



Establishing Community Based Research with American Indian Communities

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Abstract

The history of research in American Indian communities is littered with human rights abuses, harm to individuals and communities (Trimble, 2005). American Indian communities today must consider and place limitations on how, when, where, and other aspects of research in their communities as well as protecting the individuals and communities from the outcomes of reports of that research or disclosure of the community could cause. This represents a model that abandons the "helicopter" research that has been practiced by many researchers over the years and makes the community a partner in the research and a full participant in determining how it will be conducted in local communities. It also addresses ownership of the data, providing results to the participants and community, and publication and dissemination of the research. This project also shows the lengthy and multilayered approval process that is now in place because of the abuses of the past.



Background

Historically, research in American Indian communities has left many suspicious and resistant to research and how it is used. Moreover, historical examples of the research done in Native communities have reinforced racial stigmas. Although operating within the norms of Western research, the experiences of American Indian/Alaska Native (AI/AN) communities have expressed feelings of being treated like guinea pigs (animals) and researched without informed consent or access to the results. These issues resulting from previous research have long remained unrecognized as unethical. Presently, researchers working in American Indian communities should develop expertise to identify and minimize all potential harms to communities as well as the individuals within the communities.

Currently, the unethical research done with AI/AN communities is not catalogued among problematic research in IRB training and ethics courses. However, much of the research done with American Indian people has left them feeling as though previous research has disrespected them, their communities, and their rights. Historically "Helicopter" research, occurred when non-Indian researchers would conduct studies using AI/AN participants and then leave the communities without reporting the results or providing them with a summary of the implications that the research had on their community. "Helicopter" research performed by non-Indian researchers set the precedence in Indian communities for years and; upon leaving, and unbeknownst to the community, researchers would publish results in national empirically based journals or release results as reports to the media with a stereotypical bias and negative impact on the AI/AN community. Consequently, all subsequent research done in Native communities was biased due to the expectations of the participants and mistrust in the researchers. Due to such tragedy spawned by faulty and unethical research designs the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (NCPHBB) proposed regulations on research. The regulations proposed by NCPHBB required the use of Institutional Review Boards (IRB), mandatory informed consent form for the consent to participate in a study, and assessment of risks and benefits to the subjects. The aforementioned regulations were just a few proposed by the 1974 Research Act; however, the act shed light on the importance of informed and respected participant participation. Additionally, due to their **domestic nation** status, AI/AN tribes are allowed to determine who can or cannot do research in their communities and how any research may cause harm to the community as well as the individual.

Presently, ethical concerns revolve around use of the IRB, respect for and informed participants, minimal risk and maximal benefit of participants, and justice for participants. Although IRB approval and participant regulations are advantageous to the practice of ethical research, they do not satisfy the needs of AI/AN communities. According to Van Der Eb et al. (2004), community researchers need to be cognizant of the connection between participation and ethical practices. When they are included in interpreting the results they can address cultural aspects that may be unknown to the researcher. Moreover, communities have been found to agree that ethical relationships begin with: 1. Building relationships within the community; 2. Created when the researcher is transparent, and open to his/her cultural biases; 3. Can promote beneficial social change for all in the community; 4. Takes into consideration the balance of power, experience, and culture.

In conclusion, IRB approval is a necessary and valuable initial step to ensure ethical consideration of the participant and community where research is conducted. However, IRB in itself is not necessary for tribal members or tribes.

The Approval Process

1) IRB APPROVAL

Aberdeen Area Tribal Chairs Health Board (AATCHB): passes resolution supporting study.

University of North Dakota Institutional Review Board (UND IRB): responsible for Human Subjects protection (students and faculty) on the UND campus.

Aberdeen Area IHS Institutional Review Board (AAIHS IRB): responsible for all Human Subjects protection in the Aberdeen Area (ND, SD, NE., IA).

AAIHS IRB also requires Tribal Council approval:

1) A tribal resolution from each tribe or a letter from review board

2) And if utilizing IHS resources (collecting data from a behavioral clinic), a Letter of Support from the Service Unit CEO is required.

2) TRIBAL APPROVAL

Each tribe determines their own process for approval.

There are many different ways depending on the tribe:

1) The study will go straight to the Tribal Council for approval

2) The materials get sent to Tribal Health Director and he/she will bring it forward to the Health Board and once the study is approved it will go onto the Tribal Council for approval

3) The study material will go to the Health Board first and then onto the Tribal Council for approval

4) A referral by Health Board to Tribal Mental Health for review and then onto Health Board again and once approval is gained, onto Tribal Council for approval

5) A referral by Health Board to Tribal Health Director and Behavioral Health Coordinator for review and then back to Health Board again and once approval is gained, onto to Tribal Council for approval.

*Tribal Council approves the study and a resolution to agree to participate is written and sent to the Principal Investigator.

*If IHS resources are used, a letter of support of the project is required from the IHS Service Unit CEO agreeing to the use of time and resources for the project.

*However, a Letter of Support from the CEO would not be needed if the tribe opted to manage their programs under **Public Law 93-638**, also known as 638ing. Only a letter from the tribe would be needed since the program resources are managed by the tribe.

"Never look for psychological explanation unless every effort to find a cultural one has been exhausted"
(Margaret Mead 1959, p. 16).

3) TRIBAL CONTACTS

In the past 18 months, many contacts were made to each of the tribes/reservations in North and South Dakota. There are 4 reservations in ND and 8 in SD making 12 total tribes.

So far, the project has:

*Gained Tribal Council approval from 4 tribes and began collecting data at one of the sites.
*Received 3 Service Unit CEO support letters.

*Gained approval from 4 Health Boards and moved to Tribal Council agendas.

*On the agenda at 2 Tribal Councils and 2 Health Boards in the near future.

The Tribal approval process can be long and frustrating at times. Obstacles include referral to others for discussion and review followed by delays in response before going to the next level of approval and Tribal Health Board and Tribal Council meetings occurring once a month. Scheduling and long distances to travel add another level of complexity.

Definitions

PL (Public Law) 93-638: The Indian Self-Determination and Education Assistance Act of 1975, Titles I and III, have made it possible for Tribes to take specific program shares (dollars) under Title I, Annual Funding Agreement, or to become totally self-governing under Title III, Compacting/Self-Governance.

Programs under Title I that still fall under Indian Health Service (IHS) are supervised and controlled in some degree by IHS.

Under Title III, Tribes have total control over all of their health-related programs. The programs of those tribes are under close scrutiny and stand to be modified as a result of the compacting tribe's decision to govern itself.

Dependent Domestic Nations: Status of Native American tribal lands as dependent or nations within the federal system.

Helicopter research: Unethical experimenter conduct whereby the researcher "drops in" and conducts research in the community neglecting to communicate the reasons behind the research or the implications of the research to the community or the participants. The researcher does not seek tribal approval nor do they return with the results of the research.

Participatory research approach: Research approach that emphasizes the empowerment of the community members (participants), enabling them to re-establish power in the research process as well as providing enrichment and knowledge about the issue under concern.