Addressing barriers in Indigenous participation in Alzheimer's research

Sacheen L. Lawrence, UW-Madison Native American Outreach Specialist
Sydnee A. Livingston, UW-Madison School of Medicine and Public Health M1 Student
Dr. Lauren W. Yowelunh McLester-Davis, incoming UW-Madison Director of Indigenous Science Advocacy
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ABOUT me
Sacheen L. Lawrence
Member of the Oneida Nation
Mother, Wife, Grandmother, Foster Parent
Oneida Community Advisory Board member
Chairwoman, Oneida Nation School Board

ABOUT me
Sydnee A. Livingston
Member of the Red Cliff Band
First generation college student, sister, daughter, grand-daughter
University of Wisconsin School of Medicine and Public Health-M1
Association of Native American Medical Students Co-President
Today's Agenda

- Introductions and Group Assignments
- Short History of Alzheimer's Disease and Related Dementias and the History of Research in Indian Country
- Methods of Research and Data Protection for Indigenous Communities
- Success in the University of Wisconsin and Oneida Nation of Wisconsin Partnership
- Examples from the Stress and Resilience in Dementia study
- Group Discussions

Participant Introductions

- Name
- What part or community in Wisconsin you belong to
- Group together with individuals from the same or similar community
Today's Terminology

- American Indian, Alaska Native, Native American, Native, Indigenous, Tribe, Tribal, Tribal Nation, Nation, etc.
- Increasing population of elders
- High risk of developing ADRD

The Research Landscape

- Urban
  - On reservation land
  - Displaced / new home
  - Federal recognition
  - Blood quantum
- Rural
  - Off reservation land
  - Ancestral home
  - State or no recognition
  - Enrollment

A History of Research from the Indigenous Perspective

- 1950s
  - U.S. Public Health Service Commissioned Corps & University based research
- 1960s
  - Civil Rights & American Indian Movement move to restore sovereign rights
- 1970s
  - Indian Self Determination & Education Assistance Act provided access to grants and contracts to tribes
- 1980s
  - Indian Health Service Institutional Review Board processes take shape
- 1990s
  - Federal regulations on research widely adopted
- 2000s
  - National Institutes of Health Native American Research Centers for Health created
- 2010s
  - Increasing number of Tribal Institutional Review Boards & Community Based Participatory Research
- 2020s
  - Participation of Tribes in increasing vaccine availability & vaccination during global pandemic
### Harm in Research; AI/AN have experienced each harm.

<table>
<thead>
<tr>
<th>Harm in Research</th>
<th>AI/AN Example</th>
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<tbody>
<tr>
<td>Psychological Harm</td>
<td>1920s: Publishing of ceremonial details from a southwestern tribal community</td>
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<td>Physical Harm</td>
<td>1950s: U.S. Airforce used radioactive iodine to study thyroid function in AN</td>
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<td>Economic Harm</td>
<td>1970s: Center for Research on the Acts of Man study of alcoholism in Barrow, AK</td>
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<td>Social Harm</td>
<td>1980s: State Health Department study of congenital syphilis that named the tribal community in reports</td>
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<td>Legal Harm</td>
<td>1990s: Tribal agency misappropriated genetic results as &quot;Indian markers&quot; and expelled members</td>
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<td>Dignitary Harm</td>
<td>1990s: Native American Graves Protection and Repatriation Act 1990s: Study of arthritis among Nuu-chah-nulth examined migration without consent</td>
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<td>Relational Harm</td>
<td>1990s: C.D.C. use of Navajo placenames in publications despite request to not use them for privacy and protection from external stigmatization 2000s: Study of diabetes among Havasupai examined migration, schizophrenia, inter-relatedness without consent</td>
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### There are also examples of ethical and beneficial research in AI/AN communities

