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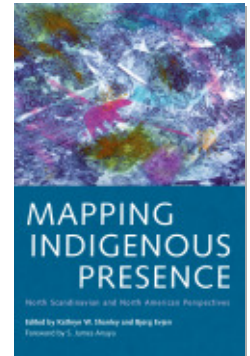
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Indigenous Methodologies in Research

Social Justice and Sovereignty as the Foundations of Community-Based Research

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Throughout time Indigenous communities have used their own cultural expertise to assess, validate, and apply experiential knowledge to improve the health of their communities and members. These inferential methods were based on generations of lived experiences gained within the context of a myriad of American Indian and Alaska Native (AIAN) communities surviving, and even thriving, within challenging and diverse geographic conditions. These Indigenous methodologies mirrored aspects of Western science by sharing principles of hypothesis testing to assess reliability, generalizability, and a variety of differential forms of validity or accuracy. They were based on the premise that health and survival require a balance of physical, spiritual, emotional, social, and economic factors, and to achieve and maintain this balance, Indigenous methodologies were needed to test, validate, and experiment. However, these methods were unique to each individual tribal community and thus varied based upon the relevant primary socioeconomic resources that were shaped by geography, tribal history, lifeways, and sociological factors influencing daily life for Indigenous nations. Recently, Western science has begun to recognize the significance of the Indigenous methodologies and how implementing these principles improves research approaches and the impact of research aimed at improving the health inequalities and disparities that many Indigenous

communities experience (Botha 2011; Kovach 2009; Smith 2005; Wilson 2008).

Specifically, it is important to recognize the severe and pronounced inequalities that impact Indigenous communities in the United States and throughout the global community. For example, in 2013, 27 percent of Indigenous groups in the United States lived in poverty compared to 14.3 percent of the general population (Macartney, Bishaw, and Fontenot 2013). The reality is that the rates of poverty and associated severe health disparities among families and individuals living on reservations are much higher. On average, Indigenous groups in the United States experience fewer educational opportunities and lower educational attainment, and 75 percent earned a high school diploma in 2006 compared with 91 percent of White students (DeVoe and Darling-Churchill 2008).

American Indians and Alaska Natives have the lowest life expectancy of any racial/ethnic group in the United States, and they have the highest age-adjusted mortality rates in the nation; they are often double that of the combined rates for the U.S. population (1,480 per 100,000 people [Christensen and Kightlinger 2013]). On average AIANs have a life expectancy that is 4.6 years less than other Americans, and the most common causes of mortality include complications due to diabetes, accidental death, homicide, suicide, and tuberculosis. The infant mortality rate, a sensitive indicator of general health of a population, has decreased recently but remains 24 percent greater for Native Americans than other groups. As a population, AIANs have lower educational attainment, higher unemployment, earn substantially less for full-time work, and are more likely to live in poverty than the total U.S. population. The reality is that the rates of poverty and associated severe health disparities among families and individuals living on reservations are much higher.

Poverty contributes to harsh living conditions that are far worse among AIANs than any ethnic group in the United States. Indigenous communities experience housing challenges related to physical problems (overcrowding and lack of plumbing or kitchens), affordability, homeownership, and homelessness. Rates of homelessness are more than three times higher among Indigenous U.S. groups compared with the general U.S. population ([23 percent] Kingsley, Mikelsons, and Herbig 2013). Combined, lower education, poverty, and harsh living conditions create injustices in which Indigenous people die at an earlier age and more frequently than other populations.

A multidimensional, culturally based Indigenous approach is needed to mitigate social unfairness effectively. To this end, Indigenous research must

incorporate primary prevention aimed at reducing extreme poverty, improving access to economic and educational opportunities, improving access to adequate housing, and addressing structural racism. In this chapter we provide contextual information regarding Indigenous methodologies and how these methods can be used to address social wrongs while honoring the values and knowledge of Indigenous people. We provide an example of how AIANs have used an intertribal Institutional Review Board (IRB) to promote social justice via increased tribal participation in the regulation of research.

