Diné Research Practices and Protocols:

An Intersectional Paradigm Incorporating Indigenous Feminism, Critical Indigenous

Research Methodologies and Diné Knowledge Systems

by

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ABSTRACT

This dissertation examines the role of tribal sovereignty and self-determination in research for Diné participants and elders from 1956-1986. The qualitative historical research study explored the following questions: How has past research been conducted on the Navajo Nation? What is the role of sovereignty and self-determination in research and research methodology for Diné peoples? And, how might Diné philosophy inform a research methodology that aligns with cultural protocols and practices? Six elders who participated in research from 1956-1986 participated in in-depth interviews about their experiences. Using Sa'ąh Naaghái Bik'eh Hozhǫ́ǫ́n and related Diné philosophy models, findings of this study inform an Indigenous elder knowledge protection model (i.e. Nihookáá' Diné Nidoolkah Bindii'ą') to support existing Diné tribal IRB protocols and policies and provides additional insight for tribal cultural protection organizations. Lastly, the researcher presents a Diné intersectional methodology for future research.

DEDICATION

The dedication of this dissertation is for the most influential and important people in my life. First and foremost, *my grandparents, Wade and Linda Begay Hadley. My great grandmother, Katherine B. Wallace. grandmother Mary Hadley-Todacheenie, paternal grandparents, James, Sr. and Phoebe Henderson. My parents, James Henderson, Jr. and Regina Hadley Lynch. My aunts; Wanda Hadley-Campbell, and Velma Spencer. My uncle and aunt, Stanley and Maxine Denetdeel and Andy and Lucy Ayze. My sisters; Valerie Yazzie and Andrea Ayze; my children, Adrielle Shundiin, Shanielle Tara, Gabrielle Gina, Edwina Sharelle, Janelle Asdzaan, Lynelle Linda and Robert James. My grandchildren; Tatum Isabelle, Seanna Dawn, Hailey Edna, Gavin Rusty, Marielle Linda, Sean Wade, Shundiin Leann, Jayden Matthew and Sage Adeline.* My extended family from Black Mesa, Rough Rock, Chinle, Ganado and Chilchinbeto, Arizona whom supported me throughout my academic journey. And finally, to Arbin Mitchell who provided me with unconditional love and endless support. Without you, I would not have completed this important academic milestone. You will always have a special place in my heart.

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PREFACE

This research examines the perspectives of Diné participants who served as cultural advisors on research conducted in the three focal communities during the 1956-1986 period of time in the Diné nation. The Diné nation, also referred to as the Navajo nation or Diné Bikeyah, is home to the Indigenous or Native American group known as the Diné (Navajo) people. The Diné are a federally recognized tribe whose ancestral homelands extend through northern Arizona, northwest New Mexico, and southern Utah. The nation is 27,000 square feet and boasts all four ecosystems. The Diné have resided there for thousands of years.

The research journey undertaken to find answers to the research questions presented in this study covers conceptions of research as applied to Indigenous ways of knowing and the role of age, community status (as an elder, spiritual leader, or cultural knowledge holder), and gender in research. This project considers how cultural protocol, learning, and practices inform the research process for Diné peoples and urges readers to consider the role and importance of acknowledging and respecting *Diné specific* cultural protocols. Perhaps most importantly, this research forced me to contend with my own relationship to research as a Diné woman and legacy of a Diné grandmother who served as one of the first cultural elder woman researcher (collecting data) and cultural expert (assisting with data analysis/interpretation) on some of these studies.

As I embarked on the dissertation journey, I spent a great deal of time reflecting on the Western research practices I was taught to use in my doctoral program. Reading about qualitative research methods from Saldaña, Denzin and Lincoln, and many others was helpful but left me feeling incomplete. Although these researchers mentioned it is

important to understand the local context of a community when engaging in qualitative interviewing, observations, or other forms of data collection, they didn't often speak of qualitative research from a tribal sovereignty or self-determination perspective nor did they mention the role of people like my grandmother in research. This left me with many questions. For instance, what role(s) do elders play in research? Are there protections in place to protect their knowledge? What about compensating them for their time or acknowledging more formally their role in research? Not only that, but since each tribal community is different and has their own set(s) of values, roles, and beliefs – especially as it relates to gender, age, and community status – how is that reflected properly in research protocols and practices? How might it influence how research is undertaken, developed, or reported?

I didn't know the answers to these questions, so I turned to research on Critical Indigenous Research Methodologies and to scholars such as Linda Smith, Bryan Brayboy, Eve Tuck, Shawn Wilson, and Margaret Kovach. These Indigenous scholars helped situate the discussion of research within the importance and urgency of action. They talked about conducting use-oriented research that addressing Indigenous people's needs, fore fronting the voices, knowledges, and perspectives of Indigenous peoples in research, and engaging in work that is rooted in protecting sovereignty and prioritizing tribal self-determination.

More than advocating for participatory action research, these scholars actively promoted an Indigenous *critical* lens to research. They urge(d) present and aspiring scholars to consider how we can identify and seek to mitigate or destabilize processes of power, colonization, assimilation, Whiteness, capitalism, and other oppressive forms of domination and control – from systems of governance, schooling, and medicine to systems

of thinking including investments in patriarchy, misogyny, and ageism – to identify actions and solutions that allow us to decolonize, promote anti-colonial action, and anti-racist outcomes for our peoples. More than anything, they stress(ed) the importance of recognizing historic trauma, engaging in research practices that do not promote harm and that focus on enhancing the well-being of Indigenous peoples as actionable outcomes and that support tribal sovereignty and decision-making above all.

As powerful and refreshing as this research was, it still lacked something. A cultural or tribal specificity needed to engage research from my own people's perspectives. And, most importantly, although Alaska Natives were talking about the role of elders in research, I still had many questions left unanswered. Thus, I decided to create my own methodology. It wasn't easy.

The dissertation journey began with one of the last classes I completed in my doctoral coursework, JUS 791: Indigenous Community Health. The course was a seminar on analyzing various Indigenous community health concerns and issues. An article that was of great interest was the *Cornell Study: The Many Farms Experiment* (McDermott, 1959). I became intrigued with the article, specifically because the communities of Many Farms, Rough Rock, and Chinle are where my family originates. The more I read, the more I became curious about the research studies conducted in these communities. I remember calling my mother and asking if she remembered researchers visiting our communities. The response I received only created more curiosity. As I further discussed the study with family members, I discovered many had been directly involved in research studies, not only in the *Cornell* study, but also in the *Rough Rock Demonstration School*

and *Navajo Mental Health Project* as well as other exploratory research and evaluation projects.

