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Personal Experiences with Tribal IRBs, Hidden Hegemony of Researchers, and the Need for an Inter-cultural Approach: Views from an American Indian Researcher

J. Neil Henderson

Introduction

Conducting research among American Indian tribes has not always involved IRB review. During much of the 20th century, most research projects started and ended at the will of investigators. By the 1970s, tribal councils were the primary gatekeepers for research requests. Beginning around 2000, many tribes added IRB expertise based on the *Belmont Report* by attending training sessions providing concepts and strategies for operating IRBs, in part in order to protect themselves as members of sovereign nations.

Cultural contradictions, however, may be seen when the *Belmont Report* is understood as a culture-specific document. American Indian tribes have cultural systems that can be very unlike the contemporary American majority population. Consequently, the basic tenets of the *Belmont Report* may not be universally applicable to American Indian life ways. For example, John Traphagan unmasks the American-specific cultural context of the *Belmont Report* by comparing American bioethics to that of Japan and finding significant differences, particularly related to the concept of autonomy, a value firmly embedded in the *Belmont Report*.[1] Autonomy is a very strong, foundational American value not shared as fully by all other societies. Simply put, "Bioethics — American style — are just that, American-style bioethics."[2] Still, Belmont remains the standard across American Indian tribes for IRB protocols.

I have conducted more than 30 years of research with American Indian populations on health, disease, and treatment. Over this time, I have observed numerous changes with regard to the ways in which to collaborate appropriately with tribal members. This paper is less a treatise on tribal IRBs and more a set of reality-based windows through which can be seen important dynamics of American Indian IRB operations not always discussed in the literature. Most important among these dynamics is the suggestion that human subject protections can best be maintained when research among American Indian tribes is seen as an inter-cultural process. The organizational cultures of funding agencies, universities, and tribal entities are all actually working as a social and organizational interlocked ecology. Researchers who simply

J. Neil Henderson, Ph.D., *is a Professor at the University of Minnesota Medical School, Duluth campus and the Executive Director of the Memory Keepers Medical Discovery Team on Health Equity where his work focuses on ending American Indian & rural health disparities. He holds a B.A. in Sociology and Anthropology from the University of Central Florida, an M.S. in Psychological Anthropology from the Florida State University, and a Ph.D. in Medical Anthropology from the University of Florida.*

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want to mollify American Indian concerns in order to conduct research as well as tribal IRBs that simply want to block research as a symbol of new found power will severely truncate progress in the improvement of health status among American Indian people. The inter-cultural model has the potential to promote true collaboration between researchers and tribes, with the result that health and quality of life can continue to improve.

My experiences with American Indian research and IRBs that I report here are the result of actual experiences with IRBs among several tribes over many years, combined with insights from being a voting member of a federally recognized tribe. My observations are situated within parameters of symbolic interactionism, ethnographic inquiry, and emic (member) perspectives of tribal versus non-tribal dynamics.

This brief article constitutes a reality-based, first-hand report on selected aspects of researcher-IRB dynamics. Much of the literature written in the scholarly model is silent on the items that I bring forward here, and I highlight those here precisely because they are little discussed. Moreover, the complexity of American Indian and Alaska Native culture, cultural dynamics, and cultural expressions across tribes (including the intra-group variations of a given population) make acknowledgement of the nearly infinite variations across and within tribes impossible to specify. I adopt the shorthand "AI tribes" and "AI culture" here with full recognition of these complexities.

Brief History of Tribal Research Permissions

Before the 1970s, research of any kind was done with most American Indian (AI) tribes with no or very little requirement for permissions, consent forms, or other efforts at collaborative consultation. Federal government structures regarding AI tribes retained their paternalism and dominance over tribal life. The Bureau of Indian Affairs (BIA) was present in the lives of tribal people, particularly those living on reservation trust land. However, the BIA functions and purposes were not related to protections related to participation in health research. In the mid-1950s, the Indian Health Service was created and funded. Clinical care was the main mission of the Indian Health Service and not use as a human research laboratory. Consequently, these nationally distributed agencies across Indian country did little to serve as a filter for research requests whether health-related or not.