Native Americans, Social Justice, and Tribal Sovereignty

American Indians and Alaska Natives comprise many distinct and heterogeneous ethnocultural tribal/Indigenous groups in the United States. The 2010 U.S. Census reported that 2.9 million people identified their ethnicity as American Indian or Alaska Native along with another racial category, a 39 percent increase from 2000 (Norris, Vines, and Hoeffel 2012). An additional 2.3 million people identified their sole racial classification as American Indian or Alaska Native in the United States. The Bureau of Indian Affairs (BIA) recognizes 562 different tribal groups, each characterized by significant within-group variation and diversity, including distinct languages, ceremonial practices, cultural norms and customs, political structures, economies, and historical backgrounds. The diversity of AIAN populations is notable and is inclusive of groups that were historically subsistence hunter-gatherers, agriculturalists, and skilled tradesmen. Traditionally, AIAN groups lived by adapting to a wide variety of ecological conditions, ranging from arctic and subarctic, grassland plains, woodlands, ocean coastal areas, and desert regions. Ceremonies, languages, and social structures varied by tribal nation and locale, which has resulted in a remarkable history of intertribal cultural diversity. However, migration from ancestral homelands often leads to urbanized Indigenous populations, where traditional activities and diets are more difficult to maintain and practice due to the influence of the dominant Western culture.

Preferred identifiers for Indigenous peoples of North America vary by geographical and tribal group. Canadian Indigenous people have used the terms *First Nations*, as well as *Inuit* and *Metis*, while groups in the United States have used the terms *American Indian*, *Native American*, or *Alaska Native*. However, as a general rule most individuals' and tribal communities'

preferred identifier is the name of their tribal nation in their Native language, such as Pikuni, Oglala Lakota, Anishinaabe, or Diné. The National Congress of the American Indian has supported the use of American Indian and Alaska Native as the recognized reference terms for the Indigenous peoples of the United States.

American Indians and Alaska Natives have the shared experience of significant population collapse, colonization, systematic oppression, and severe discriminatory practices that included forced relocation, direct warfare, the introduction of new and often fatal diseases into communities, forced removal of children to boarding or residential schools, language and cultural devastation policies, and severe systematic poverty and geographic isolation. This brief history sets the contextual stage for describing social justice and tribal sovereignty in community-based research.

Social justice is based on context, sociocultural aspects of history, and culture. We have chosen to use the term *social justice* to refer to individual or community egalitarianism, fairness, or equity as it pertains to Indigenous groups of the United States. When any of these factors are absent, an individual may experience disparities in health, education, or living conditions that are unfair, inequitable, and ultimately avoidable. Often Western scientists refer to the social determinants of health as oppression, health inequities, health disparities, undesirable social gradients, structural racism, social exclusion, and lack of social capacity. These determinants are intertwined with the past, present, and future context of AIAN communities and their health. In this chapter we use the term social justice in the milieu of community-based research, the social determinants of health and tribal sovereignty.

American Indian and Alaska Natives have established unique relationships with the U.S. federal government through the historical use of federal treaties and laws. American Indian and Alaska Native nations have established government-to-government relationships with the United States due to their unique status as sovereign Indigenous nations within this country. The treaties and laws from which these federal trust relationships and obligations emanate originated in the period of contact/seizure/colonization. During this time, AIAN nations forcibly gave up millions of acres of land in exchange for the provision of healthcare, education, and other rights as long as Indigenous nations exist within this nation or *As Long as the Grass Grows and the Rivers Flow* (Trafzer 2000). For example, the Indian Self-Determination and Education Assistance Act of 1975 gave tribal nations the authority to take over any Indian Health Service (IHS) or BIA functions. Other notable laws related to social justice and sovereignty include: the Snyder Act of 1921, the 1954 Transfer Act, the Indian Sanitations

and Facilities Acts of 1959, the Indian Health Care Improvement Act of 1976, the Indian Child Welfare Act of 1978, and the Omnibus Drug Act of 1986. While beyond the scope of this chapter, it is vital to acknowledge these historic acts in AIAN history because they continue to mandate tribal sovereignty and the many unique treaty obligations of the U.S. government to Indigenous nations. Moreover, these acts demonstrate U.S. efforts to address historic injustices that unfortunately continue to persist and contextualize the continued disparities in health observed among Indigenous populations today.

Community-Based Participatory Research and Indigenous Methodologies

Reality is not an objective truth or facts to be discovered but includes the ways in which people involved with facts perceive them. The concrete reality is the connection between the subjectivity and objectivity, never objectivity isolated from subjectivity.

—PAULO FREIRE, *PEDAGOGY OF THE OPPRESSED*

Research is not just a highly moral and civilized search for knowledge; it is a set of very human activities that reproduce particular social relations of power.

