



# 2<sup>nd</sup> Annual AIHEC Behavioral Health Institute

# American Indian Research Issues

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

- 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 with I.H.S. regulations. (Source: CCESA, 1977; Comptroller General of the United States, 1976.)

# American Indian Research Issues

- 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

- 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 Issues

- 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

- 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.
- 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.

# 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.