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<th>Example of Good Research for AI/AN Communities</th>
<th>Common Characteristics</th>
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<td>1997: The People Awakening Project Indigenous people proposed study of alcoholism focused on strengths and resilience of their community</td>
<td>•Focused on health priority of the tribe(s) •Incorporated the community values •Benefited the communities with actionable results •Strengths-based view of tribal communities •Innovative in topic or closeness of collaboration</td>
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<td>2001: White Mountain Apache Suicide Surveillance and Prevention System Indigenous community collaborated with Johns Hopkins to develop community-based surveillance, case management, and prevention</td>
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<td>2006: Safe Passage Study Multi-site study on sensitive, potentially stigmatizing issue of alcohol use in pregnancy prioritized by Tribal Institutional Review Board (IRB) review</td>
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<td>2010: Alaska Area Specimen Bank Biospecimens from 5,000 persons who participated in projects since the 1960s and previously managed by the Center for Disease Control transitioned to management by a tribal federal partnership</td>
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<td>2015: American Indian and Alaska Native Head Start Family and Child Experiences Survey Serves a large portion of Indigenous Head Start students financially and educationally following dozens of tribal approvals</td>
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<td>Present: Oneida Nation relationship with University of Wisconsin Alzheimer's Disease Research Center Primarily collaboration between the Oneida community and UW researchers with equal leadership in the Community Advisory Board (CAB)</td>
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### Community Based Participatory Research

- **Outreach**: Communication flows from one to the other to inform. Provides community with information. Entities co-exist. Outcomes: Optimally, establishes communication channels and channels for outreach.
- **Consult**: More community involvement. Communication flows both ways, participatory form of communication. Involve more participation with community on issues. Entities are cooperating with each other. Outcomes: Visibility of partnership established.
- **Involve**: Better community involvement. Communication flow is bi-directional. Form partnerships with community on each aspect of project from development to solution. Entities form bi-unilateral communication channels. Outcomes: partnership building, trust building.
- **Collaborate**: Strong bi-directional relationship. Final decision making at community level. Entities have formed strong partnership structures. Outcomes: Broader health outcomes affecting broader community. Strong bi-directional trust built.
- **Shared Leadership**:
Methods for Research and Data Protection for Indigenous Communities

- Do not participate in research
- Utilize existing bodies to participate in research with recommendations from Nation Officials and/or other advisory bodies
  - Business Committee, Community Advisory Board, etc.
- Creating a new Community Advisory Board or a different type of research review committee to fit the needs of a specific community for a specific research project
- Utilize other systems in place for protecting Indigenous individual participants, such as Indian Health Service IRBs
- Create a Tribal Institutional Review Board (IRB) and protective policies regarding jurisdiction of data
  - Planning, Infrastructure Development, Implementation, and Assessment and Evaluation
- Create a new system that incorporates individual Nation values with academic processes

My Indigenous Team

Margaret King, Outreach Specialist
Marlene Simmons, Oneida Community Research Coordinator
Cassandra Thomas, AMICA Community Researcher
Carrie Trojanczyk, AMICA Project Coordinator
Lea Strong, Oneida Community Research Coordinator
Kala Kimberly Cornelius, Nurse Practitioner Researcher

Dr. Carey Gleason
Dr. Fabu Carter
Dr. Nicholas Lambrou

What is Indian Country?

Can you name resources related to prevention or early detection available to the Indigenous population in Indian Country?
Establishing relationships

- ONCOA (Oneida Nation Commission On Aging)
- C.A.B (Oneida Nation Alzheimer's Disease Community Advisory Board)
- Oneida Aging & Disability Services
- Memory Keepers
- GLNAEA (Great Lakes Native American Elders Association)
- Oneida Nation

Recruiting Strategies

- Host research related presentations
- Attend events on reservations
- Find out if there are any current methods combating dementia or Alzheimer's in Indian Country
- Be knowledgeable of the Indigenous culture
- Hire indigenous individuals

Be Culturally Aware/Sensitive

- Use Indigenous data that pertains to them
- Develop educational materials using Indigenous people
- Attempt to incorporate Indigenous culture in materials
The genuine effort you put into an Indigenous population, the more likely you will be welcomed into the community.

The STRIDE Study
Stress and Resilience in Dementia
Community Advisory Boards

Community health leaders and outreach specialist

Study Coordinators

Monetary adjustments

Results

Frequent participant-staff communications facilitate a convenient remote protocol. Acceptability and feasibility appear high to date

Lessons Learned

Time: Flexible staff availability for communication

Giving back: Transparent benefits to individual and communities
Working collaboratively with community partners to foster bidirectional relationships has been essential to successful rollout and positive participant response.

An adaptable data collection protocol and dedicated staff invested in the concerns of participating communities are invaluable for recruitment and retention success.

Questions/Comments Welcome

Group Discussion Questions

- What was one thing from today’s session that was new to you?
- How would you apply what you’ve learn in today’s session to your own community?
- What is one thing you want to learn that expands on today's session?