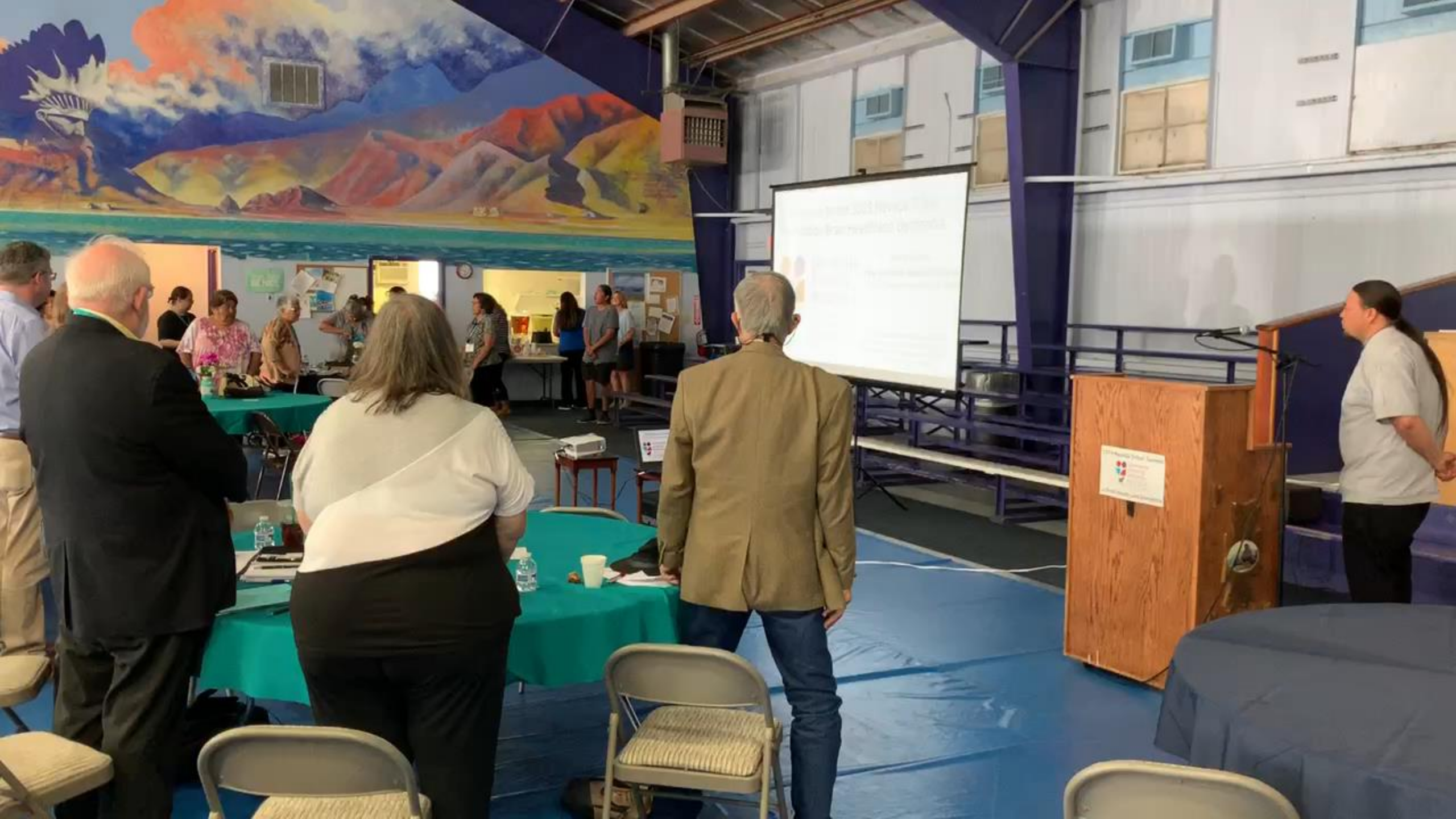
**Jennifer Carson, Co-Facilitator,  
Pesa Soaname Advisory Group**