—LINDA TUHIWAI SMITH, *DECOLONIZING METHODOLOGIES:
RESEARCH AND INDIGENOUS PEOPLES*

Community-based participatory research (CBPR) is a collaborative form of inquiry well suited for Native communities. In the 1940s Kurt Lewin prompted researchers to think about ethics, courage, and power relations. His research focused on solving social problems through action research that would help practitioners. In his article, “Action Research and Minority Populations,” he called for social scientists to have courage, “It needs the best of what the best among us can give, and the help of everybody” (Lewin 1946, 46). This call was repeated over the years through participatory action research in the fields of sociology, anthropology, community planning, and feminist theory (Minkler 2004; Wallerstien and Duran 2008). By 1970, there was an abundance of publications, history, and evidence to show that survey research had done little to address social injustice, power, and disparities. Budd Hall’s (1975) seminal paper, “Participatory Research: An Approach for Change,” describes the paradigm shift among Western researchers and the realization that knowledge is a form of power. His

work, and that of others (Freire 1972; Wallerstein and Duran 2008) was instrumental in establishing the basis for participatory action research and CBPR as we know it today in which communities identify research priorities and implement them with little assistance from Western researchers or academic institutions. As Maori Scholar Smith (2005, 29) notes,

the Western academy which claims theory as thoroughly Western . . . has constructed all the rules by which the Indigenous world has been theorized. . . . [As a result] Indigenous voices have been overwhelmingly silenced. The act, let alone the art and science of theorizing our own existence and realities, is not something which many Indigenous people assume is possible.

This history and paradigm shift is evident today in CBPR approaches that aim to address social injustice. Social equity and justice are the essential aspects of CBPR methods. The principles of CBPR highlight the fundamental recognition of appropriately engaging communities and individuals who participate in research. American Indian and Alaska Native communities have acknowledged that appropriately conducted research can be a powerful tool to redress the pervasive health disparities documented in health literature. Achieving such social justice and health equity, however, requires responsible scientific inquiry aimed at collaboratively identifying the underlying etiology of health disparities in AIAN populations. For example, the inclusion of Indigenous methodologies and a basic understanding of the ways in which cultural contexts and practices, such as ceremonies and rituals, facilitate social justice and Indigenous knowledge are required. As Vine Deloria, Jr. (1999a, 134) noted,

modern science tends to use two kinds of questions to examine the world: (1) how does it work and (2) what use is it? These questions are natural for a people who think the world is constructed to serve their purposes. The old people might have used these two questions in their effort to understand the world, but it is certain that they always asked an additional question: what does it mean?

Building such Indigenous and scientific knowledge must include the perspective of the actual life experience of research participants and prioritize the service needs of Indigenous communities. This form of knowledge building has the best opportunity to inform health policy and practice innovations. In a systematic review of 70 CBPR papers published in the last

decade, Salimi and colleagues (2012) found that CBPR has the potential to improve health and well-being in communities while decreasing the significant health disparities found to exist within AIAN communities (Beals et al. 2003; Denzin and Lincoln 2005; IHS 2002–2003).

It is now clear that, like CBPR, Indigenous methodologies are approaches that position and situate Indigenous people in the research arena. Indigenous methodologies implicitly honor the values and principles of CBPR but go beyond power dynamics, structural racism, and injustice. Indigenous methodologies are deeply rooted in a tribal community history, language, and way of being in the world as opposed to the CBPR history that is based largely on colonial imperialism. The Indigenous perspective is being revitalized, energized, and scientifically recognized by communities, researchers, universities, policy-making organizations, and funding agencies. The ethical and philosophical principles informing Indigenous methodologies call for research conducted with Indigenous populations to adopt community-situated, tribally informed, and Native scientist-led programs of inquiry (Burhansstipanov, Christopher, and Schumacher 2005; Fisher and Ball 2005; Mohatt et al. 2004). Porsanger (2004), however, cautions against privileging Indigenous scholars because there are so many “insider” views. Indigenous methodologies are “guided by tribal epistemologies, and tribal knowledge is not Western knowledge.” Indigenous methodologies require an “outsider” to make a paradigm shift and to consider a more diverse and tribally accurate way to think about how research is done and what research means for Indigenous people.