As I proceeded to further inquire about research in my communities, I began to identify parallels and relationships to the initial Cornell study. I learned there had been a short burst of research involving Navajos that had lasted roughly three decades. Shortly after, I began researching studies from the time period of 1956-1986. The information and data I located was informative and fascinating. As a researcher, I wanted answers: *How was initial research conducted among my Diné people?* I wanted to identify the protocols and practices early researchers had used. These inquiries led me to discover more deeply my grandmother's role in the community as a researcher and educator. As I explored my grandmother's life experiences, I wanted to document her legacy as an Indigenous woman researcher. I wanted to pursue how we as Diné people could modify our way of documenting our Indigenous knowledge systems and apply those teachings to the research process so that we may accomplish the vision the Indigenous researchers called for. I wanted to explore how Diné epistemology and ontology could help Diné researchers design research that allows us to interrogate power, colonization, assimilation, Whiteness, capitalism and identify actions and solutions that allow us to decolonize, promote anti-colonial action, and anti-racist outcomes to help shape policy and initiatives related to our systems of governance, schooling, and medicine. Most importantly, I wanted to know how Diné ways of thinking can inspire us to push back against patriarchy, misogyny, and ageism to attain our shared desired goal of Hozhó.

Two years after I began this journey, I have concluded that, as it stands, our current Navajo Nation IRB guidelines and Western research training could benefit from

recommendations provided by our Diné elders regarding ways to improve Diné research practices and protocols. Decolonizing research practices and protocols for my Diné people is critical if we are to prioritize the well-being and knowledges of our people. This academic research journey led me to an unexpected place: in addition to collecting data regarding the research questions guiding this study, I had to take time to develop a Diné research methodology that can guide research from the perspective of our own cultural values, teachings, and goals. The resulting methodology will be introduced in chapter two. This methodology is the culmination of all this exploration. It is a Diné process of thinking, of acknowledging self-identity including the role of age, gender, and community status in acquiring and sharing information, of knowing who you are and where you come from; of understanding cultural life experiences and value systems, and creating a legacy for future generations. As an Indigenous woman researcher, I feel the importance of approaching my research from a Diné paradigm and methodology that employs the traditional teachings and value systems of the Diné people.

Why focus on research?

So far, I have provided a rationale for why I developed my own research methodology. However, I haven't explained why I chose to focus this study on research. Why is it important to learn about the role of elders in research that has long since been completed? The answer, in short, is because the actions and experiences of those who have come before us can help shape and benefit the lives of those who come after us. In short, if we don't explore and understand how research has affected our people, we won't know in what ways we can improve the process or outcomes in order to enhance our well-being and support our tribal self-determination and sovereignty.

Research, as I learned in my doctoral program, is about ideas in motion (Grande, 2008). This suggests that research is both a noun and a verb. It is both a process and an end result. In order to understand the goals, practices, and scope of research, it is important to understand what shapes and informs the process and its purpose.

Research has been defined as the act of gathering, organizing, and interpreting information with the intention of using data as a guide to make informed decisions or to help us better understand the world around us (First Nations Information Governance Committee, 2007). Without intention to apply the information gathered, to identify a potential solution to a pressing social problem, to determine whether a particular program, intervention, solution or idea has worked, and/or to better understand a phenomenon, information remains static. In other words, information collected only becomes part of research, or data, when you *do* something with it.

When you collect information, analyze it, and apply findings to the context under inquiry to inform existing and future practices or decisions *then* does that information become data in the *process* of research. Research is then one method to create and inform existing knowledge about a phenomenon, process, or context.

For Indigenous peoples, it is important to remember two things. First, Indigenous peoples have always been researchers. Though we never used the term to brand ourselves with the title, we have been observing our environments, flora, and fauna and making educated decisions about how to build shelter, feed ourselves, and live in harmony with the environment since time immemorial. Our creation stories help us understand the astros and our place in the world and remind us of the sacred and powerful places within the lands we inhabit. These knowledges fortify us and the places we come from.

Second, we must remember that Indigenous peoples engage in this kind of process – in research – with a sense of purpose. We take information, or gather and collect data, with the intention of giving to others. In short, data is intended to be applied and/or used to provide safety, enhance the well-being of our peoples and environment, and even to identify solutions to current tribal issues, challenges, or problems.

The first point bears expansion. Indigenous peoples have been researchers for centuries. Our ancestors collected information that has helped us survive and thrive in our environments. Their research has taught us important lessons about diet, hunting, fishing, shelter, education, navigating territory, and it has taught us how to become a successful community. For Indigenous peoples, research is important because it allows our community members to survive and thrive and, for those who live and work within academic structures, it allows Indigenous scholars to investigate, validate, contest, and acknowledge our own knowledges and practices.

For hundreds of years, however, proponents of Western European and Euro-American imperialism and colonization have dismissed the ways of Indigenous peoples. And despite the fact that Indigenous peoples have been researchers since our very beginning, the history of Euro-Western research practices foisted upon Indigenous peoples has established a legacy among many indigenous communities wherein we are not immediately considered researchers. Furthermore, the research we have been subjected to by non-members have left a legacy such that "research is [perceived to be] 'probably one of the dirtiest words in the Indigenous world's vocabulary'" (Smith, 2012).

Even with this history of Western research positioning us as the subject or object of research and not the research*er(s)*, noted Indigenous scholar Linda Tuhiwai Smith

believes research has an important aspect of academic investigation as a process and points to the need to conduct research in a way that align with our tribal values, languages, protocols, practices, and needs. Ensuring research is driven by us and engaged in a culturally responsive and respectful manner is one way to decolonize our way of thinking in a colonized world.

That said, how do I, as a Diné woman scholar, engage in research centered around the second point? To take or collect information with the idea of giving it, or sharing it, with others to enhance our well-being? First, the task is to focus and reflect on who I am as a person: woman, mother, grandmother, a granddaughter of healers and traditionalists, wife, born and raised in Diné Bikéyah, speaker of our ancestral language, educator, and rising elder. Next, I must consider how those identities shape or influence my perspective as a person and my role in research. Should that influence how I engage in dissertation research? If so, how should it influence the research process? In order to answer these questions, I needed to engage in self-reflection. I had to come to terms with the fact that I am a Diné research legacy. In short, I had to consider how my grandmother's role in research, and in training me to be a researcher, has shaped my own ideals and values about the goals, practices, and scope of research and how those shape and inform my own research process and purpose.

Inheriting a Diné research legacy

My fondest childhood memories are of growing up in the canyons, arroyos and red plateaus of Ganado and Kits'iilí (Black Mesa) in the heart of the Navajo Nation. During my younger years I grew up with no running water or electricity. My earliest years were

spent with my paternal grandmother who tended to the livestock and burned wood to maintain a warm home and place to cook for our family.

In my early childhood, my maternal grandparents also had a huge influence on my life. I started school at a local parochial school where my mother and aunts also received an education. My grandparents often visited and took me on trips. One of which was my first airplane ride on Trans World Airways to Washington, D.C., I was 6 years old.

At a young age, I soon learned cultural protocols, I recall early morning prayers and offerings for safety and blessings for positive outcomes. My grandmother shared with me various cultural practices and protocols for conducting oneself with others who were not family. The customary greeting of Yá'át'ééh, acknowledging yourself as a Diné with an acknowledgment of your four clans and the place you represent, and finally defining the purpose of your visit. It was during this time I was introduced to a world of many different people: African American, Asian Americans, and Latinx peoples. I was taught to respect all people.

