Building Collective Agendas and Tools to Manage Research: Tribal Community Experiences

Community-Campus Partnerships for Health Conference Call Series on Building Community Capacity for Research
March 24, 2010

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National Congress of American Indians
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• Oldest, largest, and most representative national Indian organization serving the interests of tribal governments
• Established in 1944 as a representative congress of Indian tribal governments
• Serves as a forum for consensus-based policymaking
National Congress of American Indians

• Addresses the broad spectrum of issues that tribal governments are concerned with: from cultural preservation and natural resources and from education to economic development

• Aspects of our work: advocacy, legal analysis, policy development, public/media education and outreach, policy research, and tribal capacity building
“Outsiders have researched us to death, and the research doesn’t even benefit us.”

-Former Councilman Eddie Tullis
Poarch Band of Creek Indians
“Data is political.”

-Dr. Stephen Cornell
Director, Udall Center for Studies in Public Policy, University of Arizona
“Tribes need data to support their own self-determined agendas.”

-W. Ron Allen
Chairman, Jamestown S’Klallam Tribe
NCAI Policy Research Center

- Established in 2003 as a national tribal policy research center that would focus solely on issues facing tribal communities
- Forum for forward-thinking, deliberate, proactive Indian policy discussions and the development of policy scenarios
PRC Funders

- Administration for Native Americans, U.S. Department of Health & Human Services
- Annie E. Casey Foundation
- Bill and Melinda Gates Foundation
- Ford Foundation
- National Institute of Justice, U.S. Department of Justice
- NeighborWorks America
- Oneida Nation of Wisconsin
- Shakopee Mdewakanton Sioux Community
- Stewart Title Co.
- W.K. Kellogg Foundation
PRC Vision

supporting Indian Country in shaping its own future
PRC Values

• Research in service to community
• Direct implications for communities and improving their well-being
• Community-driven agenda and all aspects of the work
• Honor community and cultural contributions to the work
PRC Values

• Partnership with communities and other organizations
• Respect tribal sovereignty and ownership of data
• Indigenous knowledge is as valid as academic knowledge
• Research should build community capacity
Core Buckets of Work

• Clearinghouse
• Research Support
• Capacity Building
• Think Tank
PRC Work

• Making data available and translating research into practice
  – Web-based data clearinghouse of publicly available
  – Annual Tribal Leader/Scholar Forum
  – Topical convenings
  – Research products
PRC Work

• Research support
  – Identify research questions prioritized by tribal leadership
  – Inform development of appropriate research plans
  – Identify/adapt/create appropriate measures
  – Data analysis
PRC Work

• Tribal capacity building
  – Information about tribal options for regulating research
  – Data collection, program evaluation, and research curriculum
  – Research tools
  – Technical assistance
  – Identify promoters and inhibitors of effective community-based participatory research (CBPR)
PRC Work

• Think tank
  – Forecast emerging policy issues
  – Convene critical stakeholders to “have the conversations that no one else will”
  – Develop policy scenarios and assess impact of various policy options
Building Agendas for Research

- Communities of Practice Program
- Networks diverse stakeholders around key issues to Indian Country to build collective research and policy agendas
- Serves as an informal forum to discuss research and policy priorities, share input on current projects
- The collective agenda helps strategically focus resources (financial, academic, etc.) to meet Indian Country’s priorities
Tribal Leader/Scholar Forum

- Selected researchers share their work with tribal leaders and other participants at our Mid-Year session
- Tribal policymakers offer feedback to researchers about the impact, and potential next steps of their work
- Special emphasis on the practical, real-life implications of research
- This year’s focus: law enforcement/public safety, health care, natural resources, energy development, strategies for strengthening tribal governance
Questions?
Tools for Communities to Manage Research
Research Curriculum

• Foundations of Research: An Indigenous Perspective
  – Introduction to how tribal values relate to research; these are emphasized throughout the curriculum.
  – Introduction to the context and situations in which a tribal leader may need a working knowledge of research and related issues.

Module 1 available at: http://www.ncaiprc.org/research-curriculum-guide
Research Curriculum

• Managing The Designing And Planning Of Research
  – Designing a research study
  – Developing a research plan

• Using Ethics As A Guide For Managing Research
  – Identify, understand, and apply basic ethical considerations related to conducting research
Research Curriculum

• Conducting Research With Others
  – How to choose, evaluate a research partner
  – Tribal research policy: Institutional Review Boards (IRBs), research agreements, etc.
  – Skills for being an effective partner

• Understanding Evaluation
  – Designing, implementing a program evaluation
  – Culturally competent evaluation techniques for tribal communities
Research Regulation Papers

- Policy and Practice Considerations
- Guide to Reviewing Research Studies
- Tribally-specific considerations related to research
- Could be useful to other communities also re: collective decision making, regulation of research

Papers available at: http://www.ncaiprc.org/research-regulation-papers
Ethical Values

• Belmont Report
  – Federal ethics guidelines for research
  – Respect for persons, justice, beneficence

• Native Ethical Frameworks
  – Akwesasne Task Force on the Environment
  – Skennen (peace/justice), Kariwiio (good word), Kasastensera (strength/power)
Legal Ways to Regulate Research

• Legal Contracts with Researchers
  – Explicitly sets the terms for research conduct
  – May require substantial time and resources to develop
  – Consider using template contract
  – Models:
    • Indigenous Peoples Council on Biocolonialism
    • Canadian Aboriginal AIDS Network
Community Review Board Models

- Institutional Review Board (IRB)
- Community Advisory Board (CAB)
- Existing community committee
- Contracting with outside IRBs
- Consortium Review Board
IRB Training Resources

- Collaborative IRB Training Initiative (CITI)
- Family Health International curriculum
- National Cancer Institute
- Office of Human Research Protection
- NCAI Research Curriculum

http://www.ihs.gov/MedicalPrograms/Research/irbTrain.cfm
Research Review Checklist

- Tool for community review of research
- All stages of a study
  - Proposal
    - Informed consent forms
  - Ongoing reports
  - Publications and products
- Community, individual risks and benefits
- Narrative for checklist - paper
Research for Change

- Conducted by NCAI PRC, University of Washington, University of New Mexico
- Study of promoters of effective CBPR
- Native and non-Native communities
- Governance a key variable
- Quantitative and qualitative methods
- CBPR Community of Practice
Conclusion: Lessons Learned

• Communities (Native and non-Native) can use collective power to regulate research
  – Research review processes
  – Legal contracts/enforcement

• Education for building capacity
  – Defining research and other academic terms
    • Glossary
  – Confidence to engage with researchers

Authority to regulate research
Questions?
Contact Information

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