Unlike CBPR and Western knowledge, Indigenous methodologies are difficult to define because Native people have their own knowledge systems. As Deloria (1999b, 35) writes, “the Indian perspective of the natural world . . . already has a fundamental principle of interpretation/observation that pervades everything that Indians think or experience. Thus verification of existing knowledge and the addition of new knowledge is simply a matter of adding to the already considerable body of information that Indians possess.” Guiding principles and commonalities of CBPR, Western knowledge, and Indigenous methodologies are informed by understanding the shared meaning of different knowledge systems. This perspective and the commonalities of Indigenous values, ethics, and morals in the literature are reinforced by our collective experiences.

Indigenous methodologies are based on a relational worldview—the belief that all things are connected and interdependent—and rely on a holistic view of the universe. Indigenous methodologists have described the research framework as a “nest” that serves as a container for process and

content. The process is necessarily one that values and honors good (or healthy) relationships: namely those based on respect, reciprocity, and responsibility. These values are present within many cultures and communities. However, these distinct, diverse, and tribally identified worldviews and principles guide Indigenous methodologies and emphasize community health and collective principles that promote humility, active listening, equitable relationships with human and nonhuman entities, group cohesion, and the spirit of generosity. These Indigenous values, shared by many other cultures, serve to promote communal wellness while simultaneously acknowledging the importance of culturally based or traditional methods of healing, knowledge acquisition, education, prevention, and intervention to mental health or physical forms of distress. Indigenous methodologies are rooted in spiritual epistemologies and guided by individual and community experience that is metaphysical in nature. The content and characteristics of Indigenous methodology may include researcher preparation, decolonizing ethics, gathering knowledge, making meaning, and giving back.

Is it possible for us to find a common ground—a place where we can begin to understand each other? We believe that the shared space of Indigenous and qualitative methodologies is common ground where “insiders” and “outsiders” and Western and Indigenous researchers can speak truth to each other. This space would benefit both and build a global perspective that could ultimately create a more effective and inclusive scientific perspective. Global health and public health requires that we strive to identify the places of commonality, as well as distinction.

Equally important, considering how the discriminatory and oppressive colonial practices have extended into the scientific history of this nation, is a history characterized by examples of unethical and even harmful research conducted on (not with) Indigenous populations. This legacy has established a frequently identified and historically rooted distrust of research for many Native people and communities. However, there is evidence that the decolonization of Western research is well underway. Most would agree that Western research has moved beyond positivist and postpositivist approaches into more flexible interpretations of the subjective reality in which Indigenous methodologies are situated. However, to move forward with Indigenous methodologies as a pathway for social justice, we must caution researchers that the past cannot be repeated. The history of Western research in the United States was, and sometimes is, a form of colonization, categorization, and structural racism.

The fundamental belief in the essential nature of objectification in research within Western science has led, over the centuries, to the abuse of

Native American research subjects. In the seventeenth and eighteenth centuries American Indian body parts, particularly skulls, were collected from war sites and studied by military doctors to “reveal character and mental capacity” (Hodge 2012, 434). In the 1950s the United States Air Force (USAF) used Native elders to recruit 120 non-English speaking Alaska Natives for a study involving radioactive iodine. The Alaska Native participants were required to ingest radioactive iodine over 200 times resulting in their suffering from unsafe exposure to radiation. The USAF wanted to know if Natives survived the cold by having higher metabolisms. Results of this research found the obvious: Natives did not have higher metabolisms, but they knew how to dress and eat for the cold weather. The research involved breastfeeding women, women of childbearing age, and their children. Furthermore, the USAF did not obtain consent from individuals or collect demographic information to allow for follow-up that would address undesirable health outcomes related to overexposure to radiation. Most troubling is what Shore writes about the research abuse, that Natives were “trading their participation for much needed medical treatment in rural villages” (Hodge 2012, 434).

Another study conducted in the 1950s by the U.S. Public Health Service (PHS) involved Navajo uranium miners. The aim of the study was to examine how radon in mines impacted health outcomes. The PHS had never gained consent of the miners and did not inform them of the known risks of lung cancer from exposure to radon (Samet et al. 1984). Other populations throughout the global community have been exploited as research subjects—so much so that in 1948 after World War II, the United Nations created the Universal Declaration of Human Rights ([Declaration] United Nations 1948). This Declaration was based on equality and dignity for all human beings and the idea that fundamental rights and freedoms were not luxuries but necessities for all people.