My grandparents diplomatically modeled the proper cultural practices of speaking and working with mainstream society. Colonization of boarding schools and forced assimilation to society influenced my grandparents to demonstrate proper etiquette and presentation. Nonetheless, you would never know that under a velveteen shirt and calico skirt decorated with turquoise and silver jewelry and traditional tsiiyééł (hair bun), my grandmother was a high school graduate of Shiprock High School, a veteran, the first Diné woman to serve in the Army Women's Auxiliary Corp during World War II, and the first teacher for the Many Farms community. My grandfather was a well-groomed man with distinct features who wore a silver inlayed multicolored bolo tie and polished cowboy

boots. A Diné man who also served his country, first from the Kits'ilii community to receive a colonized education, an artist who studied at Santa Fe School for the Arts, and a retired commercial worker for El Paso Natural Gas. Distinguished leaders are who I directly descend from.

In 1968, my grandparents returned to their homestead in Black Mesa where they began a new life of community advocacy and leadership. Later, my grandparents would become well-respected leaders and advocates for their community as elected school board members, local Chapter Officials, and strong advocates for Diné language and culture education. They traveled often and I would almost always accompany them.

In the fall of 1975, my family and I moved to Rough Rock, Arizona. During the academic school year and Monday-Friday I lived in school housing on the Rough Rock Demonstration School campus with my mother, grandparents, and siblings. During the weekend, winter and summer breaks, we spent our days at Ilchį́į́'dáhats'osí, a place near the sacred land of Kits'iilį́ with no running water or electricity. As a family we cared for the sheep and goats; planted corn, squash, potatoes, and melons; and hauled water from the local windmill. This is where my cultural roots were developed. The 'place' where I learned the essence of my existence and relationship with mother earth and the universe.

My grandparents ensured a safe and supportive bilingual and bicultural learning environment. By the eighth grade, I managed to become proficient in two languages: Diné and English. More importantly, I acquired knowledge of the ways of my people from my local elders, particularly from my grandparents, and other clan relatives. From my relations, I learned to treasure who I am and where I come from. My personal academic achievements can be attributed to my maternal grandparents, my mother, and aunties.

They all had a monumental impact on my educational, physical, emotional and spiritual development.

Most of my adolescent years were spent traveling in my grandparent's pick-up truck. We traveled many miles over the course of my teenage years. I particularly remember my travels with my grandma, Linda (Begay Hadley) like it was yesterday. I can still feel the warmth of the sun and the dust blowing in my face. I vividly remember driving through the dirt roads, washboards, and arroyos to visit various elders and medicine people.

Every trip with grandma began the same way. First, we would pack our lunch – usually boiled mutton backbone, boiled potatoes, a *Del Monte* fruit cup, and *Fresca* soda. I would gather my clipboard, pen and black *Sanyo* cassette tape recorder and hop in back of the pick-up truck, place our travel items securely in an old wire basket, tied down, and make my place on the passenger side. Before every trip, my responsibility was to record the beginning mileage.

As we got onto the main paved road (Highway 191), grandma Linda would offer prayers to Grandfather Sun and Mother Earth, the prayers always began with "Kodóó hózhǫ́ǫ dooleeł" (From here beauty begins), followed by Hózhǫ́ǫjí (Beauty Way). Songs and prayers were offered for all of our relations and living things. Soon after, grandma Linda would pause and provide me with traveling details – who, why and where we were going – an itinerary for the day.

My role as her granddaughter and apprentice (which I was but didn't realize until years later), was to write down odometer readings, dates, times, places and names of persons we were visiting and labeling each cassette tape with the name of the medicine

person or spiritual healer, date, and time. My other responsibility was to prepare offerings for each relation we visited. In short, I was learning to follow a research and cultural protocol for visiting relatives. The offerings consisted of bag of *Blue Bird* Flour, *Loretta's* Cinnamon Rolls, mutton, a six-pack of *Shasta* soda, and herbal tea. Most of our visits lasted 2-3 hours. Another responsibility was to ensure we had enough *Ever Ready* "C" batteries in the event the cassette recorder stopped working.

In the summer of 1983, I was hired as a summer student worker. In this position I also served as data recorder and transcriber for the *Rough Rock Mental Health Project: Medicine Man Training Program*. Coincidentally my grandma Linda served as the Assistant Director of the project and was the lead investigator for this federally funded mental health project. My job duties were to record and transcribe interviews with Navajo traditional ceremony practitioners.

The best part of this job was the ability to travel and work with grandma every day. It was a dream job. Since I had been previously trained to conduct interviews, I would follow the same protocols as I had done so many times before as a pre-teen. However, as a mature 16-year-old, I now had the opportunity to visit Navajo practitioners, herbalists and diagnosticians also known as Hand Tremblers or Star Gazers. My prior experiences traveling with grandma would soon pay off. This time, my role was more sophisticated. Not only was I able to accompany my grandmother and listen to the interviews she conducted, I was able to be part of the process. I took notes, recorded interviews, and transcribed the words spoken in the Diné languages. The most rewarding part of my job was listening to traditional stories and legends and learning the history of over eleven ceremonies, chants, and protocols.

As a girl I often traveled with my grandmother, not knowing what she was doing at the time. Nearly half a century later, I came to understand why my grandmother traveled across the Navajo Nation year after year: she was documenting Diné historical knowledge and cultural practices. My grandmother Linda was a researcher—one of the first of Diné women researchers. As her eldest grandchild, my goal is to carry on my grandmother's legacy, to document and protect Diné research practices, nurture elders' knowledge, and use this research to provide policy recommendations to the Navajo Nation Human Research and Review Board (NNHRRB) and to researchers working with Indigenous people worldwide.

Today, I find myself in the land of the O'otham people, acquiring knowledge from the same university where she brought me thirty-three years ago to begin my educational journey as an undergraduate student. Now, as a doctoral student, I choose to complete a qualitative historical research study on the work she started and document Diné research teachings from local elders so that our Diné teachings and knowledge systems can be carried on for generations to come while protecting our elders and medicine people from harmful colonized research practices.

Why research on research matters

Researching research, to some, might seem like navel gazing. However, the topic of Indigenous research and sovereignty has been of increasing concern in recent years, as reflected in the work of Indigenous scholars such as Bryan Brayboy (2011) and colleagues Sandy Grande (2008, 2015), Lloyd Lee (2014), K. Tsianina Lomawaima (2000), Margaret Kovach (2009), Linda Tuhiwai Smith (2012), and Denzin, Lincoln, & Smith (2008). While growing, the research in this area remains limited for Indigenous

peoples in the U.S. Southwest, home to more than forty-four Indigenous nations. We need to better understand how Indigenous peoples shape their own research policies, protocols, and guidelines to protect the elders, land, language(s), and knowledges implicated by the past and present studies. Further research is needed that examines how tribes enact their own sovereignty and self-determination to outline protocols and guidelines for research and research methodology that align with their own epistemology and promote protections for the well-being and cultural knowledge of their tribal citizens and research participants.

