Research Ethics in American Indian/Alaska Native Youth Contexts: A Toolkit.

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Tulane University School of Social Work
Overview

- Problem of Disparities for Indigenous Peoples
- Historical Trauma and Colonization
- Qualitative Description Method
- Results

Researcher’s Toolkit—Strategies for Culturally Sensitive Research
Variability and Commonality Across Communities

- Diversity among 566 AI/AN communities is great.
- Commonalities exist—including prevalent mental health disparities.
- Disparities interlinked with colonial tactics widespread losses
  - from extensive warfare, land loss, forced relocation, assimilation, boarding school attendance, and government attempts to destroy language, spirituality, and culture (King, Smith, & Gracey, 2009; Norton & Manson, 1996; Salois & Holkup, 2006).
Reducing Health Disparities

- Culturally congruent prevention and intervention efforts needed.
  - U. S. Trust Responsibility

- A critical gap in research to ameliorate the mental health disparities
  - Numerous barriers to conducting this work.
  - Research has negative connotations and has been described as a “dirty” word by some AI/AN peoples (Burnette, 2011; Smith, 1999).
Research Challenges and Trust

- Understandable mistrust of outsiders and research itself is widely documented
- Information about AI/AN communities was collected as a colonial tool to manipulate and dominate “the other.”
- Researcher have been opportunistic while offering no tangible benefit to the AI/AN communities themselves (Smith, 1999; Swisher, 1996; Sobeck et al., 2003; Weaver, 1997).
Ethnic background of researcher/practitioner

- Debate about who should work with AI/AN communities.
- Socialization
- Growing Resentment
- Role of non AI/AN researcher/practitioner
  - Step aside?
  - Ally?
- Awareness of these dynamics important
Method

- Qualitative description can be especially useful for work with:
  - vulnerable populations,
  - to reduce mental health disparities,
  - and to understand cultural nuances, because it describes a phenomenon with the voices of participants themselves rather than through the highly abstracted interpretation of researchers (Sullivan-Bolyai et al., 2005).

- Phenomenological overtones
Research Questions and Sample

- What are the lessons learned from the experiences of researchers who work with AI/AN communities?
- What strategies can be illuminated from current researchers’ experiences for use by other researchers who work with AI/AN communities?
- Thirteen expert AI/AN (n=6) and nonAI/AN (n=7) researchers:
  - across multiple disciplines: seven were from social work, and the remaining scholars were from public health, psychology, health and human development, nursing, counseling, and political science.
  - 15 to 37 years of research experience
Data Collection and Analysis

- Semistructured interviews (6 in person)
  - “How has your experience in doing this type of research affected the way that you see the well-being or mental health disparities of Native people?”
  - “How have situational or contextual factors affected your work with AI/AN people?”
- Qualitative content analysis
- Rigor strategies (Milne and Oberly, 2005) Used member checks, peer review, flexible interview schedule, participant driven data, and data driven coding.
Results

Trust emerged as an overarching metatheme along with following six themes:

1. The impact of history,
2. Relational research as fundamental toward trust building and collaboration,
3. Incorporating cultural sensitivity and strengths
4. Risk reduction and power balancing,
5. Unique research considerations in working with AI/AN communities, and
6. Honoring multiple worldviews
Trust

- Activities on a continuum between trust building and trust breaking
- Exploitation in history and research compromised the baseline trust.
- Relationships central in trust building, gaining entrée, and collaboration.
- Researchers reduce the risk of exploitation by dismantling power differentials.
- Designing research from a tribal perspective reduced the risk of exploitation and facilitated trust building.
  - Took extra time and patience
  - Researchers needed tangible support the extra resources to build rapport and collaboration with AI/AN communities in a culturally sensitive way.
The Impact of History

- Researchers emphasized the history of trauma that many AI/AN communities had endured, “Colonizers have used the same strategy, not just in America . . . missionaries, merchants, and military.”
- Connection of these losses to disparities in wellbeing:
- Grief manifested in later symptoms of “later substance abuse, intergenerational family violence—things like that.”
Relationships as Fundamental Toward Trust Building and Collaboration

- Social Culture
- Personal qualities: reciprocity, cultural humility, respect for people, a sense of goodwill, genuineness, and authenticity in trust building.
- Collaboration was mutually beneficial and complementary.
  - “We have a mutual understanding—mutual respect.”
  - “I couldn’t do the work that I do . . . if I didn’t have nonmembers . . . working with me.”
Reinforcing Cultural Strengths and Lifeways

- Incorporating AI/AN strengths, a family focus, a tribal perspective, and community-based and qualitative methodologies that resonated with AI/AN communities.