Entry into Indian Country to conduct health research remained very unregulated. For example, David E. Jones, an anthropologist interested in AI life, began working with an Oklahoma Comanche medicine woman in the latter part of the 1960's whom he had met through the chance occurrence of helping her young nephew with his fishing gear (personal communication). Jones and this boy occasionally encountered each other at their favorite fishing hole near Lawton, Oklahoma. On a few occasions, Jones had driven the boy from the fishing hole to his aunt's house where the boy asked to be dropped off. However, on one of these drives the boy said, "You can't drop me here today because my aunt is healing someone." This piqued Jones's interest. Over time, Jones was able to meet the boy's aunt, which eventually led to a series of interviews and one of the most popular ethnographic sketches ever written.[3]

Jones's interviews with Sanapia did not involve any permissions at the tribal level because in the late 1960s (although there are a few exceptions), there simply was not much of an issue with regard to tribal permission, particularly to work with one tribal member. However, Jones's professional and personal behavior was very respectful of Sanapia and

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proceeded in ways satisfactory to her. For example, during recorded interviews with Sanapia, if she chose to tell Jones information that was not for public consumption via his oral or written dissemination, she simply sat a loudly ticking clock on the body of the recorder to obscure what she was reporting. When she felt comfortable with having other speech recorded, she moved the clock back on the table and audible recording continued. Additionally, the publication of the resulting book was done without any tribal review but was allowed by Sanapia because she thought that her knowledge of traditional healing would otherwise be lost at her death. She perceived the interactions with Jones as a particularly fortuitous opportunity for preserving this knowledge.

Individual decision making by tribal members with regard to participation in health related research, such as with Sanapia, occurs. This is true today even in the presence of tribal IRBs. AIs are not only citizens of their own tribal nation but of the United States as well. They can choose to express or suppress either status as they wish. However, researchers today who begin to accrue a research sample of even a small number of tribal members on trust land without tribal authority would never again be allowed to conduct research there, and tribal authorities often issue strong advisories to tribal citizens that these researchers do not have permission to conduct their research. On some reservation land, the researchers could be literally expelled, an action enforced by tribal police.

From about the 1970s into the 1990s, tribal councils served as the gatekeepers for the review of research requests. During these decades, some tribes began to engage in more activities related to tribal self-destiny. Research requests were required to be presented at tribal council meetings. In my experience, after a presentation made by the researcher, the researcher would leave the room and be contacted at a later time with regard to the council's decision. At the end of the research project, it was common for researchers to present their results to the tribal council.

Beginning around 2000 and up to the present, formalized tribal IRBs modeled after the requirements of the *Belmont Report* from the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research began to take over the role of deliberation regarding research requests. The leadership of IRB committees would attend nationally offered training on the conduct of IRB processes. One effect was to create some common ground of procedure between tribal members working on the tribal IRB and the research team because researchers were familiar with IRB processes. However, not all tribes have IRBs. For example, in Oklahoma, a state with the second largest native population and with 38 federally recognized tribes, only three tribes operate IRBs.[4]

Sociocultural Context of Research with AI Populations

Distrust on the part of non-majority populations with regard to researchers and participating in health research stems from past and perhaps some present research abuses. Ultimately, such abuses are often less due to medical hegemony and more the result of *cultural* hegemony reflected in resultant structural and behavioral discrimination. Abusive behaviors are derived from a deep foundation of cultural precepts including unquestioned ethnocentric derogatory beliefs about others that rationalize improper treatment.

Cultural beliefs are both conscious and unconscious and can be very subtle, yet all the while very significant. Because cultural beliefs are imbued with the ability to evoke feelings, prejudicial behavior can be accompanied by feelings not only of hate and fear but also of saintly righteousness. Such feelings are involved in the perpetuation of harmful prejudicial behavior regardless of its obvious injustice as seen from the viewpoint of the recipient.[5]

Many AIs see much of their lives through the lens of colonialism, historical and multi-generational trauma that is the outcome of cultural hegemony and discrimination.[6] The cultural hegemony of the majority population is a product of a culturally-based cosmological set of presumed truths. While it is impossible and misleading to set forth a static trait-list of cultural factors, there are some broad strokes very common across the American population.[7] For example, empirical observations of macro behaviors among the majority population and in cross-cultural context indicate that many hold beliefs in a supernaturally ordained superiority of their own population over others, a value placed on hyper-individualism, individual achievement, a value placed on excessiveness, and a belief that financial gain is evidence of the inherent goodness of the majority group.[8] Such cultural beliefs result in a fantasy of American and white exceptionalism that simultaneously functions as a justification for derisiveness about non-majority populations, their beliefs, and ways of life.