This research study takes up this important area of investigation. Specifically, I examine the role of tribal sovereignty and self-determination in research for Diné elders; conceptions of research as it applies to Diné research practices, epistemologies, the role of elders as cultural knowledge keepers, as well as the importance of cultural protocol(s) and their implications for the Navajo Nation Human Research Review Board in advancing sovereignty and self-determination for the Diné people.

The dissertation is organized into six chapters. Chapter one presents the background for the study, research questions, and an overview of how the study was conducted. In chapter two, I expand on the methodologies that informed the study and present a vision for a feminist Diné research methodology informed by Sa'ąh Naaghái Bik'eh Hozhǫ́ (SNBH), a Navajo theory of long-life happiness (Lee, 2014, 2017), and related Diné philosophical/theoretical models that can guide research. I use the concept of Hozhǫ́—beauty, harmony, and peace (Werito, 2014)—to guide this research vision and draw from current research practices and protocols to inform a decolonizing research stance. The SNBH model serves as the central guiding body of knowledge for the

proposed research vision and it is briefly connected to discussions of Critical Indigenous Research Methodologies (CIRM) (Brayboy et al., 2012; Kovach, 2009; Smith, 2012).

Chapter three presents an overview of research conducted in Diné Bikéyah from 1956-1986. I pay specific attention to research that was conducted in Many Farms, Rough Rock, and Chinle, Arizona. This time period was selected because of the early research conducted by Cornell University and other subsequent research conducted in the Many Farms and surrounding communities of Rough Rock and Chinle, Arizona. The three communities are of high interest as they are the communities of my relations and homeland. My grandmother began her community work during this period of time and research participants are now elders of the communities. Elders were interviewed about their experiences with non-Diné and Diné researchers and particularly their involvement with grants under the U.S. Public Health Service.

Chapter four presents the findings of the interviews with elders who participated in these studies, including their recommendations for policies, protocols, and practices that should guide research conducted in Diné Bikéyah. I use these findings in chapter five to propose policy changes for the NNHRRB – the body of community leaders who determine which research will be allowed on the Nation. And, lastly, chapter six provides a vision for future research.

A note about the unusual writing format used in this dissertation

Given the demands of my doctoral program and the need for use-oriented research that is beneficial or useful to tribal communities, the formatting of the chapters contained in this dissertation may seem a bit unusual. Chapter three is written as a book chapter that presents an overview of tribal sovereignty and self-determination in research and presents

a historical account of how research was practiced on Navajo during the time period mentioned. Chapter four is written as a journal article manuscript, presents research findings, and informs a philosophy of research based on the recommendations of elders. Elders experiences related to research and their recommendations on how to improve research protocol so that it reflects Diné epistemology and protocols are shared. The findings are then applied in chapter five, which is written as a policy paper that evaluates how current NNHRRB protocols and policies align with the Diné epistemology and cultural processes presented in this research. This policy paper will propose considerations of revisions to existing NNHRRB policy to better align with the well-being of Diné research participants, especially elders, and protection of cultural knowledge. The intention of these differently formatted chapters is that they will be submitted for publication post-defense. The policy paper will be shared directly with the NNHRRB.

Conclusion

I began this prologue by stating that research is defined as the act of gathering, organizing, and interpreting information with the intention of using data as a guide to make informed decisions or understand the world around us (*First Nations Information Governance Committee*, 2007). Moreover, I indicated that research is about ideas in motion (*Red Pedagogy the Un-methodology*, 2008). Indigenous research is important for Indigenous scholars to investigate, validate, argue and acknowledge Indigenous knowledges and practices. Yet for hundreds of years, proponents of Western European and Euro-American imperialism and colonization have dismissed the ways of Indigenous people. Indigenous scholars have argued historic academic research practices have

relegated Indigenous voices and ancestral knowledge to the periphery while continuing to oppress society and peoples of Indigenous nations.

Since research has historically been undertaken in a manner that is unresponsive to the needs, interests, and desires of Indigenous peoples, many Native peoples believe research is not relevant or useful to their communities and have developed a deep distrust of research and researchers. The result is that for many Indigenous communities' "research is probably one of the dirtiest words in the Indigenous world's vocabulary" (Smith, 2012, p.1). Indigenous historian and scholar Vine Deloria (1969) famously stated that, "research has been a practice difficult to digest and devoid of any meaningful application for Native peoples" (p. 34).

Both Smith and Deloria highlight three important points. First, research has been conducted in a way that is culturally irrelevant or disrespectful to Native communities. Second, the methodology used in research is not 'Native friendly' and is almost impossible for an average Native person or participant to understand research terminology or the results of research. Third, the topics under investigation may not be of interest or desire for the community to have the research conducted. Therefore, research is limited in how useful it is for Indigenous communities.

Nevertheless, Smith (2012), acknowledges the suppression of Indigenous knowledge systems and offers recommendations for reclaiming and reconnecting, through research, with one's place within Indigenous society. Indigenous scholars such as Smith believe research can be an important aspect of academic investigation as a process and specifically points to the need to conduct research in an effort to decolonize our way of thinking in a colonized world. The present study is valuable because research practices

and protocols have historically either had negative effects on Indigenous people or have not served their needs at all.

Thus, since research has been conducted in the past without much input from the People, it has disproportionately benefitted the individual researcher and/or organization (i.e. funding agency) more than Native peoples. The Navajo Nation has not been immune to this. Generations of forced colonized education and research plague Diné communities, denying our people their right to express original voice and knowledge systems in research. It's time we use the lessons of the past, and the voices of our elders, to develop a healthy vision for our future.

CHAPTER 1

STUDY BACKGROUND AND CONTEXT

The preface offered a general introduction to the study. This chapter presents the rationale for the study including study background, research questions, need for the study, study significance, methodology, research design, and ethical considerations. The next chapter presents a vision for a feminist Diné research methodology.

Introduction

The topic of Indigenous research and sovereignty has been of increasing concern in recent years, as reflected in the work of numerous Indigenous scholars (e.g., Brayboy et al., 2011; Denzin, Lincoln, & Smith, 2008; Grande, 2008. 2014; Lee, 2014; Lomawaima, 2000; Kovach, 2009, Smith, 2012). Research in this area remains especially limited for Indigenous peoples in the U.S. Southwest, home to more than forty-four Native American nations. This dissertation project argues that further research is needed that examines how southwestern tribes enact their own sovereignty and self-determination to outline protocols and guidelines for research and research methodology that align with their own cultural ways of thinking and practices and how they enact regulations to promote protections for the well-being and cultural knowledge of their tribal citizens and research participants.

This study focuses on the role of tribal sovereignty and self-determination in research for Diné participants and elders from 1956-1986, a critical period for research on the Navajo Nation, and is further centered on research conducted in three communities located in the heart of the Navajo Nation: Chinle, Many Farms, and Rough Rock, Arizona. This research study takes up this important area of investigation and examines

the role of tribal sovereignty and self-determination in research for Diné (Navajo) elders. The study specifically explores elders' conceptions of research as it applies to research practices, Indigenous epistemologies (ways of thinking), the role of elders and cultural knowledge keepers in research, and cultural protocol. Findings from this study will be used to inform recommendations for the Navajo Nation Human Research Review Board in advancing sovereignty and self-determination for the Diné people (chapter 5).

