Working effectively with IRBs
AIHEC Behavioral Health Institute:
3rd Annual Conference

- Stone Child College, May 24, 2016
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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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