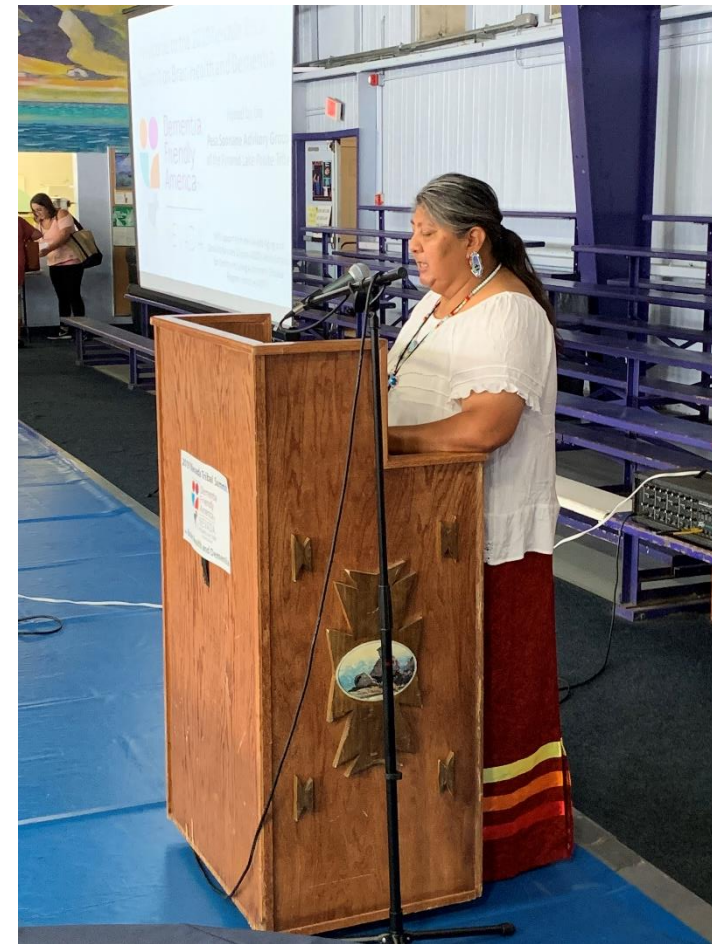
Telephone: (775) 682-7072

Email: [jennifercarson@unr.edu](mailto:jennifercarson@unr.edu)

## Tribal Summit Success:

- **114 people representing 14 tribes participated**
- National speakers included: Mike Splaine, Dave Baldrige, Dr. Peter Reed, and Dr. J. Neil Henderson
- Launched the *CDC Road Map for Indian Country*