The questions guiding this dissertation are as follows:

1. What key research studies were conducted in the three focal communities during the period 1956-1986?

    A. What was the purpose of these studies?

    B. How did Diné participate in the studies?

    C. What was the researchers' role in relation to Diné participants?

    D. Whose interests did the studies represent?

2. What are the perspectives of Diné participants on research conducted in the three focal communities during the period 1956-1986?

    A. How was Diné sovereignty and self-determination reflected, if at all, in these studies?

    B. What recommendations do Diné elders have for how to engage in culturally appropriate research practices for research conducted in or on Diné Bikéyah?

3. What can we learn from past research and the perspectives of Diné participants on the role of sovereignty and self-determination in research for Diné peoples?

A. How can Diné philosophy inform a research methodology that aligns with cultural protocols and practices?

B. How can this research contribute to Nihookáá' Diné Nidoolkah Bindii'ą' (Earth Peoples Research Framework) as a potential research model?

This qualitative historical research study uses data triangulation. Archival records and analysis as well as in-depth interviews with the Diné (Navajo) elders (ages 70+) inform the study findings. Interviews were conducted in Gallup, New Mexico during the Spring and Summer of 2019 with five Navajo elders. An interview protocol for case studies using I.E. Seidman's (2013), *Interviewing as Qualitative Research* (4th edition) was used as part of a three-part individual interview consisting of 90-minute individual interviews for participants who participated in research from 1956-1986. The questions selected were designed to allow participants to freely share their experiences. The interview protocol contained questions examining their personal experiences with research in their respective communities. Lastly, the research approach used was informed by a methodology that builds on Diné ways of knowing (in particular, Sa'ąh Naagháí Bik'eh Hózhóón) and more broadly, Critical Indigenous Research Methodologies (CIRM). These knowledge systems and methodologies are the most appropriate for understanding Diné epistemologies and ontologies and for guiding appropriate research behaviors when working with Indigenous communities.

Need for the Study

Past research has not followed Navajo epistemological and ontological beliefs about relationships and the purpose and protocols for conducting research. A large number of studies conducting on the Navajo Nation from 1956-1986 were conducted by non-

Navajo researchers who relied on Western methodologies that did not necessarily reflect, honor, or prioritize the needs, vision, and desires of the Navajo people. Furthermore, in the past 20 years the number of Navajo PhDs has risen. Those researchers are indicating that current Western methodologies available are insufficient and inappropriate for conducting research in Navajo communities (Lee, 2014). While CIRM exists, these methodologies are helpful in presenting Indigenous worldviews to research, but they are not tribally specific. Because there are over 570 federally recognized tribes, it is important to understand that not all tribes share the same epistemological and ontological commitments and thus tribally specific methodologies are needed. Thus, there is need for a Navajo specific methodology and research methods that is culturally respectful and appropriate and aligned with Navajo epistemology and ontology.

Theoretical Foundation

The following theories are used to extend current discussions and understandings to guide this study. First, the Sa'ąh Naagháí Bik'eh Hozhǫ́ (SNBH) and related Diné philosophy models are used and integrated. In the past, Western theories have been used to study Indigenous peoples in a broad spectrum; however, there is limited qualitative research on protecting elders and Indigenous knowledge systems that use Diné traditional or culturally specific models.

In order to develop a Diné research protection model; Nihooką́ą' Diné Nidoolkah Bindii'ą' (Earth People Research Framework) must be used to support existing Navajo Nation Health Research and Review Boards and Diné human protection organizations, such as the Navajo Nation Human Rights Commission and the Office of Navajo Historic

Preservation which both serves as a forum to preserve and protect the Diné people and their way of life.

Second, the Diné Sa'ąh Naagháí Bik'eh Hozhǫ́ model and related Diné philosophies are used as a theoretical model while connecting these frameworks with discussions related to Critical Indigenous Research Methodologies (Brayboy et al., 2012). The intent was to interview and analyze data received from Diné elders and their historical research experiences with non-Diné and Diné researchers. This allowed me to examine the relationships between the researcher and research participants and to complete a documentary analysis of the theories presented from Diné elders insights into the context and relationships of research practices during the time period of 1956-1986.

Key Terms

Grande (2007) defines **research** as the act of gathering, organizing, and interpreting information with the intention of using data as a guide to make informed decisions or understand the world around us (p. 2). **Historical-qualitative research** involves interpreting past events to predict future ones. The steps in historical research are to formulate an idea, formulate a plan, gather data, analyze data, and analyze the sources of data (nd.). **Sovereignty** used by Lomawaima & McCarty (2006) refers to "the inherent right of a people to self-government, self-determination, and self-education. Sovereignty includes the right to linguistic and cultural expression according to local languages and norms…" (p. 9). **Self-determination** is the enaction of sovereignty and, according to Kathryn Manuelito (2005), "is communal, positive, and integral to a Navajo philosophy of living" (p. 80). **Elders** and **cultural knowledge keepers** are defined as those who are recognized by the community as Niháhastóí dóó Nihizáanii (our male and

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female elders), cultural stewards, and possessors of community, cultural, and tribal memory. Many elders are over the age of 60 and, since epistemology can be intimately tied with heritage language, are fluent speakers of the Diné language. Lastly, **Navajo Nation Health Review and Research Boards (NNHRRB) is** defined as the official Board tasked with protecting the rights, welfare, and well-being of Diné research participants, and ensuring compliance with relevant local, state, and federal research laws and regulations.

Diné terminology and culturally specific terms will be emphasized throughout this study including terms such as **Diné** meaning the "The People," which is the way I prefer to reference Navajo people. **Nihokáá' Diné** is a term meaning to the "earth people." **Sa'ąh Naagháíí Bik'eh Hózhǫ** translates to "Circle of Life in Beauty," a Diné fundamental methodological concept that frames the Diné way of thinking using the four elements of planning, thinking, living, and evaluating.

Methodology and Research Design

Berg (2001), suggests five areas for conducting research: 1) to reveal or uncover the unknown; 2) to answer questions which have yet been answered; 3) to search and identify the relationship of past happenings and their links with the present; 4) to record and assess past activities and achievements of individuals, agencies and institutions; and 5) to assist in the understanding of human culture. In order to answer the research questions guiding this study, a qualitative methodology with a historical qualitative research design was used. This dissertation uses a qualitative research methodology to build upon Diné ways of knowing (in particular, SNBH) and more broadly, applies a historical research design and CIRM research (with emphasis on Diné Knowledge

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Systems) paradigm to inquiry. These ways of knowing are the most appropriate for understanding Diné epistemologies and ontologies as it relates to historic research.