Self-protection by AIs, as operationalized through IRB review, is partly the result of their sometimes paradigmatic differences in cultural foundations in comparison to the majority population. The broad cultural approach to life cuts across many AI nations (recognizing variance in acculturation, individual perspectives, and intra-group dissimilarities) includes a sense of common community rather than vertical stratification

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of status and class, a value placed on inter-personal and inter-group cooperation, a value of ecological and fiscal constraint, and a sense that the large accumulation of wealth is a sign of greed that constitutes an inappropriate affront to the group. These generalized AI cultural factors are in many ways in opposition to the broad majority American cultural framework. American Indian cultures can be so different that they constitute the experience of a life lived embedded in a different cultural paradigm, in spite of living in a common national space.

An example of foundationally different cross-cultural beliefs of American biomedical health beliefs in contrast to AI cultural explanatory models of health and disease is found in a personal incident in which I was speaking at an elder AI conference. A question came from the audience about what to do about depression. I first launched into the obligatory biomedical approach in which I described cognitive behavioral therapy, medications, and that the best outcomes came from a combination of the aforementioned. While I was voicing my opinions, an AI man in the audience who was wearing a big cowboy hat was slowly and continuously shaking his head left and right in an obvious effort to show his negative critique of the standard biomedical model for responding to depressive episodes that I was giving. However, I continued and suggested that the many traditional healing modes such as sweat lodges, use of traditional healers, and use of plant-based medicines that were present across tribes could also be a very important primary or concomitant strategy for alleviating depression. As I said these last words endorsing traditional healing, his head shaking began to move vertically up and down indicating that I had finally gotten onto the right track. In other more analytical words, the biomedical model did not resonate with his culturally-based explanatory model for depression and its treatment. The reference to traditional healing, on the other hand, did fit with his (and presumably many other tribal members) concepts of appropriate treatment. This non-materialistic, spiritually based therapeutic approach reflects some very different foundational cultural beliefs about health, disease, and tribally appropriate treatment.

AI health beliefs that vary from general Western cultural views may not always be easily detectable by outsiders[9] and, therefore, frustrate those trying genuinely to behave in culturally sensitive ways. This is partly due to the process of acculturation resulting in composite native life ways that are derived from both their own native culture and that of the majority culture.

Acculturation processes have operated in ways to conceal, but not always eliminate, some of the native cultural values specified above. But such concealments are most apparent in social situations with those of the majority population. For example, the workplace is a part of the American life space in which the major rewards are for individual financial gain. This approach to work is completely consistent with the winner-take-all "supercapitalism" of American business.[10] American cultural economic values include the belief and behavior that the economic exploitation of others is acceptable, is sanctioned as a sign of good business practices, implicitly agrees that fiscal injury to workers and their families is an acceptable cost of doing business, and de-regulation (which may be considered de-protection of workers) is acceptable for fueling the economic engine. These traits are well captured by Howard Stein's book title using the aphorism, "It's nothing personal, just business."[11]

Public perceptions of contemporary AI culture are highly varied. Expectations of AIs in full regalia and barely able to speak English still persist as a common stereotype. More accurately, AI people are multicultural and experience contemporary life as a mix of native indigenous cultural systems and mainstream American life. Many people who live an explicitly

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multicultural life become very facile at expressing their indigenous culture at certain times and situations while suppressing their mainstream American cultural knowledge base. The reverse is also very common on a daily basis.

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What are Negative Factors of the Three-Level IRB?

Human subject protections are absolutely needed for any and all research projects. Consider the fact that conducting health related research with other population segments in the United States does not require that IRBs seek permission from some authority representing the population segment. However, federally recognized tribes are governmentally recognized as independent nations. As such, they are able to regulate activities to which their tribal members may be exposed. The limitation of tribal oversight is that it extends primarily to the population living on the tribal trust land and, in actual practice, may not apply to those who may be living in urban areas away from tribal land.

Tribal oversight is not without cost. IRB review for research projects with tribal nations has identifiable unintended negative consequences with which researchers must contend. The unintended consequences are mainly mundane and tedious factors that relate to the interaction of organizational cultures of tribes and universities butting up against each other. Resulting conflicts or contradictory procedural exigencies from the different organizational cultures can potentially dampen enthusiasm in conducting health research with tribal populations.

Research projects with AI populations produces a unique human subjects protection triad: 1) a proposal that satisfies the protection of human subjects as reviewed by the funding agency, 2) IRB review process by the university that is done when a grant is awarded that involves human subjects, and 3) the tribal IRB in which the research would occur. One of the consequences of this three-level review is that the earliest data collection after the notice of award for a grant can be 13-15 months later. Most health related grant proposals, such as those from the National Institutes of Health, specify a research design intended to be accomplished in no more than five years. This is true for proposals that are exclusively for or include members of AI tribes. Functionally, research designs often require 60 months in order to effectively accomplish their specific aims, but in the case of AI health research, there may only be about 45 months to do so. The compression of the research design can have a negative effect on the quality of the work although the possibility of a no-cost extension may permit the research process to be completed without time compression. However, this can put the investigators into a lag with regard to the continuation of their program of AI health research because the necessary time extension prevents them from writing the follow-on next research project.