Even with the exploitative aspects of the research history, what we have learned through the Declaration is that well-intentioned researchers can enact a series of events that have ultimately resulted in unintended or unanticipated negative impacts upon Indigenous communities. In 1972 researchers from the northeastern United States entered an Alaska Native community to examine attitudes and values about alcohol use and collect psychological histories and data on the people’s drinking habits. Researchers reported that alcohol use and social problems related to cultural changes were due to increasing wealth associated with oil development. Researchers went beyond describing the results and made recommendations for how the community should deal with alcohol use, including establishing

alcohol education programs, slowing the cash flow to communities, and investing in projects elsewhere. This research culminated in a *New York Times* headline January 22, 1980: "Alcohol Plagues Eskimos, Sudden Wealth Sparks Epidemic of Alcoholism." An investigation into the research findings called into question the results of the study, identifying them as erroneous and promoting sensational statistics. Publications and reports from this research were deemed ethnocentric and parochial, demeaning, and denigrating to the Inupiat people (Foulks 1989, 12). This well-known study represents what one faculty member from the Inupiat University of the Arctic in Barrow, Alaska, called a faulty methodological orientation of research and a superficial understanding by researchers (Foulks 1989, 12). While it may be subjective to determine whether these conclusions are accurate, it is certainly the case that research that does not prioritize Indigenous voices and methodologies places Indigenous communities and science at risk. Researchers may not realize how their conclusions play into long-time patterns of oppressive power over communities by governments and churches.

More recently, researchers from Arizona State University collected DNA from members of the Havasupai Tribe. This small tribe has one of the highest rates of diabetes in the nation, and researchers promised tribal members that their DNA might provide insight to this health issue. However, the researchers used the DNA for other purposes: to examine mental illness, traditions, and theories about where the tribe originated that were in direct opposition to the tribal creation stories and spiritual beliefs. The research was only discovered when a Havasupai undergraduate student happened to attend a public lecture on the research findings. In 2010 the university's board of regents agreed to pay forty-one tribal members \$700,000 and to provide other forms of assistance to the tribe including the return of blood samples from the tribal community (Harmon 2010).

Faulty methodological research orientations have unfortunately persisted in Indigenous communities. Community-based participatory research provides a paradigm of orientation to research that, based on Indigenous research standards, holds the potential to promote tribal sovereignty and equitable community engagement. Western scientific inquiry is guided by principles of beneficence and the idea that the benefits of research be wisely balanced with the potential risks to human participants. These elements of social justice frame future approaches that hold promise to promote knowledge, health, and benefits for Indigenous communities.

Community-Based Participatory Research and Social Justice

The emergence of CBPR holds significant promise to Native communities and to the more global pursuit of social justice because it has and will promote social change. Community-based participatory research includes principles that are complementary to the intersection of Indigenous knowledge and Western science because Native people have the knowledge of cultural and contextual factors that contribute to understanding disparate conditions. Western-trained scientists are proficient in the language and methodologies required to communicate the results of research within the dominant Western biomedical worldview. However, translating these findings in effective and applied ways within Indigenous cultures requires that Indigenous viewpoints, knowledge systems, and healing methods be understood, acknowledged, and when appropriate, integrated.

The key principles of CBPR foster respectful relationships, utilize a strengths-based perspective to build capacity, and facilitate co-learning and collaborative, equitable partnerships in all components of the research project. The cyclical and iterative process assures that the dissemination of findings and knowledge are shared appropriately and in a manner that will redress the social inequities experienced by AIAN communities. Within the literature there are numerous reports of successful CBPR approaches rooted in Indigenous epistemologies that lead to social justice. The People Awakening Project, but one example, used participatory action research, a form of CBPR, to examine community needs relating to alcohol abuse, prevention, and treatment (Mohatt et al. 2004). The research relied on Indigenous values and ways of knowing combined with culturally adapted quantitative methodologies to generate an in-depth understanding of sobriety. The results of the research empowered communities and led to awareness about positive factors that could help more effectively to support sobriety for Native people within this community.