Denzin and Lincoln (1994) describe qualitative research as multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials - personal experience, introspective reflection, life story, interview, observations, historical texts and analyses, interactional approaches, and visual texts -- that describe routine and problematic moments and meaning in individuals' lives.

Furthermore, this study utilized an historical research design. Data consisted of primary sources including first-person accounts that involve the oral or written testimony of eyewitnesses, letters, observational notes, photographs, recordings, drawings, life histories, anecdotal notes and journals. In addition to historical research, Creswell (2013), Saldaña (2017) have inspired an understanding of qualitative research as the discovery and understanding of experiences, perspectives, thoughts of participants and a body of work that further explores the meaning and purpose or reality of the world in which we live. Qualitative practices in turn create a representation of a particular reality for the present research study participants using field notes, interviews, conversations, photographs, recordings and anecdotal memos to interpret life experiences of community elders and document their stories for future generations. Because this study was interested in the past experiences of Diné peoples in past research, a qualitative research methodology with historical research design was deemed the most appropriate.

Historical research is a common research design for studying past events, phenomena or occurrences (Tao, 2015). It can be defined as the process of investigating past events systematically to provide an account of happenings in the past (Historical Research, n.d.). It is a flowing and dynamic explanation or description of past events which include an interpretation of these events in an effort to recapture implications, personalities and ideas that have influenced these events (ibid). A qualitative historical research approach allowed the researcher to explore the role of sovereignty and self-determination in research on and with Diné peoples over the critical 30-year time period. I combined the qualitative historical research approach with critical qualitative analytical techniques to inform research findings on, by, and for Diné peoples in ways that will promote social change. In the findings section, I describe the life experiences collected through recordings, observational notes, interviews, and archival data. In this research, six elders guided the research process through interviews and storytelling (Braun, Browne, Kaʻopua, Kim, & Mokuau, 2014).

Pairing a qualitative historical research design with CIRM is important and intentional. As stated in an earlier section, research with Indigenous communities has been historically of little to no use due primarily because of inappropriate research practices. For nearly a century, non-Native researchers had their own agendas for investigating Indigenous people. Combining qualitative historical methodology and design with a participatory research design along with the power of CIRM (which provides an Indigenous approach to qualitative methodologies) ensures the findings of this study are relevant, respectful, and applicable to Indigenous peoples. This approach allowed participants to incorporate Indigenous ways of knowing to their responses and

demonstrate how such philosophies and practices can be advantageous for empowering Indigenous communities with little or no harm during research. Regardless of failed research conducted throughout Indian Country for political and colonial agendas this dissertation research demonstrated how incorporating respect, relationality, responsibility, and reciprocity (principles from CIRM), with a qualitative historical research approach, can significantly integrate Indigenous Ways of Knowing into an ethical Indigenous Research Protocol. Further, this combination allows the researcher to inform applications of findings to future decisions and initiatives that promote sovereignty and self-determination for Indigenous peoples. Moore, Monaghan and Hartman (1997) justify historical research as people learning from the past and helps to link the past with the present. It also encourages interdisciplinary inquiry and understanding (ibid). Secondary sources used were scholarly articles, reference books, textbooks and newspaper articles related to the research studies under examination.

Participants

Participants were selected from the communities of Rough Rock, Many Farms and Chinle, Arizona. Six participants from each community who participated in research during the time period of 1956-1986 were interviewed. Three women and three men were selected based on their experiences with research during the time period from 1956-1986. Each participant was interviewed on their research experiences with non-Native and Native researchers.

At least one of six elders were identified as a Diné ceremonial practitioner. A traditional introduction which includes an emphasis on shared relationships between the researcher and participants through the Diné kinship system was established and

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practiced with each participant prior to the formal interviews. Interviewees ranged in age from 60 to 91 years of age. All participants spoke the Diné language and, all but one elder completed the interview in the English language with a few Diné phrases. Interviews were conducted, off reservation, in Gallup, New Mexico. **It is important to note that during the course of the study, one elder passed away and his wife of 60 years concluded phase 3 of the interview.**

Sampling

Given the historic nature of this project, it was difficult to identify living participants for this study. Moreover, many participants in this age group may not have regular access to telephones or technology making communication difficult – especially in terms of setting up interview times and locations. Therefore, the researcher used convenience sampling (and some snowball sampling) to identify study participants. The researcher began by reaching out to elders in Rough Rock, Chinle, and Many Farms area verbally during social gatherings and community social ceremonies. The Beauty Way Ceremony was targeted because they are specifically open to community elders and ceremonial practitioners. The researcher described the study and invited Navajo researcher elders who participated in research from 1956-1986 to participate in the study.

Prior to interviewing research participants, I spoke with local community elders and inquired about possible participants for my research study. Based upon recommendations, I visited each possible participant and initiated a relationship to gently probe their interest in participating in further research study. Next, I established rapport and relationships with each of the interested and prospective participants. During our formal introductions we exchanged information about our clans, family origin, and

purpose of the research study. Establishing kinship and clanship is essential to building relationships among the Diné people (ADD, 1998). Multiple visitations to each prospective elder prior to conducting the interviews was of critical importance to establish rapport before any data was collected for this study.

One of limitations associated with these sampling techniques relate to confirmation bias. Researchers tend to remember points that support their own hypothesis and points that disprove other hypotheses. Confirmation bias is deeply seated in the natural tendencies people use to understand and filter information, which often lead to focusing on one hypothesis at a time (Sarniak, 2015). To minimize confirmation bias, as a researcher I sought to continually reevaluate impressions of participant's respondents and challenge preexisting assumptions and hypotheses. Asking quality questions at the right time and remaining focused on sources of bias enabled me to ensure a high-quality qualitative research analysis.

Data Collection

Data collection was conducted during the Fall, Spring and Summer of 2019 and relied primarily on archival records and analysis as well as in-depth interviews. A series of individual interviews were administered to research participants. An interview protocol for case studies using I.E. Seidman (2013), *Interviewing as Qualitative Research* (4th edition) was used as part of a three-part interview consisting of 90-minute interviews for participants who participated in research from 1956-1986. The questions were designed to allow participants to freely share their experiences. The interview protocol contained questions examining their personal experiences with research in their respective communities.

The three-interview series model used in this study involved conducting three separate interviews with each participant (Seidman, 2013). A series of individual interviews were conducted and complemented by document analysis of elder perspectives on past research conducted in their respective communities. The interviews followed Diné protocols in combination with I.E. Seidman's three-part, 180-minute interview format that includes the following: A *focused life history, details of experience, and reflections on meaning.* Interview questions allowed participants to freely share their experiences and were conducted in Navajo and/or English, based on the participants' preference, and audiotaped. As a native Navajo speaker, I transcribed and translated the interviews.

Part one of the interview protocol centered on eliciting a *focused life history.* The interview probed into the participant's personal history as it relates to the study focus and research questions. During this interview, participants/elders were asked to share their personal stories, including their experiences with research studies. The second interview focused on *details of experience.* The purpose of this interview was to ask questions that elicit more detailed experiences with the topic of research. During this interview, I solicited participants' experiences with research in terms of research benefits, Diné sovereignty, and self-determination. The final interview was focused on *reflections on meaning.* During this interview, I asked participants to reflect on what their experiences mean to them personally in terms of the research questions (for a copy of the interview protocol, please refer to Appendix 1).

