Navajo Community Discussions on Genetic Research

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Overview

• Genetics and Diné (Navajo)
• Moratorium on Genetic Research studies
• Discussions on Issues/Concerns with Genetics
• Opinions, Attitudes, and Challenges
Genetics and Navajo

- People come from Dinéyah according to Creation stories and Origin beliefs
- Families are structured by a Matrilineal Clan system
- The Long Walk reduced the population to 8,000 in 1864
- The Navajo Nation is a sovereign nation with its own judicial system

Community concerns: Genetics

- Bottleneck effect as a result of The Long Walk
  - Many rare Mendelian and Complex diseases
- Concerns with Genetic research studies
  - Migration studies (HGDP, NGP)
  - Genetic Ancestry testing
  - Misuse of blood/saliva/DNA samples
  - Ownership and Return of Samples
  - Data-Sharing policies
  - Intellectual Property
  - Gene Therapy and/or Cloning
- General distrust of western science
The Moratorium

The Navajo Nation approved “a Moratorium on Genetic Research Studies conducted within the Jurisdiction of the Navajo Nation until such time that a Navajo Nation Research Code has been Amended by the Navajo Nation Council.”

- Approved in August 2002

Community Discussions

- “A Gift of Life” 40 minute documentary (2002)
  - Medicine Men, Political leaders, IRB members, etc
  - Video distributed, screened in Chapter houses and schools
- Community Conversation on Genetics (April 2009)
  - Community (n=100): General members, Academic institutions, Community-based organizations and Programs, Diné College students, Navajo IRB, IHS
- Genetic Research Panel (December 2009)
  - Panelists (n=5): Bioethicist, Medicine Man, Genetics Researcher, Science Educator, Lawyer
Opinions and Attitudes

- Discussions with key informants and stakeholders
  - Medicine Men
    - “We shouldn’t do it”
    - “We’ve known about genetics for a long time”
  - Medicine Men’s Association (w/ 102 people present)
    - After a long discussion, MMA was opposed to allowing genetic research based on traditional and cultural values
  - Native American Church
    - Would approve the motion to allow genetic research if we had rules, regulations, and policy in place

Opinions and Attitudes

- Discussions (cont.)
  - IRB members
    - Had “the impression that the moratorium was temporary” but haven’t visited the issue since 2002
  - Diné Policy Institute
    - Very interested in partnering, creating a “much needed” Genetics, Ownership, and Intellectual Property Policy
  - Physicians
    - We see many families with rare diseases, we need better dx and tx, Genetic tools are promising
  - Parents
    - I have to “maneuver the system alone” and teach my children, advocate, communicate with doctors and medicine men
Review Process

- Navajo Nation Human Research Review Board (NNHRRB) reviews all proposals
- Approval requires a 12-step process (*list is not exhaustive*)
  - **Community Involvement**: Agency Council approvals, Formal Partnerships
  - **State Benefits**: To Navajo Nation and to Researcher
  - **Project Description**: In-person presentations, Informed Consent forms
  - **Return of Results**: Quarterly Reports, Dissemination plan, Data policy, Data transfer to Navajo Nation

Parting thoughts

- Understanding the community’s culture, history, and needs is crucial in designing research studies in those communities
- Helpful to understand the role of community representatives, stakeholders, and gatekeepers
- Conducting research in communities is time-consuming but also rewarding