



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