Quantitative methodologies rooted in Western science frequently clash with Indigenous methodologies because they require research to be generalizable, valid, repeatable, and measurable, and they are driven by hypotheses testing and a biomedical model. Quantitative methodologies articulate differences using numbers but fail to account for the complex contextual and cultural differences in Indigenous populations. Another criticism of quantitative methodologies is that they fail to address the reasons for which numeric differences exist. For example, in a 1990 study about poverty, suicide, and homicide among Native Americans, data from twelve

IHS areas were examined to ascertain if there was a relationship between poverty and suicide or homicide. Statistical analyses reported significant correlations between these variables in eleven of the twelve IHS areas. However, the quantitative methodology failed to explain why the service area with the highest rate of poverty had the lowest rate of suicide and homicide (Young 1990). Curiously, one year later, the same author published another study with similar results but relied on anomie and social learning theory as explanations for the differences rather than examining culturally protective factors that were likely related to the resilience of the community (Young 1991). This research relied solely on quantitative methodologies and called for more research to examine differences. This research is an example of how Western-trained researchers often try to quantify what Indigenous people already know—in this case, poverty, suicide, and homicide rates are elevated in some Indigenous communities. Such research is unethical by many standards; more specifically, it perpetuates stereotypes about AIANs and fails to provide any tangible benefit to AIAN communities. Research driven by Western scientific principles has failed to address social injustice, and rather describes, relates, quantifies, and generalizes differences in research outcomes found within Native communities, as described above. Research based on these aims often results in more funding for Western-trained scientists to conduct additional inquiry with or on Native communities, but this form of research fails to address the reasons for which injustices exist. Little of the research funding reaches the community in ways that ameliorate social issues or injustices. Further, the Western scientific research agenda often fails to promote Native researchers, and Indigenous people continue to be objectified. Thus, explanations found within qualitative research methodologies via in-depth interviews, oral histories, and lived experiences are needed to address injustices experienced by and in Indigenous communities.

Determining the cross-cultural equivalence of measures is complex and often requires a step-wise validation of multiple dimensions. A rigorous approach would ensure equivalence of five major dimensions: content, conceptual, semantic, technical, and criterion equivalence. For the purposes of this chapter, two of these concepts will be briefly discussed here. Content equivalence refers to the process in which each item is examined to ensure it is relevant to the worldview of the culture being studied. Conceptual equivalence refers to the idea that a measure is assessing the same theoretical concept in each culture. For example, does an Indigenous group have a theoretical concept such as “depression,” and if so, how does it compare or contrast to the Western theoretical concept? In addition, do the

Western quantitative measures developed to categorize levels of depression fit with the Indigenous group's worldview? Careful examination of theoretical concepts and measurement of the concepts are required. A critical analysis ensures researchers and the researched that what is being studied is relevant and respectful (Shore et al. 1987).

Cultural validity strategies take into account and understand that cultures will have different worldviews, beliefs, practices, and relational styles. Researchers are susceptible to bias that could detrimentally affect instrument selections and their applications. Cultural validity strategies ensure tribal communities and researchers that the work conducted will not be offensive and that it will be respectful. Focus groups have been used to validate a measure culturally. This methodology has enabled researchers to learn from the people being studied, generate data that can enrich and inform the concepts being examined, and inform item development on measures. This step is of critical importance and reduces the likelihood researchers will impose their own ethnocentric bias and arrive at erroneous conclusions about an Indigenous population. A side benefit of focus groups is that they also provide space for in-depth, generative discussions that strengthen and deepen researcher-researched relationships, produce greater understanding of differing worldviews, and facilitate co-learning.

Indigenous and non-Indigenous scholars have identified the importance of qualitative research. There is significant potential benefit from examining the ethnographic etiological understandings, healing methodologies, and ways of assessing research questions and interventions. Weiss, one of the first researchers to use a qualitative method of inquiry, reported that as a graduate student in the 1930s he conducted "depth interviews" for American manufacturers to ascertain why people purchased or failed to purchase various products (Weiss 1994). Weiss found qualitative interviewing useful, continued to use it, and eventually came to believe it was preferable when endeavoring to understand the complex experiences of people. Weiss maintains that "an open and trusting alliance" between the interviewer and the participant is a requirement for an effective interview. From these humble beginnings a quiet revolution was launched. Qualitative research investigates in an in-depth and holistic fashion, typically through the collection of rich narrative data using a flexible research design in an effort to understand a phenomenon. The history of qualitative, as well as mixed-methodological, science tells the story of a movement inclusive of reformation and transformation. Many Native, as well as non-Native scholars, would agree that all inquiry is moral and political (Beals et al. 2003; Denzin and Lincoln 2005; Norton and Manson 1996).