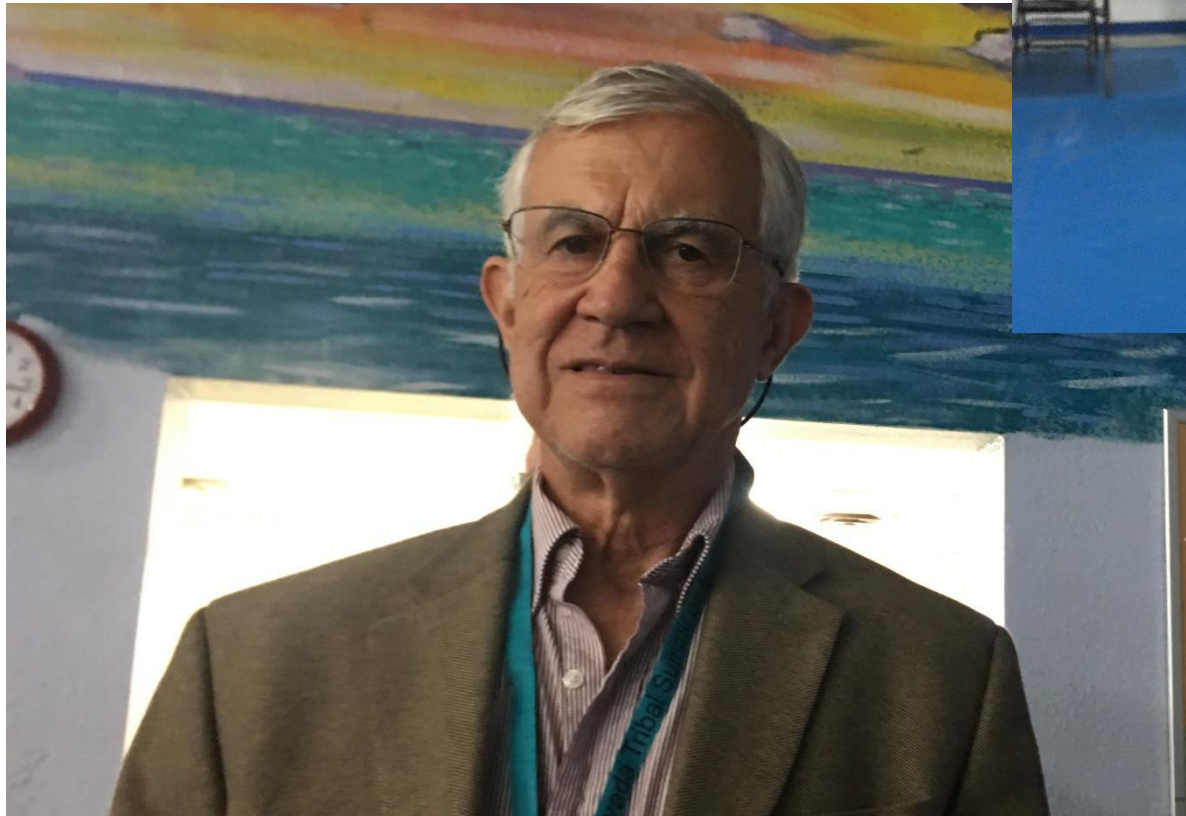




















# Tribal Summit Evaluation



## 2019 Nevada Tribal Summit on Brain Health and Dementia Post-Conference Survey

Age: \_\_\_\_\_

I am currently living with dementia:    Yes    No    I prefer not to answer

I am a care partner for someone living with dementia:    Yes    No    I prefer not to answer

Please circle your primary affiliation:

Tribal Administration	Tribal Elder	Aging Services Professional
Tribal Senior Services	Tribal Member	Dementia Friendly Nevada Member
Tribal Health Clinic	Community Member	Other: _____

Please consider each of these questions and circle your response:

1. This process was useful in helping me generate ideas related to how to implement the Roadmap for Indian Country in my community.

