HONORING TRIBAL SOVEREIGNTY: SECURING AN IRB APPROVAL FROM THE NAVAJO NATION

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SUMMARY: In this article, we consider the process of attaining approval from a Tribal Institutional Review Board (TIRB) as a tool to gain the cultural competency needed to work within Tribal Nations and minimize harm. From this position, we argue that non-governmental, government, and private organizations should also seek approval from such institutions. Our contributions to the field are twofold. First, we offer practical advice for researchers looking to work with Tribal Nations and in particular, with the Diné (Navajo) Nation. Second, we reemphasize the danger a lack of cultural competency, even with well-meaning aid, can have on a nation's citizens.

Keywords: Tribal Sovereignty, Navajo Nation, Human Research Review Board, Ethical Research, Cultural Competency

Introduction

United States history is replete with tensions and violence between Indigenous people and the settlers who followed. Historically and today, researchers have routinely interacted with "isolated" populations to study the genes or culture that have supposedly had less interaction with the wilder world (Tierney, 2001; Zeggini, 2014). Unsurprisingly, these interactions instigate ethical issues (see Borofsky and Albert, 2005) as many prioritize 'Western' knowledge over alternate ways of knowing and being and the rights of their participants.

Cultural competency is a concept that is inherent, abstract, and continually evolving, thus making it difficult to define (Quist and Law, 2006). In a number of disciplines the concept and importance of cultural competency has been growing, particularly in healthcare (Clifford et al. 2015; Wells, 2000; Weech-Maldonado et al., 2002) and social work (Jani et al., 2016; Garran and Werkmeister 2013; Melendres, 2020). Fewer consider cultural competency issues that

pertain to organizational involvement with disadvantaged, and of interest here, Indigenous people.

In this article, we relate our experience of attaining approval to conduct research on the Diné (Navajo) Nation from their Tribal Institutional Review Board (TIRB). We argue that successfully navigating this process necessitates applicants attain a level of cultural competency required to conduct research with the community and minimize potential harm. Many TIRBs operate differently compared to university review boards, and, as such, the process is often difficult to navigate and can lead to frustration on the researchers' behalf and increased tensions between parties (Onakomaiya, 2023). This article provides first-hand knowledge and detailed information on the Diné Nation TIRB to clarify the process for future researchers. Practically, this will ensure more researchers are successful, and if taken seriously, reduce the harm caused by a lack of cultural competency.

Finally, we suggest expanding the reach and responsibilities of TIRBs and similar institutes to oversee and review the work of private, government, and non-governmental entities. This would require these entities to increase their cultural competency and ensure effective engagement with the tribal nations and reduce harm. We recognize the practicalities of such an endeavor are significant, but with the potential harm that even well-meaning actions can have, we consider it essential.

Tribal IRBs

In 2004, the Havasupai Tribe brought charges against the Arizona Board of Regents and Therese Ann Markow after it was discovered that blood samples collected by Arizona State University for research on Type II diabetes were used without consent in studies investigating schizophrenia, migration, and inbreeding (Garrison and Cho, 2013). This incident is simply one well-known case in which the relationship between ‘Western knowledge’ and institutional ethics has collided with traditional ways of knowing and vulnerable populations.

This case is one example of research negatively impacting Native American communities. The academic and medical research oversight has led to research focusing on the negative aspects of history without adequately addressing the ongoing trauma. Research has also focused on the “exotic” aspects of Native culture leading to cultural appropriation and commodification. Worse, is the coercion, deception, and lack of informed consent in studies that have led to complete distrust between researchers and Indigenous communities.

Recognizing governmental regulations and academic oversight designed to protect participants in research has routinely failed, Indigenous Nations have introduced tribal nation-run IRBs (Around Him et. al. 2019; Deloria 2009; Harding et.al. 2012). Commonly known as Tribal IRBs, they are created and run by community members cognizant of competing claims between research goals and the specific traditions and beliefs of the nation they represent.