Qualitative research methodologies have routinely been used by researchers who study oppression, domination, suppression, alienation, and hegemony. As a consequence of this important research, participants previously ignored were given voice: women, feminists, people with disabilities, sexual minorities, and Indigenous people. The agenda for the third edition of Denzin and Lincoln's (2005) book, *The Sage Handbook of Qualitative Research*, was to provide a platform from which scholars could "create and imagine a free democratic society" and "change the world in positive ways."

Qualitative researchers maintain that our underlying beliefs guide the selection of research questions and methodology just as surely as they shape our actions. When we inquire about the nature of reality, by virtue of asking the question we are acknowledging the notion that there are many realities (ontology). Likewise, when we inquire about the relationship between the researcher and the researched, we must also make decisions about how to engage in the research process. As we explore the role of values, we acknowledge that research is value laden and biased. And finally, when we ask what the process of research is, we are using inductive logic, studying the topic within its context, and using an emerging methodological design. Knowledge and understanding emerge through the inductive approach.

Applying a Western theoretical model to an Indigenous population can, at its best, impose a poorly fitting model and, at its worst, promote ethnocentric assumptions that may actually harm the community of the research focus. Minimizing this risk requires that researchers develop theory and methods appropriate to Indigenous people by including them in all aspects of the research. Grounded theory is the methodology that enables this to occur; grounded theory allows for the inductive construction or generation of a theory from the data. By grounding theory in data, grounded theory researchers address some of the common criticisms of qualitative research methods, namely that they are theoretical. Also, grounded theory allows researchers to test previous theories and modify them so they are more appropriate for the population. For example, in a study by Hernandez, Antone, and Cornelius (1999), grounded theory was used to test the theory of integration among First Nations clients with diabetes and to assess how clients perceive their diabetes, how they live with diabetes, and the most appropriate education strategies for the population. Autoethnography is a qualitative research method based on firsthand experiences that allow researchers to explore personal interaction through social, cultural, or political contexts (Atkinson et al. 2002). Ethnography tends to focus on an entire cultural group, and a "good ethnography" requires a prolonged

stay at the research site where the researcher endeavors to stay engaged with the methodological process in the context and to reduce the “distance” and the “objective separateness” between her/himself and those being researched (Guba and Lincoln 1988; Wolcott 1999). Denzin and Lincoln (2005) are optimistic regarding ethnographers’ abilities to move the discourse forward, and they are hopeful that their research will also contribute to a more socially just world. As ethnographers have inquired about the experience of marginalized people, they have often included participants in the design, data collection, analysis, and write up. As a consequence, the participants’ “voices” are heard throughout the research process. Included in this methodology are advocacy roles and an action agenda for change. Nevertheless, quantitative and qualitative research is subject to regulations imposed by the U.S. federal government, and research with sovereign Indigenous communities requires additional protections. Indigenous communities within the United States have begun systematically to claim and assert their sovereign rights to regulate human subject protections for research.

Federal Guidelines and Institutional Review Boards

Current federal guidelines for research involving human subjects do not address multiple challenges and possibilities existent within Indigenous research contexts. The definition of research found in 45 C.F.R § 46 is a systematic investigation, including research development, testing, and evaluation designed to develop or contribute to generalizable knowledge. However, the prioritized relational worldview found within Indigenous communities requires specific adaptations to the definition and regulation of research (Cross 1997). This integration begins with tribes, as sovereign independent nations, defines what research is, and then creates policies that address gaps in the current federal research protection guidelines. The unique cultural and social implications of research among Indigenous communities require oversights of human research protections established by the Belmont Report, as well as protections for the community (Alderte 1996; Freeman and Romero 2002; U.S. Department of Health and Human Services 1979).

There is a growing awareness within Indigenous communities of what constitutes research based on a Western worldview. As an example, in 2009 tribal health directors and elected tribal leaders from Montana and Wyoming met in Billings, Montana, at the Montana Wyoming Tribal Leaders

Council to discuss the development of an intertribal IRB and the current context in which research occurs and is regulated within AIAN communities. Attendees were most concerned with the need for Indigenous methodologies to address known health disparities through interventions that work. Attendees felt research that would not result in a tangible community benefit was unethical. Many attendees also voiced the need for research that gives back to the community in the way of teaching, tribal scholarships, infrastructure building, and sustainability. Emerging constructs, such as community-level needs for confidentiality, differential definitions of human subjects research inclusive of blood tissue samples, and the need for AIAN scientific and community reviewers emerged as distinctive themes of this consensus-building effort.