Strongly Agree    Agree    Neutral    Disagree    Strongly Disagree

2. I think most of the information provided by the Roadmap for Indian Country is applicable to my community.

Strongly Agree    Agree    Neutral    Disagree    Strongly Disagree

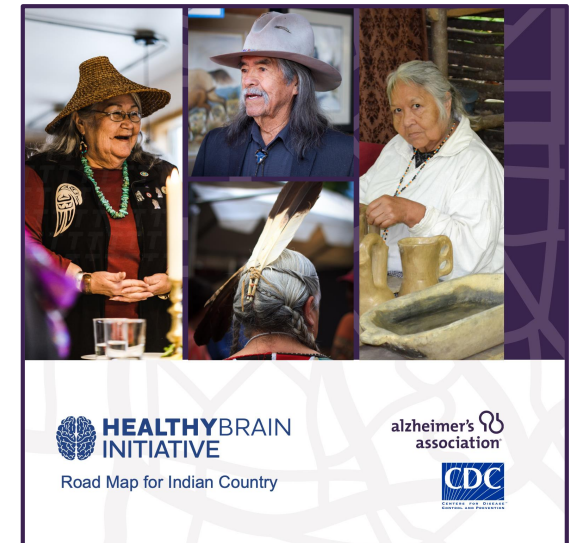
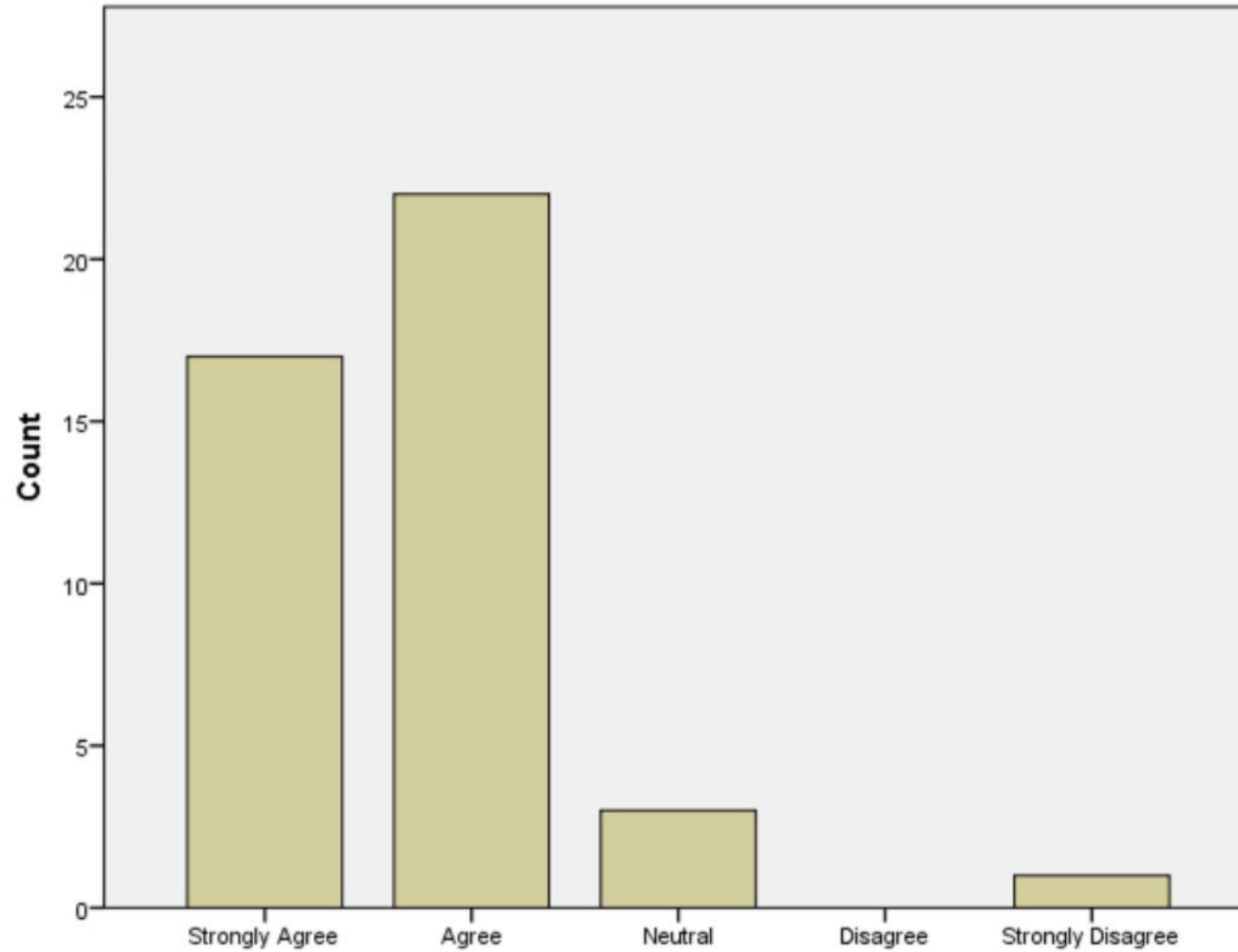
3. This Summit allowed me the opportunity to make connections with people who I would not have otherwise met.