TIRBs, in essence, are the bridge between ‘Western’ means of knowledge and alternate viewpoints often ignored in IRBs. TIRBs provide their nations an element of control over the research being conducted and, as such, are able to incorporate research beneficial to their specific

needs. Critically, TIRBs emphasize the need for trust and reciprocal cultural education between academic researchers and Diné community members and the need for the two parties to be equal partners in study design, data collection, methodology, interpretation, and publication with academic and other external researchers (Harding et. al. 2012; Tsosie 2021). In short, TIRBs exist to minimize the lack of cultural competence of researchers by enforcing culturally appropriate methods to promote several goals including but not limited to setting ethical standards, addressing cultural knowledge gaps, identifying benefits for the nation, and reducing misunderstandings and misinterpretations of data.

A New Stance

In Diné, there is a saying, *baa dá'hóchí'* - some information should be protected and restricted. The process for researchers to gain approval to conduct work on the Diné Nation is implemented by Navajo Nation Code Title 25: Navajo Nation Human Research Code, established in 1996. The Navajo Nation Human Research Review Board (NNHRRB) exercises the sovereign rights to regulate, monitor, and oversee all research activities within the Navajo Nation's boundaries and protects the rights, welfare, and cultural integrity of Navajo individuals and communities participating in research projects (Navajo Nation Human Research Review Board, 2024). The NNHRRB reviews research proposals to assess their compliance with ethical standards, cultural sensitivity, and the potential impact on and benefits for the Navajo Nation and also serves as the Institutional Review Board for the Navajo Area Indian Health Service. The NNHRRB process involves several steps. The first, for university-based research, requires external review and clearance of any proposal from the researchers' home institute. Following approval, the specific chapter within the nation must give clearance to the research. Once approved, the Navajo Heritage and Historic Preservation Department will review the proposal. For some, the nature of the project may require approval from other entities such as the Diné Hataałii Association.

Local Chapter House

Our study began when one of the researchers was notified by a community member from the Diné Nation that contaminated wood was being distributed by a non-governmental organization (NGO). The community was severely affected, and we wanted to understand the situation to avoid future transgressions. After we received approval from the Principal Investigator's university, we needed permission from the community we wanted to enter. There are 110 communities within the Diné Nation with a chapter house (town hall) that is led by elected officials and community members.

The Chapter held hybrid chapter meetings, so attendees could attend virtually. One author attended over Zoom, and the other attended in-person to present our research proposal before the chapter officials and community members at the monthly meeting. The officials asked us clarifying questions and opened the forum to the community. Two community members were very vocal in approving our study and informed us of similar instances where external

organizations providing aid harmed residents in the community. One example, concerned barrels donated to haul and store water for homes only for it to be discovered years later the barrels were polluted and not suitable for potable water.

Historically, research with Indigenous people has focused on knowledge, with the participants often left feeling used. Traditional IRBs do require benefits for the participants, but these are often offered to the individual, not the community. While entrance into a raffle or small donation of money may help, viewed within the specific transactional relationships that have exemplified Indigenous/institutional relationships in the past, such small tokens are easily viewed in a negative light. The response we received at this meeting demonstrates a recognition of our desire to prioritize our future participants' lived experience over knowledge, and a concerted effort to make our participants equal partners in the construction of any knowledge gathered. After several follow-up emails to the chapter house president and secretary, we received a signed approval letter, a chapter resolution.

Navajo Heritage and Historic Preservation Department

Once approval is granted by the local chapter house, formal applications can be made to the Navajo Nation Heritage And Historic Preservation Department (NNHDP). The NNHDP is tasked with "Protecting, Maintaining, and Balancing Navajo Cultural Heritage in a Changing World" (Navajo Nation Heritage And Historic Preservation Department, 2024). One key feature of this process is the rights and ownership the NNHDP has to any research conducted within the nation. Incidents like the Havasupai case are a clear example of the need for such oversight, yet, acts as a deterrent to conduct research for some. Leading up to our application, colleagues voiced their concern over this condition. As we noticed with our colleagues, NNHDP ownership and oversight led to ideological concerns over the objective nature of research and separate debates about intellectual property rights. Interestingly, the very same conditions of ownership apply to researchers operating from universities in that, for example, the technology produced within is the sole property of the university. There are differences between the two in regard to the oversight of individual publications, yet, in our early experience with the NNHDP, we have yet to see a fear or concern for this critical work.