The discussion led to the development of an intertribal IRB and prompted a fundamental shift in the way that research is written, funded, monitored, and implemented within Native communities served by the intertribal consortium. A call for social justice again underscores the need for inclusive forms of scientific practice within Indigenous communities.

Many tribes have developed IRBs and have stressed the need for research that would translate into increased knowledge in the communities based on tribal research priorities and strategic health, environment, and education plans (Montana-Wyoming Tribal Leaders Council 2010). Tribal leaders also have voiced the need for clear documentation of the tribe's rights to the data and all publication rights.

Multitribal or tribal IRBs include tribal research and epidemiology centers, urban and rural Indian health boards, tribal colleges, and tribal governments (Office for Human Research Protections 2005). In order to serve both community interests and federal human subject protection regulations held in 45 C.F.R. § 46, most tribal IRBs have been established using the federal requirements for research regulation, and additional protections have been added to address areas not covered by the federal regulations (Sahota n.d.). For example, 45 C.F.R. § 46 does not address publication of private communal knowledge; protection of communities; respect for elders and knowledge of a community; respect for AIAN communities, their strengths, and survival; promotion of resiliency and active community involvement; or respect for and promotion of tribal sovereignty. In response to this, many tribal IRBs have additional protections including community-level protections, review by cultural committees or elders, Indigenous values, publication and dissemination agreements, issues related to monetary benefits versus exploitation, and consideration of the meaning of research questions within the context of the cultural relationships upon which research questions are premised (Kelley et al. 2013).

In the tragic history of research in the United States on Native people, tribal or community IRBs are not mentioned. In 1974 the National Commission for the Protections of Human Subjects of Biomedical and Behavioral Research was established in response to concerns about human subjects' protections in biomedical research. From this, the U.S. Congress passed the National Research Act requiring IRB approval for all federally funded research involving human subjects. In 1979 the Belmont Report was published outlining ethical principles and guidelines for the protection of human subjects in research. Then, in 1997 President Clinton apologized to African American survivors of the Tuskegee syphilis experiment, yet none of these acts or apologies addressed the research injustices on Native people or lands. There remains a lack of awareness about the history of research on Native people in the United States. This lack of awareness leads to flawed research approaches, harms communities, and perpetuates a Western-dominated research agenda where the oversight of human protections is given to the Western institutions.

When Western institutions regulate their own research, they often cannot be objective. Nor, seemingly, can Western institutions and their IRBs begin to understand the social injustices experienced by Native communities as a direct result of the Eurocentric dominant research paradigms embraced by many Western-trained researchers.

Researchers must be aware of the differences in culture and context within AIAN communities when conducting research in cultures different from the ones from which they come. A brief review of research on Native people suggests that when researchers are not aware of the cultural and community context, the outcomes have questionable meaning to tribes. Research must acknowledge tribal sovereignty and its implications. Research that fails to acknowledge differences is viewed as exploitation by many tribes and advocates for social justice. We feel it is possible to reverse social injustice and promote social contexts that determine desirable health outcomes in Native communities.

Conclusion

Inclusion of a multidimensional, culturally centered, Indigenous approach to research is required to pursue social justice more effectively and reduce health disparities for AIAN populations in the United States. Indigenous research approaches must also seek to incorporate primary prevention aimed at reducing extreme poverty, improving access to economic and educational opportunities, improving access to adequate housing,

and addressing structural forms of racism. In this chapter we have described the context in which Indigenous methodologies can be used to promote social justice and honor the values and knowledge of Indigenous people. We have provided a summary of the use of intertribal IRBs as a means to promote social justice via increased tribal participation in the regulation of research regulation with AIAN populations. Indigenous methodologies span thousands of years; however, only recently has Western science become interested in how such methodologies may improve the accuracy and depth of research outcomes. Within this effort to promote a more just, inclusive, equitable, and ultimately accurate portrayal of science, there is promise for Native people who experience injustice to hope for a future of improved Indigenous health. Developing more effective and just scientific knowledge and methods for Indigenous populations can improve more global efforts to promote health and reduce disparities in morbidity and mortality for diverse populations.

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