Unlike NIH and university-based IRBs, tribal IRBs very seldom have any trained researchers as members. Consequently, staff of the tribal healthcare program that have clinical degrees are typically brought in as permanent or ad hoc members. Clinical expertise does not necessarily confer research design or biostatistics expertise. It can also be noted, conversely, that most university-based IRBs do not have tribal members to provide comment commensurate with AI concerns.

Many tribal IRBs do not function as research design critics. The tribal IRB seems to function primarily on the basis of their perception that a given research project will produce benefits for the tribal population in a timely fashion rather than for more open research questions that may not have clear, immediate outcomes even if they could still have expected future benefits. Also, the tribal IRB will make decisions based on their perception of safety risks for tribal members who may be the research participants. Most often, tribal IRB membership must rely on the veracity of what a candidate researcher reports to them regarding level of risk.

Research teams accept the professional obligation to share their results through dissemination of journals, presentations at professional meetings, and books. Findings from research projects done through an AI tribe with a functioning IRB and that are written into a journal article draft often must be reviewed by the IRB prior to submission for review by a journal's editorial process. Such review may often be required for oral presentations and posters given at professional meetings. The primary reason for this is that the tribe will be able to engage in impression management[12] regarding how their image may be disseminated. If research findings are very negative or may suggest that tribal operations are not working

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well for the health of the tribe, the IRB can disallow the draft from submission to a journal or oral presentation. Alternatives include that the draft can proceed to journal article review provided that the tribal name is not given. These publication restrictions are made clear to researchers at the beginning of the tribal IRB process. The tribal concept is that since the data came from their tribal membership, whether behavioral or physical, the outcomes likewise are their property.

How does Tribal Research get Started?

Tribal authorities expect specific approaches when researchers wish to open a dialogue about conducting research that involves tribal members. For example, before any tribal member is queried about a research question, permission must be granted by tribal authorities to proceed. Health related research permission-seeking may begin with an email, phone call, or physical letter requesting information on how to proceed. Contact information can be gotten from tribal websites. The receiver of such a query will provide contact information to the tribal IRB. If the tribe does not have a constituted IRB, the person inquiring will likely be given instructions on how to make a presentation to the tribal council. It is preferable to make the presentation in person because it is very common for the location of tribal complexes to be in areas far removed from the urban location of most universities. This will demonstrate symbolically and in practical terms that the researcher is willing to leave the halls of academe to mix with the research participant community.

Presentations may include a written synopsis as well as a 15-minute or so PowerPoint overview. This would be followed by a period of questions by the IRB committee. Some committee members are clinicians who have some ability to interpret research designs and statistical operations. Other members are lay members from the community and may have limited formal education. However, one of the major roles of the IRB is to be vigilant in protecting the tribal membership from what might be considered hazardous experimentation. The IRB will also assess as best they can what the possible social disruptions to their small communities may be. If any such hazards are detected and cannot be reduced or eliminated, the research protocol would likely be denied.

Research that addresses known tribal concerns will be highly valued compared to other research, which may be very important scientifically but lacking obvious and immediate practical application. Tribal IRBs generally do understand that research takes a long time. Researchers should be realistic in discussing with the tribal IRB their best estimate at when useful findings can be put into practical use in the tribal community.

At the conclusion of this event, the researchers are excused from the meeting and typically return to their home institution where they await the outcome from the IRB. One possible outcome is that more information is needed and that may be provided in person or electronically. If permission is granted to conduct the research, it is typically provisional in order for drafts of consent forms to be developed, reviewed, revised, and finally accepted as an agreeable version.

Tribal IRB review can be done after the university's IRB has reviewed and deliberated on the research design and consenting issues. The tribal IRB does not take into account the university and its IRB review outcome. Consequently, there are times when there will be conflicting outcomes across the two IRBs. Then, the process of negotiating the problematic IRB reviews begins.

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Acknowledging that the process in which researchers approach tribal IRBs constitutes bringing into contact two different organizational cultures with the potential for conflict introduces a problem that is seldom discussed. There is a solution.

