

# Working effectively with IRBs

## AIHEC Behavioral Health Institute:

### 3rd Annual Conference

- *Stone Child College, May 24, 2016*
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# Hy'shqe siam -

## Thank you, respected teachers

- *Community Institutional Review Board (IRB) members*
  - Sam Deloria, Lisa Preston, Kathleen Alexis, & others
- *Native IRB leaders*
  - Dr. Francine Romero, Dave Oreiro, & others
- *IRB staffs*
  - Helen McGough, Moira Keane, Ada Sue Selwitz, Shannon Sowards, & others
- *Participants in research projects*
- *Researchers who walk their talk*
  - Tessa Evans-Campbell, Wylie Burke, Jaime Donatuto, Stacy Rasmus, & others
- *Wife* - Carolyn Robbins

# Outline: *with, Question, proactive*

- Work *with* the IRB
  - Planning research
  - Before applying
- *Question* what the IRB requires
  - Before applying
  - After IRB's response
- Be *proactive* – be your own IRB
  - do not rely on the IRB to protect
  - Do your own protection

# Why IRBs?

- One example – Barrow Alcoholism Study
  - ~1970
  - Document the adverse impact on an Inupiaq community
  - Harmed the community economically
  - Much worse:
    - Stigmatized the community
    - *Self-stigmatization*

# Are IRBs sufficient?

- NO
- [1] Barrow Alcoholism Study
  - Approved by an IRB
  - “Harm to Community / Tribe” seldom recognized as a harm
  - “Self-stigmatization” seldom recognized as a harm
- [2] IRBs vary in how well they observe regulations
  - “Increasing distrust” about research / researchers
- [3] National IHS IRB
  - Personal experience

# Work *with* the IRB

- When planning your research
  - Researcher's tunnel vision
  - Ask yourself, “What potential harms are present?”
  - -> Include in plan “How plan minimizes those harms.”
- To develop your application
  - Clarify intent of questions & purpose
  - Clarify potential harms & how to minimize
  - Consent *process* and consent document

# *Question what the IRB “requires”*

- Many IRBs are willing to listen to research and adapt what the IRB “requires,” if appropriate
- For instance:
  - IRB’s usual approach may not be practical in your context
    - Your alternate approach may accomplish the same benefits
  - IRB may not understand “potential harms & benefits to community” in your context
    - Distrust of research and researchers
    - Self-stigmatization, external stigmatization
    - Potential harm to the Tribe’s legal standing

# *Be proactive – be your own IRB*

- Identify & minimize potential harms yourself
  - Need to gain & maintain trust, and minimize potential distrust and potential harms
    - Minimize distrust: Use the word “research” in all materials
    - Minimize distrust: Use the word “experiment” (if it is) in all materials
    - Minimize potential harm: “Frame” or “reframe”
  - Potential harms to communities that only tribal review process may reveal
    - Authentic CBPR approach helps do this



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