

# Research In and With Tribal Communities: History, Evolution, and Vision

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# Acknowledgements

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# Goals of this talk

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Provide an historical context for research in and with tribal communities

- What has research looked like in the past?
- What does research look like now?
- What is a vision for the future?

*Indigenous peoples have been, in many ways, oppressed by theory. Any consideration of the ways our origins have been examined, our histories recounted, our arts analyzed, our cultures dissected, measured, torn apart and distorted back to us will suggest that theories have not looked sympathetically or ethically at us.*

Smith, L. T. (1999).  
*Decolonizing methodologies: Research and Indigenous Peoples.*  
New York: Zed Books.

# Barrow Alaska Study in 1979

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- Press release of findings states, “Alcohol Plagues Eskimos”
- Standard & Poor’s rating of the community dropped, and community was precluded from receiving funds for municipal projects

# Havasupai case in 2010

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- Tribe provided blood samples to researchers at the University of Arizona, for what they believed was a study to understand the genetic basis for the high rates of diabetes in their community and find a cure
- Consent stated research was to study the “causes of behavioral/medical disorders”
- Genetic links to diabetes like those found in another tribe were not found among the Havasupai so the research did not find the cure for diabetes the tribe hoped for
- 2 dozen other research publications came from these data – including one reporting a high degree of inbreeding, and one that challenged tribal beliefs about their origins in the Grand Canyon, and in the tribe’s view, the basis for their sovereign rights as a tribal nation
- Tribe sued the University of Arizona, and settlement was made in April 2010, awarding \$700,000 to 41 research participants and the return of the blood samples to the tribe

# Criticisms of Past Research in Tribal Communities

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**Research driven by questions generated outside the community**

**Research conducted primarily by outside investigators**

**No real relationship between community and researchers**

**Inflexible approach based on western scientific methods**

**Dissemination efforts focused in scientific outlets**

**Research  
Question**

**+**

**Western  
Scientific  
Approach**

**=**

**“Knowledge”  
adding to the  
scientific  
literature**



**Tribal  
Community**

30+ years of Research  
in one Tribal Community:  
Example of how  
Research Partnerships can Evolve

## 1980s

- Researchers new to community
- Targeted research project
- Began building relationships in community
- Engaged tribe in approval process
- Engaged local partners for help in adapting measures
- Began exploring options for community dissemination

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1980s

1990s

- Return to community for large scale research project
- University investigators partnering with local research staff – setting up field office, hiring and training local research staff
- Increasing reliance on expertise of local partners for adapting methods and measures
- Agreements with tribal government for approval of projects and regular review of findings/dissemination
- Provision of community research summaries and presentations

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2000s

- Move to intervention studies – driven by tribal partners
- Questions increasingly co-created by community and university partners
- On-going field office, employing and training interventionists and research team
- Tribal partners playing more integral role in identifying grant opportunities and generating research projects
- Increasing reliance on local expertise for measurement and methodology
- Tribal Research Review Board created – grassroots group of local researchers, service providers, cultural experts
- Established presence in community
- Greater involvement in community dissemination efforts (e.g., local health fairs) – typically led by local staff

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1990s

2000s

2010s

- Continued emphasis on interventions, application of research
- Tribal partners building infrastructure for more independent research, greater control of research agenda, transitioning to leadership role in research
- Increased funding directly to tribe – ARRA infrastructure building, NARCH grants
- Instituted community research conference; actively exploring ways to communicate research findings effectively to community members

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Lessons Learned in this Process  
about Best Practices for Tribal-University  
Partnerships for Research

# Useful and Appropriate Models of Research for Tribal Communities

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- Models for partnerships between communities and researchers
  - *Community-Based Participatory Research*
  - *Tribal Participatory Research/Kinship Models*
- Research driven by community questions
- Research to provide information that will be directly useful to community
- Western scientific ways of knowing working together with cultural ways of knowing contribute to shared success

# A tiered model of involving the community in the “community base”

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- **Tier 1: Project Core Staff**
  - The team that is primarily responsible for the research/evaluation
  - Can be tribal staff, program staff, field staff for university-based research
- **Tier 2: Advisory boards**
  - Community experts who provide broader perspective, substantive expertise
  - e.g., EAST Council
- **Tier 3: Broader input from community**
  - Focus groups, interviewees
  - Reaching out for broader community input
  - e.g., parents, youth, teachers, service providers

# Evidence-Based Practices

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## What is “evidence”?

- Scientific Criteria
  - Randomized Control Trials as the gold standard
  - Efficacy (*in the lab*) vs. Effectiveness (*in the world*)
- RCT in Indian Country?
  - Exclusion and Refusal
- “Best Practices” that may not really be best for tribal communities
  - e.g., “proven” usually not proven with American Indians, Alaska Natives, Native Hawaiians

## Alternative ways of thinking about evidence

- Dr. Fox and Dr. Bigelow

# Interventions Developed from Within

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- Culturally-based interventions
  - Building from the ground up

OR

- Culturally-adapted interventions
  - Using EBPs as a starting point
    - Surface adaptations
      - e.g., language, symbols
    - Deep structure adaptations
      - e.g., storytelling, tiyospaye
    - Supplementation
      - e.g., interweaving cultural curriculum
- Pros and Cons

# Some Priorities Moving Forward

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- Finding the right balance of western science and “tribal science”
  - Educating tribal researchers in western science
    - Principal Investigators (study leaders)
    - Research teams
  - Educating western researchers in tribal culture and ways of knowing
- Building research oversight infrastructures in tribal communities – IRBs, RRBs, etc.
- Building tribal administrative infrastructures for navigating research funding systems – from application process to tracking expenditures, complying with federal requirements, etc.
- Finding ways to communicate research findings effectively to those in the community who can benefit from them

# Tribal Community

## Research Question



Western Scientific  
Ways of Knowing



Cultural Ways of Knowing



**New Knowledge**

# What researchers can do to support the partnership

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- Be informed about tribal culture, norms, and practices
- Be informed about tribal protocols for research & follow them
- Work with community partners to identify questions that need to be answered
- Provide consultation on how research can answer these questions:
  - Consider what is feasible
  - Propose a research design
  - Propose research measures
- Work with community partners to review evaluation plan and change it based on what will work for the community
- Provide summaries of research progress and findings in straightforward language
- Seek ongoing input and feedback throughout the research process, making changes as needed to ensure success

# What communities can do to support the partnership

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- Help researchers understand cultural customs and practices
- Ensure that community stakeholders are represented in discussions
- Work with researchers to identify questions that need to be answered
- Consult with researchers on the research plan
  - Identify potential barriers to successful implementation
  - Provide input on procedures and measures, insuring a good fit with the community culture and language
- Assist researchers through the tribal approval process
- Help interpret findings in cultural context

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