Interviews were conducted in Gallup, New Mexico. The consent process took place in Gallup, New Mexico and consent forms were obtained in person. At each stage

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participants were spoken to in their preferred language. For those participants who do not speak English, but prefer a written copy, a Navajo language form was provided. However, participants who were fluent Navajo speakers and did not read the Navajo language received an oral translation in the Diné (Navajo) language.

Interviews were used to answer research questions one and three. In order to answer research question two, archival research was needed. A series of collected and analyzed relevant research documents were obtained to support research during this time period. Research conducted on the Navajo Nation during the years of 1956-1986 was analyzed, including the Cornell Study, the "Many Farms Experiment," and the Rough Rock/Navajo Education Evaluation Study and Navajo Mental Health Case Studies. Specific studies analyzed were the "Health Experiment at Many Farms" in which the purpose of the *Navajo-Cornell Field Health Project* was to study discrete diseases and disease patterns in a non-technological society, and to develop methods to provide delivery of modern medical services to a community where health care was limited or non-existent (McDermott, Deuschle &Barnett, 1972). *Rough Rock/ Navajo Education Evaluation Study* such as Roessel's (1970, 1980) work on Navajo education and Linda Hadley's *Rough Rock Navajo Mental Health: Medicine Man Training Project Case Studies* (1982-1985) were also analyzed. Data collection occurred during a 10-month time period. All interviews took place in Gallup, New Mexico at an agreed upon quiet and private location and modest travel stipends were provided to participants to defray travel costs. At each stage of the interviews, participants spoke in their preferred languages of Diné or English.

Data Analysis

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Hsieh and Shannon (2005) indicate, "qualitative content analysis is defined as a research method for the subjective interpretation of the content of text data through a systematic classification process of coding and identifying themes or patterns" (p. 128). The analysis of research participants' interviews was designed in a series of a three-part interview process. The approach allowed the interviewer and participant to plumb the experience and to place it in context. The first interview established the context of the participants' experience. The second allowed participants to reconstruct the details of their experience within the context in which it occurs. And the third encouraged the participants to reflect on the meaning their experience holds for them (Schuman, 1982). The process of analysis included re-reading and analyzing, first, responses related to establishing rapport through introductions, family origin, and purpose of the study. The second part was analyzing and assigning codes to interview responses as well as anecdotal memos and researcher journal entries. Third, themes were created from the codes drawn from transcription and memos.

Data analysis was accomplished, in part, through the use of MAXQDA, a qualitative analysis software which allowed me to record audio of the interviews, develop themes, and code key words in the Diné language. This process provided me the opportunity to use key Diné terms as codes and identify each participant's experiences and cultural knowledge systems. MAXQDA was used to transcribe and code interviews, journal entries and anecdotal notes. As I completed this process, I began developing themes and codes and sub-coded areas that were closely related to each theme. "Emergent categories were used to organize and group codes into meaningful clusters"

(Hsieh & Shannon, 2005, p.1279). A descriptive coding method was used to analyze data (Saldaña, 2016). All coding was completed via MAXQDA in the Diné language.

Ethical Considerations

Institutional Review Board (IRB)

The Arizona State University Research and Ethics process began the week of June 2018. CITI Training was completed along with the IRB application on September 30, 2018. During this study, participants received information about the interview and consent was obtained. Interviews took place at a mutually agreed upon location that was accessible to both the interviewee and the interviewer (in Gallup, New Mexico). The in-depth interview questions selected are designed to allow participants to freely share their research experiences. The three-interview series model involves conducting three separate interviews with each participant. Each interview lasted approximately 90 minutes. The first interview is the Focused life history – eliciting the participant's personal history as it relates to the study focus and research questions. In this section, I asked participants/elders to share their personal stories, including their experiences with research studies. The second interview is the Details of experience – these questions sought to elicit more detailed experiences with the topic of research. In this section, I solicited participants' experiences with research in terms of research benefits, Diné sovereignty, and self-determination. The third and final interview is the Reflections on meaning ask participants to reflect on what their experiences mean to them personally in terms of the research questions (Appendix 1). With the permission of participants, interviews were audio recorded and transcribed. All data was stored on a password

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encrypted laptop stored daily in a locked office. Besides demographic information (age, sex, community), no other identifying information was collected.

Protection of identity and data

Identities of participants were kept anonymous using fictional names. Data was stored on a password protected laptop. All data was stored separately using an encrypted password at my locked home office. All participants signed an informed consent form (Appendix 2). Names of participants were never recorded nor attached to any data. A pseudonym replaced each participant's name. The consent forms were accessible through secure message encryption. Prior to digitalization, forms were transported within double locked containers until they were digitalized. Audio recordings were treated in the same manner as the consent forms.

Risks

Potential risks to the participants included discomfort in recounting their stories relating to their participation in research. It is possible participants felt slightly inconvenienced because of the time and travel spent responding to interviews.

Benefits

The potential benefits for individual participants participating or taking part in the research would be to receive an incentive or small traditional gift and to document historical and Indigenous knowledge for Diné people; community members and families.

Compensation

Due to the history of researchers taking Indigenous knowledge without compensation, an incentive was required for this research. Diné traditional gifting/offering protocols were utilized and included but were not limited to food,

ceremonial tobacco, honorarium (not to exceed $250/participant for all three interviews),

corn pollen, and/or cedar for smudging. The honorarium amount was determined

appropriate based on discussions with elders and was based on cost of travel and time.

Personal funds were used to compensate participants and/or supplemented with support

by Navajo Nation Dissertation Completion Scholarship.

Positionality

It was important for me, as a Diné person from these communities, to conduct this

research given my own personal connections with the elders in my community and my

status as a fluent speaker of the Navajo language. The elders who were interviewed and

who participated in past research are the knowledge keepers, cultural stewards, and

possessors of community, cultural, and tribal memory. This memory has historically been

transferred inter-generationally through oral storytelling. Since many elders are 70 plus

years of age and speak Navajo but younger generations do not[12] it is important to have a

Navajo speaking researcher conduct this study. Moreover, for younger generations, tribal

and cultural memory as well as traditional stories are not only transmitted through oral

storytelling but also through written records of these oral accounts. This study adds to

this growing body of work so that future generations can benefit from this knowledge.

Lastly, as a member of the community under investigation having grown up and worked

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[1] Navajo Human Rights Commission was established to collect data regarding discriminatory acts against citizens of the Navajo Nation by private citizens, businesses, organizations and foreign governments within and outside the Navajo Nation.

[2] According to Navajo Head Start, 97% are English speakers (NHS Home Language Survey, 2015).

in the area all my life, this positionality allowed the researcher to establish rapport, credibility, and accountability with the participants of the study.