Strongly Agree    Agree    Neutral    Disagree    Strongly Disagree

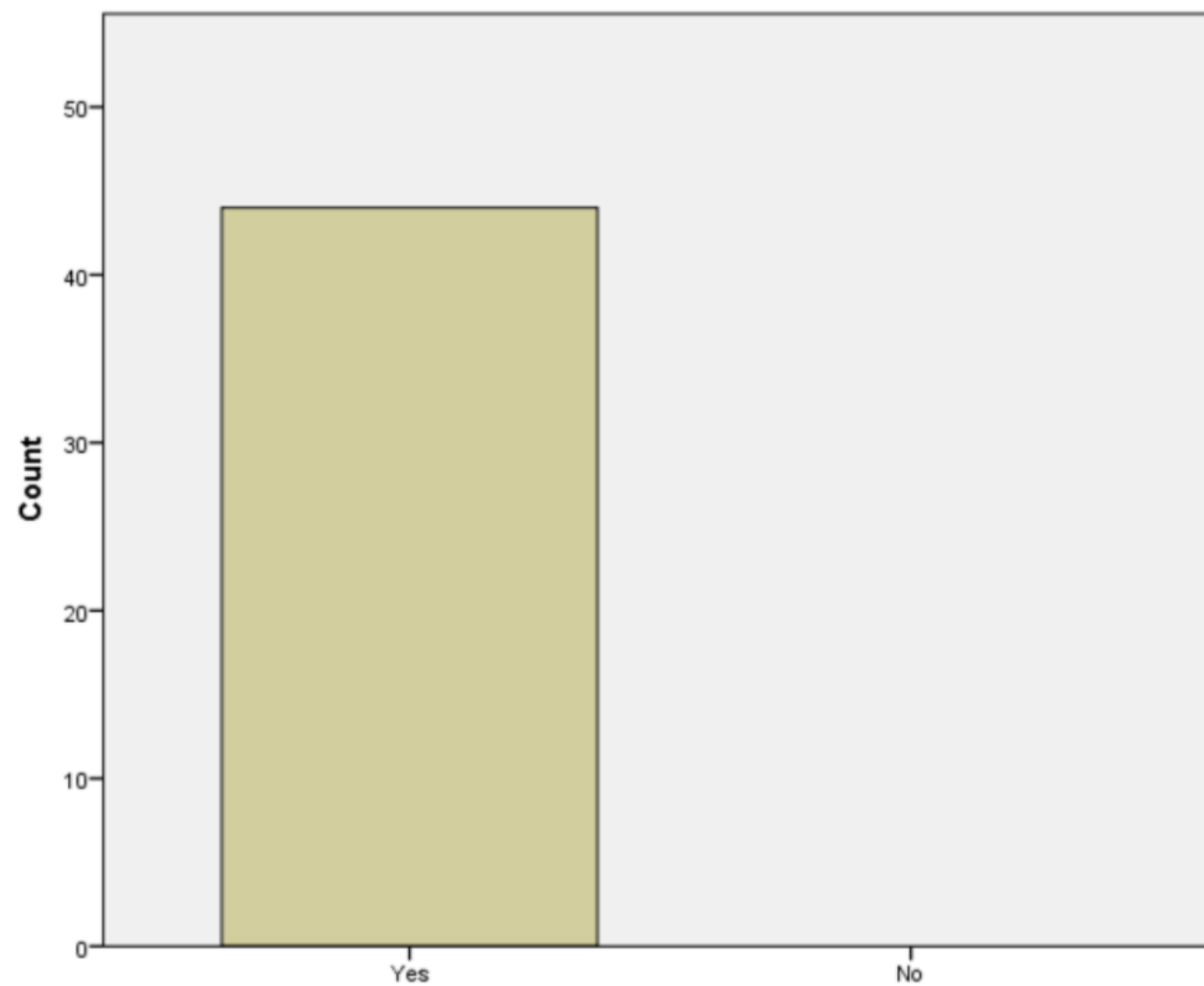
4. If resources were available, would you like to see this type of event occur annually?

