4th Annual Behavioral Health Research Institute
Research In Indian Country

Framing an indigenous perspective about research within Native Nations
Existence of Research In Native Country

- Research has always existed in our Native communities.
- Based on oral tradition and history
- Indigenous Ways of Knowing
  - Practical use of information
- The interconnectedness of all things
  - Keen observation of environment
  - Observation of individual and communal experience
  - Multiple perspectives and participation over time

Source: Dr. Nate St. Pierre and others
History: Natives As Subjects to be Researched

• Natives were of scientific interest during the 19th Century
• Natives as subjects
  • Anthropologists
  • Archeologists
    • Grave Robbing
    • Dr. Samuel Morton, the father of American physical anthropology, collected large numbers of Indian crania in the 1840’s to prove Indians were racially inferior and doomed to extinction
    • Destruction of sacred sites
• Western Perspective
  • Male dominated thus lacks gender balance with little female voice
  • Cultural extraction/mining
  • Impact of Christianity and suppression of spiritual practices
  • Research to “solve” the Indian problems
American Indian Research Issues

• Historical Trauma
  • Mistrust
    • Genocide
    • Disease/Biological Warfare

• Research *Done TO* AI/AN
  • 1950s – U.S. Air Force’s former Arctic Aeromedical Lab
    • Study to identify the role of the thyroid gland in human acclimatization to cold weather.
    • Alaska Native recruited (women, men, and children).
    • Many participants were non-English speaking.
American Indian Research Issues

• Research *Done TO* AI/AN
  • 1970s – Indian Health Service’s sterilization of American Indian women and girls without their knowledge or consent.
    • 3,406 women and girls sterilized (ages 15-44)
    • Medical consent forms were found to be inadequate, illegally obtained, and not in compliance with I.H.S. regulations. (Source: CCESA, 1977; Comptroller General of the United States, 1976.)
  • 1990s – Arizona State University’s Type 2 Diabetes Study
    • Havasupai Indian Tribe
    • Blood samples approved for diabetes study used for non-related studies without the Tribe’s knowledge (and non-IRB approved studies)
      e.g., Genetic basis of schizophrenia
    • Discussions between ASU and the Havasupai Tribe produced no resolution
    • 2004 the Tribe sued ASU for fraud, breach of fiduciary duty, negligence, and trespass (Potknonjak, 2004).
    • ASU has formally apologized to the Tribe.
American Indian Research Issues

• Struggle to adapt concepts of contemporary research and indigenous cultures and world views
  • Defy standardization (560 Tribes)
  • Variation by Tribe and by Level of Acculturation
  • Contradictory Values e.g. paying traditional healers

• Response to the Need for Research (What drives research?)
  • Scholarship
  • Contribution to the Behavioral Health Narrative
  • Search for answers to help society
  • Evidence-Based Solutions/Support
Inclusion of Native People in the Contemporary Research Process

Building our own research capacity.
Research oversight
American Indian Research Oversight

• 1995 – Navajo Nation became the first tribe to establish its own Institutional Review Board.

• Other Tribes and Native communities have followed suit.
  • Some enforce additional conditions e.g.,
    • Progress Reports
    • Final Report
    • Presentation at an annual conference
    • Community Feedback (prior to finalizing study and prior to publication).
    • Employment of Tribal Members
    • Ownership over all equipment used in the research
    • Oversight and ownership of the data specific to tribal members
American Indian Research Oversight

• Important distinctions of Tribal IRBs
  • Universities or Government IRBs focus on the individual and are designed to protect the individual rights of study subjects
  • Tribal IRBs extend this protection to the tribe and special groups e.g., healers, elders, and children
  • Emphasis is placed on family, community, and tribe.
• Tribal IRBs require researchers to understand the influence of culture in designed research questions, methodology, and analysis.
American Indian Research Issues

• Belmont Report (1978) summarizes ethical principles and guidelines for research involving human subjects (in response to the problems resulting in the Tuskegee Syphilis Study 1932-1972), identifies three fundamental ethical principles in research using human subjects:

1. Respect for persons (allows for informed consent)
2. Beneficence (Do no harm)
3. Justice (Ensure reasonable, non-exploitative, and well-considered procedures are administered fairly and equally.

• Basis for today’s IRBs.
American Indian Research Engagement

• Community-Based Participatory Research (CBPR), as operationalized by American Indian communities, means that:
  • tribes are equal partners,
  • participating fully in the identification of the problem, the research design, the selection of measures, subjects and findings.
  • CBPR as the “Gold Standard” per The National Tribal Behavioral Health Agenda (12/2016)

• American Indians are a collective society whose decisions are made by the group or by elders, and not on an individual basis, so this dynamic is an important cultural process to consider in designing research.
Beyond Engagement

• Tribal communities defining the research questions.
  • Tribally Driven Research – Thomas & Allison Ball

• Determining how best to share indigenous research/knowledge within Native communities and with other communities
  • Application & Implementation vs. appropriation
  • Contextualization vs. standardization