RESEARCH ETHICS IN AMERICAN INDIAN AND ALASKA NATIVE YOUTH CONTEXTS:
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QUESTIONS POSED

• Are there differences in research ethics when working with tribal and Native youth?
• What are the key elements of research ethics training for researchers working with tribal and Native youth?
• What tools would be helpful to develop for researchers & community leaders to improve research with tribal and Native youth?
CONFIDENTIALITY

• Issues
  • How is individual youth privacy/confidentiality maintained in small communities where everyone knows each other?
    • Participation in studies/interventions that address stigmatizing issues
    • Participation in focus groups in small tribal community where everyone knows each other
  • What are the unintended consequences of maintaining community confidentiality?
    • If communities are not named, will they be able to argue for resources they need?
    • If communities are not named, are important inter-tribal differences addressed?
    • If communities cannot be named, how do we include our tribal partners as authors?

• Possible solutions
  • CBPR to address these issues up-front
YOUTH CONSENT

• Issues
  • For youth being raised in the context of extended kin care where mom or dad may not be primary, or available at all, who is the legal guardian? And has guardianship been established “legally”?
  • Should youth without a documented “legal” guardian be turned away from participation in research that could benefit them?
  • Should the named guardians consent be accepted, regardless of “legality”?

• Possible solutions
  • Institutional review board input
  • Tribal research review board input
REFERRAL CONTEXT

• Issues
  • Participation in surveys or interviews is likely to identify a need for services among youth – e.g. mental health concerns, substance abuse, child abuse/neglect
  • The research project is often not designed to address the issues that come up – either because it is not an intervention study, or the intervention is addressing other issues
  • Existing community resources may be limited for addressing the issues raised – e.g. due to long wait lists, lack of services altogether, or confidentiality concerns of being associated with a particular program

• Possible solutions
  • CBPR – work with community research partners to identify potential issues and resources in the community as well as outside of the community for addressing potential issues
  • Document these issues and provide feedback to tribal community stakeholders/leadership
SUSTAINABILITY

• Issues
  • Communities and funders both want assurances of sustainability
  • This is a challenge in communities where resources – both financial and human capital – are stretched thin
  • What is a researchers obligation to find support to address the issues that are brought to light, or to find support for continuing interventions shown to be effective?

• Possible solutions
  • Acknowledge these limitations up-front
  • Be willing to step outside of the academic box and connect with others who can advocate for these resources to be directed to tribal communities
  • Opportunities include working with NCAI, participating in research conferences/meetings that reach tribal leaders, tribal program audiences, and funders
TRIBAL LAWS & REPORTING

• Issues
  • Tribal laws may be different than state laws for reporting child abuse or threat of harm to self/others
  • For example, some tribes require that elder abuse is reported; some require that drinking during pregnancy be reported; some require that domestic violence be reported; some require that serious substance use by a minor be reported
  • Can come up when you least expect it...

• Solutions
  • Be fully informed of tribal reporting laws and have a plan for how your research staff will handle reports when these issues come up
  • Make sure that research participants are fully informed of your duty to report
  • Do not shy away from these issues
• **Issues**
  - Some tribes will not accept an observation only design, and require an intervention
  - Simple pre-/post design is not sufficiently rigorous to test the effectiveness of the intervention, so a comparison group is needed
  - Some tribes will not allow an RCT with a “no treatment” or “care as usual” control group
  - Even if tribes are ok with this – is this defensible given the level of need?
  - But there are implications for cost and personnel if two interventions are given

• **Possible solutions**
  - Much room for research design innovation that allows for designs that address these concerns while also producing the evidence needed to support replication and dissemination of “evidence based interventions”
  - Provide research design trainings for researchers
UNANSWERED QUESTIONS ABOUT AI/AN YOUTH DEVELOPMENT

• Issues
  • How to assess differences within communities with respect to developmental trajectories? Sample sizes may be too small to detect within group differences
  • What is the influence of culture on development? How is culture measured at all developmental periods?
  • Much research is focused on risk and problems – we need to focus on positive youth development as well
  • Existing measures may be limited in their ability to adequately capture AIAN youth development

• Possible solutions
  • Funding to support measure development
  • Promoting national studies of AIAN youth development
CROSS-CUTTING SUGGESTIONS FOR NEXT STEPS

- Web-based resources
  - CITI Course for working with tribes
  - Clearinghouse for research with tribal communities
    - Access to papers and reports
    - Access to researchers whose expertise matches the needs of communities
- Increased forums for promoting partnership between tribal stakeholders
  - Tribal leaders
  - Federal funders
  - Researchers
  - Policymakers
  - Tribal program leaders
- Social media to spread the word about research
  - Dissemination of the latest findings
  - Information about conference opportunities
  - Make sure that innovations in research with AIAN communities reach non-AIAN communities
- Promoting national studies of AIAN youth health and development
- Building capacity for AIAN researchers and community partners (including tribal research review boards)
CENTERS FOR AMERICAN INDIAN & ALASKA NATIVE HEALTH RESOURCES

• Conference and training opportunities
  • www.tribalearlychildhood.org
  • www.ncreconnect.org
  • http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/NERC/ni/Pages/ApplicationProcess.aspx

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