Yes    No

**This process was useful in helping me generate ideas related to how to implement the Roadmap for Indian Country**



**If resources were available, would you like to see his type of event occur annually?**



# Post-Summit CDC Road Map Talking Circles



**Circle 1:** Discuss all Road Map questions, identify community strengths and gaps, and choose three questions to discuss in greater depth.

## ***COVID-19 Pandemic and Stay-at-Home Order***

**Circle 2:** Return to the three chosen questions, and collaboratively develop goals based on the strengths and gaps identified in Circle 1.

**Circle 3:** Chart a plan of action to meet the goals developed during Circle 2.



Road Map for Indian Country





## STARTING THE CONVERSATION: IDEAS FOR INITIAL DISCUSSIONS ABOUT ALZHEIMER'S

Listening and learning are the first steps toward developing a broad response to Alzheimer's and other dementias. The Healthy Brain Initiative's *Road Map for Indian Country* encourages AI/AN leaders to start a conversation within their communities about how dementia affects all generations — individuals living with dementia, their families, other community members who help provide care, and even future generations who may lose cultural traditions or heritage to memory loss associated with Alzheimer's.

An initial community gathering to discuss dementia could begin with an invocation drawing on the community's traditions, such as a prayer or performance of a tribal song. The person leading the discussion may then acknowledge Elders and thank hosts for the space and refreshments. After sharing a personal story about journeying with a loved one who has dementia, the leader could explain the goals of the gathering.

The discussion leader asks the community questions, such as:

- » Without identifying individuals, how have persons living with dementia fared in our community?
- » What kinds of people and groups in our community are helping people living with dementia with day-to-day living or getting places? How are these caregivers faring?
- » Do we have traditions about keeping ourselves healthy that include keeping strong our memories, ability to learn, and make decisions?
- » Do our diabetes or heart disease efforts help us learn about dementia and the brain?
- » What kinds of information or training would help family and friends better support our older adults who need care?
- » How could professionals who serve our community (like our doctors, senior centers, van drivers and first responders) better support our older adults who need care?
- » What groups in our community or in nearby communities could help us promote wellness across the lifespan, support caregivers, and enhance the safety and well-being of older adults with dementia?
- » What might we do as a next step? By whom and by when?

# Talking Circle 1

January 29, 2020 | 5:00 – 8:00 PM

Nine Participants, including six Tribal Members

## Strengths Identified

- Traditional cultural practices that support community and brain health
- Family support of people living with dementia

## Gaps Identified

- No care partner dementia education programs developed in partnership with tribes
- Lack of awareness regarding brain health and dementia among professionals such as first responders and social services staff





## Talking Circle 2

- “How could professionals who serve our community (like our doctors, senior centers, van drivers and first responders) better support our older adults who need care?”
- “Do we have traditions about keeping ourselves healthy that include keeping strong our memories, ability to learn, and make decisions?”
- “What kinds of information or training would help family and friends better support our older adults who need care?”



**Postponed due to COVID-19**, but still planned for whenever we can safely gather in-person!



## Semi-finalists in the Robert Wood Johnson Interdisciplinary Research Leaders Program *(pending)*



- Carla Eben, Jennifer Carson, & Tessa Swigart
- Proposed project: Promoting health equity through the investigation of and solutions for modifiable risk factors for dementia among the Pyramid Lake Paiute Tribe



# Questions and Discussion about ***Brain Health Initiatives*** in Indian Country



Please feel free to reach out:

[ceben@plpt.nsn.us](mailto:ceben@plpt.nsn.us)

[jennifercarson@unr.edu](mailto:jennifercarson@unr.edu)

[dave@iasquared.org](mailto:dave@iasquared.org)