University Researchers and AI Tribes: An Inter-Cultural Project

The potential for cultural conflict of various degrees of seriousness arises when two or more cultures come into contact. It is normal and always present at least to some degree. For the context of this discussion, the two types of cultures coming into contact are organizational cultures, one university and one tribal. This is not to discount the importance of the social culture from which the individual researchers come or the foundational conceptual and behavioral influences derived from the broader culture in which the US American government and university is rooted. Like-

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wise, the broad and socially variegated culture of a given tribe is very important for consideration during the research discussions as well. Culturally balanced interactions between a research team and a tribe, however, do not always happen.

The university and its agents of research who are embedded and sometimes ensnared in multiple organizational bureaucracies are one side of the inter-cultural dynamic. Such bureaucracies include, for land-grant institutions, their state government legislatures and their changing proclivities and priorities, as well as the organizational facets of the agency from which the funding derives, such as the National Institutes of Health. The combination of these bureaucratic entities and their procedural rules can comprise a collective set of demands that can at times serve to facilitate research and at times serve to constrain the research enterprise, such as in time and/or money limits.

The second organizational culture on the other side of the inter-cultural dynamic is the tribe. Researchers collaborating with a tribal entity should understand that federally and state recognized tribes constitute complex and constantly changing organizational entities at least as detailed and sometimes vexing as that from which the researchers come. AI tribes today are embedded in federal government bureaucracy through federal oversight, seeking and receiving federal grants for multiple kinds of programs that includes health care for the tribal members, and the facilitators and constraints pertaining to the legal operation of for-profit businesses owned by a tribe.

Recent histories of tribal research abuses may cause one to leap to an assumption that it is the researchers that are typically to blame. On other hand, could it be that tribal interests reflected in their organizational and social culture are not always the most research friendly? This is not to indicate any overt hostility, but that the two organizational and social cultures simply may not easily fit together.

Many tribal cultures have epistemologies with regard to knowledge and knowledge claims that are radically different from those extant in universities. For example, sickness as a native concept is one that often has a theme of spiritual balance in a person's life, family, job, and place for which disruption causes pathology and/or emotional upset.[13] Empirical biomedicine, while having a slight historical connection to balance reflected in the concept of homeostasis, values more highly a pathophysiologic-based analysis and allopathic treatment approaches to curing disease. Nonetheless, it is true that many tribal members today are well educated and have had massive exposure through school and various media that teach the basis of empirical science applied to health. However, the hegemony of the biomedical paradigm does not necessarily result in the loss of the more spiritual and balance-oriented native constructs explaining health and disease.

The result of the simultaneous exposure to the native and biomedical model of health and disease is often a mix of the two models. Such a mix typically is not balanced as half of one and half of the other. The proportion of the two models can vary along a continuum. The variance is a function of different social situations that are encountered during the course of daily life. For example, a tribal patient may seek health care at a tribe's biomedically-oriented hospital and receive treatment and prescriptions consistent with that model. While in the clinical setting, a patient's behavior may be very consonant with the healthcare provider working with them. Yet, the same person may go home and, in the privacy of his own home setting, act on more of his own cultural and personal health

If any one, cross-cutting statement can be made about contemporary American Indian life regardless of culture, economy, and politics, it should reference the enormous depth of heterogeneity present all across Indian Country. Any topic that is discussed in terms of American Indian life must take into account the inter-tribal and intra-tribal heterogeneity that is present both biologically and culturally. Whether a tribe has an officially constituted IRB recognizable to university researchers or whether a tribal council is the gatekeeper for research requests, those wishing to present research requests must show appropriate respect and adherence to tribal procedures for assessing such inquiries.

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beliefs than what was received at the hospital. This dynamic is common in all populations. The difference here is that the researchers and the tribal members both come to the healthcare setting with radically different cultural assumptions through which all messages are filtered.

Summary

If any one, cross-cutting statement can be made about contemporary American Indian life regardless of culture, economy, and politics, it should reference the enormous depth of heterogeneity present all across Indian Country. Any topic that is discussed in terms of American Indian life must take into account the inter-tribal and intra-tribal heterogeneity that is present both biologically and culturally. Whether a tribe has an officially constituted IRB recognizable to university researchers or whether a tribal council is the gatekeeper for research requests, those wishing to present research requests must show appropriate respect and adherence to tribal procedures for assessing such inquiries. Simultaneously, the research process should be conducted from its inception to its completion with the recognition of inter-cultural dynamics operating between the research team and the native community. Both entities bring together social and organizational cultural features that may require negotiation on both sides for optimal outcomes. Culturally respectful actions facilitate the research process and its goals that, in turn, can improve the health and well-being of tribal members.

Note
The author has no conflicts to declare.

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