We must make a disclaimer, however, as we have not yet completed our study. As such, our assessment of the NNHDP and critical work is based on the responses and relationships we have built with the NNHDP committee and the broader community. Their help in identifying potential issues and guidance for dealing with them has been a helpful area for learning the nuances of Diné culture within the TRIB process.

Diné Hataalii Association

The Diné Hataałii (medicine men) Association (D.H.A.) is tasked to "protect and preserve all Diné traditional ceremonies, including the protection and preservation of songs, prayers, processes and sacred sites" (Diné Hataałii Association, 2024). The association

disseminates, researches, teaches, and promotes knowledge of Diné ceremonies and the Diné Ceremonial Law.

The main contention of our research proposal involves Diné philosophy, and as a result, required approval from the D.H.A. Under the recommendation of a NNHRRB member, one of the authors met with the association in person to discuss the research project. Critically, the knowledge of the Medicine Men about traditional beliefs provided additional nuance and understanding to our research providing us more avenues and areas to explore.

The Diné Hataałii Association can be seen as an added step and obstacle to gaining approval. The association was difficult to pin down, and the discussions between committee members were often in the Diné language. However, research conducted within the nation must accept the sovereignty of the nation and the location where the research takes place. Far from the lab, research within the Diné Nation deals with real people with cultural customs and ways of being that may feel disconcerting. The ability to overcome and persevere through these moments are exactly what demonstrates cultural competency.

Discussion

In the previous sections we have shared our experience navigating the Diné Nation TIRB. We know this will be helpful for future researchers to gain approval and conduct ethical research on the Nation. In this final section, we extend the importance of cultural competence to organizations operating within Indigenous communities and relate the danger and harm cultural incompetency can have. Our research project examines the relationships between aid organizations and the nation. The interviews we have conducted have highlighted the importance of cultural competency for researchers and organizations alike.

During the pandemic, immediate need for firewood was felt within the Nation. A religious non-governmental organization wanted to help and sent wood that had been collected after hurricane-like winds tore through trees and homes in Utah. The wood was distributed to the Diné Nation residents without informing them of the origin. In traditional Diné philosophy, wood collected from a natural disaster is considered contaminated and if burned, it will spread disharmony to the surroundings. Unfortunately, this small gesture has had detrimental effects within the community and clearly expressed by one of our participants who received some of the wood. Rattled with asthma, arthritis, and IBS, once she learned of the origins of the wood and that it did not conform to traditional beliefs, she attributes her ailments to the burning of contaminated wood. From a `Western' perspective this may seem erroneous, but for our participant, it is truth and leads to a very practical issue. To have a Medicine Man cleanse her house and body will cost $3,000 USD, a sum not easily attained by many people.

The non-governmental organization acted in ways they deemed ethical, providing a solution to a problem, however, the lack of knowledge about the culture had serious detrimental effects within the community. Our participant is not the only one to have taken and burned the wood, and she is not the only one to lose trust in external organizations.

Our participant's experience demonstrates the tremendous cost to one Diné Nation resident due to a non-governmental organization's lack of cultural competence. We argue that any organization wanting to enter the Navajo Nation to do business, research, or provide aid, must go through the NNHRRB process to gain cultural competence. In the spirit of wanting to help a community, the aftermath of the aid has accrued additional expenses for a community that is already struggling. Had the organization sought insights from the TIRB, this harm may have been averted.

Conclusion

As researchers, it is important to be familiar with the future participants' culture and context. We are trained that research is objective and fundamentally neutral, but this is far from reality. Research projects carry the writer's view of the world and their blindspots to the existing complexities of studies. Prior to jumping into a project, it makes ethical sense to become familiar with the culture and surroundings. The NNHRRB encourages researchers to do this thereby enhancing cultural competency.

Finally, our research project investigates the lack of cultural competency and the harm dismissive actions have had on many on the Diné (Navajo) Nation. We suggest that the TIRB and similar entities are an invaluable resource for NGOs, governments, and private industry to increase their cultural competency and ensure their goals and objectives can be implemented with the least harm and greatest possible benefit for the communities they interface with.

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