- A non-AI/AN researcher remarked on, ‘the incredible strengths’ of AI/AN communities:
  - You know, these communities have existed for 10,000 years, some of them. And the fact that ... [they] still exist given what they’ve gone through, in terms of imperialistic domination, federal policies from the United States and Russia, and others ... is amazing.... I think that the answers to any research question that you could ever come up with lies within the community. I mean, we can help, but I think, you know—they know the answers, and we don't. And I think that part of the reasons why the problems have continued is because researchers haven’t believed that.... Where I’ve seen profound change has been when the communities have come up with their own solutions.
Risk Reduction and Power Balancing

- Great risk for AI/AN persons to bring in an outsider
- Cultural humility, “We look for the power differentials and try to dismantle them.”
- Trust, risk and vulnerability, transparency, reputation, and commitment were core concepts.
Distinct Research Considerations

- Ethnic identity, “[Suicides] never come at times when people are doing their traditional subsistence activities. It happens later, when they’ve returned to the villages and they’re not in the extended family network.”

- Spirituality, connection to place and land, Indigenous principles: “connection to the land—land as sustenance,” as well as “the commitment to the spirit”

- Time and patience, distance, and confidentiality
Honoring Multiple Worldviews—Are we There Yet?

- Education as an assimilative force:
- One AI/AN researcher commented on the need for flexibility and respect for cultural practices.
- There could be difficulty in getting tangible support for this.
## Best practices for Research

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<td>Funding sources can foster culturally congruent research and intervention by allowing for traditional customs allocating funds to AI/AN communities and infrastructure.</td>
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Best Practices: Case Example working with al/AN Youth

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Work supported by

- Silberman Faculty Grant Program
- Fahs-Beck Faculty Grant Program
- Newcomb College Institute of Tulane University
- University Senate Committee on Research Grant Program, Tulane University
Historical oppression: intergenerational impacts of societal-level historical traumas, but also the proximal, contemporary, and chronic stressors that AI/AN peoples disproportionately experience, such as poverty, discrimination, and the resultant social and mental distress (Burnette, 2015).

An ecosystemic framework of resilience places primacy on the interactions and interconnections among risk and protective factors across individual, couple, familial, cultural, community, and societal levels (Waller, 2001).
Implementing the plan: What worked

- Committing Long-term
- Completed dissertation, which informed current study
- Followed Tribal Protocols: Reported to Chief and Tribal Council
- Worked with cultural insider
- Invest resources: Gained financial support
- Reciprocity and transparency:
  - hired tribal research assistants
  - Participant compensation
- Enabled self-determination: Met with organization heads
- Followed guidance of tribal member
  - Recruitment: Community News, Facebook, Posting at all community agencies, Word of mouth
Description of the design

- Worked with two Southeastern Tribes: Very different experience and approach
- Focus on Family resilience: having community members identify risk and protective factors across multiple levels
- Culturally congruent methodology: storytelling, family, group based
  - Focus group—12 each tribe
  - Spoke to Elders, Adults, Youth, and Professionals (30 each)
  - Family interviews—30 each tribe
  - Over 200 total participants from each tribe
  - Follow-up survey
- Examine whether emergent risk and protective factors identified by community members predict wellbeing, health, violence
Data collection and analysis considerations

- Data collection
  - Patience and persistence
  - Locating community helpers and insiders
  - Devote time

- Data analysis
  - Research assistant from each tribe
  - Invest resources
  - Culturally congruent, training future experts
  - Honoring multiple worldviews
What worked

- Began with Professionals (easiest access), adults
- Make use of tribal strengths: word of mouth
- Focus groups first—Boys and Girls Club, Parenting groups
  - Parent permission
  - Gain familiarity/comfort for individual interviews though groups first
- Elders different for different tribes—preferred groups
What worked cond.

- Background of researcher
- Fluidity and Flexibility—Some preferred group interviews, recording
- Credibility and trustworthiness of information (balance of rigor and flexibility)
- Compensation
- Incorporating Strengths
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<td>Build a reputation for doing worthwhile work.</td>
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<td><strong>Go the Distance</strong></td>
<td>Travel to AI/AN communities, which might be a long distance away.</td>
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<td><strong>Demonstrate Patience</strong></td>
<td>Understand that relationship, trust-building, and the research process take time.</td>
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<td><strong>Enable Self-Determination</strong></td>
<td>Incorporate the tribe’s input and participation throughout.</td>
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<td>Avoid imposing a Western perspective.</td>
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<td>Build on the many strengths within AI/AN communities.</td>
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<td>Consider community, family, and individual confidentiality and how to ensure it, especially in tight-knit communities.</td>
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