Implications of Research

The findings of this study will be used to advance work or other initiatives including topics surrounding Indigenous research, IRB policies, practices and protocols, elder protection, sovereignty, self-determination and the protection of Indigenous knowledge systems. This doctoral research specifically focuses on the role of Diné sovereignty and self-determination in research for Indigenous elders from 1956-1986, a critical time period for Diné research occurring in the communities of Many Farms, Rough Rock, and Chinle areas. There are significant research studies conducted in the 30-year time period of 1956-1986 including Dermott's (1968) Cornell Study; "The Many Farms Experiment" (Platero, 1971), Rough Rock Demonstration School Erickson Study (Erickson and Schwartz, 1969), the Navajo Mental Health Project (Roessell, 1982) at Rough Rock Demonstration School, and other case studies documented by Linda Hadley (1980-1992). The prospective research covers past and present research practices as it applies to Indigenous epistemology and cultural protocols. Findings are used to inform a revised policy for the Navajo Nation Health and Human Review Board that considers Diné research epistemology that supports and promotes sovereignty and self-determination rights of our Diné people (presented in chapter 5).

As stated in the preface, research on elder protection and the role of tribal sovereignty and self-determination in Diné research and research methodology is limited. Few studies have explored the role of Indigenous epistemologies and protocol in research while almost no studies in the U.S. have examined the role of Native elders and cultural

knowledge keepers in research. Lastly, the impact of IRB processes on protecting the well-being and cultural knowledge of Indigenous communities remains to be explored.

I have mentioned elsewhere that research has been conducted in a manner that is not culturally respectful or congruent of Native communities, the jargon researchers use is almost impossible for the average Native person or participant to understand what is written or results, and the topics under investigation may not or interest or relevant for tribal communities. Thus, research has been conducted in the past without much input from the People. Even though there currently exists a NNHRRB, it is time to reclaim rhetorical and research sovereignty and guide research from a Diné philosophical perspective. Since it is unclear if the NNHRRB is based on Western research practices or Diné epistemological values and protocols, it is necessary to review NNHRRB procedures and make recommendations, informed by Diné elders and past research participants, for procedures that prioritize the well-being and cultural knowledges of participants, especially Diné elders, cultural advisors, and keepers of sacred and cultural knowledges in research. Lastly, this research is important to not repeat past protocol failures.

Findings from this historical research qualitative study describes the role of sovereignty and self-determination in Diné research and research methodology, specifically, it proposes a research approach that informs Diné epistemology and promotes protection for the well-being and cultural knowledge of Diné elders.

Study Significance

This study expands knowledge on the topic under investigation by presenting knowledge on research epistemology and methodology in the following ways: how it

may be used to protect Diné elders and cultural protectors and to develop a Diné theoretical model for research and elder knowledge protection. The study fundamentally benefits the field of Justice Studies through promoting rhetorical sovereignty (Lyons, 2000) – allowing Indigenous peoples to frame the parameters of the research conversation, and by presenting a framework that ensures Indigenous knowledges are protected from harmful, exploitative, or irrelevant research and by presenting a vision for tribal nations to prioritize tribal sovereignty and self-determination in research.

Currently research on elder protection and the role of tribal sovereignty and self-determination in Diné research and methodology is limited. Only four studies have examined the role of Native elders in research (Arolnith, 1994; Clemmer, 2011; Lee, 2014; NNHRRB, 2003; Schrag, 2006). Even though there exists an NNHRRB it's time to reclaim rhetorical and research sovereignty and guide research from a Diné philosophical perspective it is unclear if the IRB is based on Western research practices or Diné epistemological values and protocols. Therefore, it is necessary to review NNHRRB procedures and make recommendations, informed by Diné elders and past research participants, for procedures that prioritize the well-being and cultural knowledges of participants, especially Diné elders, cultural advisors, and keepers of sacred and cultural knowledges in research. Lastly, this research is important to not repeat past protocol failures.

This study also adds to the body of literature on Indigenous research methodologies by proposing a tribally specific methodological research approach that highlights the importance of intersectionality in research. The process of conducting critical research involves a process which surrounds an issue that is rooted in social

injustice with an attempt to create social change, while acknowledging the author's positionality (Miles, Huberman, & Saldana, 2014). CIRM emphasizes that research should not be conducted simply for the sake of conducting research, but to raise awareness an issue identified by an Indigenous community (Brayboy, Gould, Leonard, Roehl II & Solyom, 2012). The utilization of CIRM is guided by the elders to improve and benefit their communities through their Indigenous Knowledge systems and experiences.

Findings from this study are not only helpful to community elders and Indigenous researchers who may wish to engage in future research but can be used to inform the Navajo Nation Human Research Review Board (NNHRRB), the Diné nation's IRB, to recommend policies in ways that prioritize Diné sovereignty and self-determination. Study findings can help to inform general discussions about research on, by, and for Indigenous peoples in ways that will promote social change. Yet, most importantly and unexpectedly, this research inspired me to think about how Diné language, epistemologies, and gender intersect to inform a research methodology that is uniquely responsive to women of Diné Bikeyah.

Conclusion

The present study is needed because research practices and protocols have historically either had negative effects on Indigenous people or have not served their needs at all. Because research has been conducted in the past without much input from the People, research has disproportionately benefitted the individual researcher and/or organization (i.e. funding agency) other than Native peoples. The Navajo Nation has not been immune to this. Generations of forced colonized education and research plague

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Diné communities, denying our people their right to express original voice and knowledge systems in research.

Currently research on elder protection and the role of tribal sovereignty and self-determination in Diné research and methodology is limited. Only four studies have examined the role of Native elders in research (Arolnith, 1994; Clemmer, 2011; Lee, 2014; NNHRRB, 2003; Schrag, 2006). Even though there currently exists an NNHRRB it's time to reclaim rhetorical and research sovereignty and guide research from a Diné philosophical perspective it is unclear if the IRB is based on Western research practices or Diné epistemological values and protocols. Therefore, it is necessary to review NN HRRB procedures and make recommendations, informed by Diné elders and past research participants, for procedures that prioritize the well-being and cultural knowledges of participants, especially Diné elders, cultural advisors, and keepers of sacred and cultural knowledges in research. Lastly, this research is important to not repeat past protocol failures. It's time to reclaim rhetorical and research sovereignty and guide research from a Diné philosophical perspective.

This qualitative historical research study relied on archival data and in-depth interviews. A methodology that builds on Diné ways of knowing (in particular, SNBH) and more broadly, Critical Indigenous Race Methodology (CIRM) was used. These knowledge systems and methodologies are the most appropriate for understanding Diné epistemologies and ontologies. More specifically, the concept of Hozhó was also used to examine and decolonize current research practices and protocols.

Although I did not initially set out to do this, engaging in this study inspired me to develop a feminist Diné research methodology which I describe in more detail in the next

chapter. This theoretical framework begins with Sa'ąh Naaghái Bik'eh Hozhó (SNBH)—

a Navajo theory of long-life happiness (Lee, 2014, 2017) —and related Diné

philosophical/theoretical models. The concept of Hozhó—beauty, harmony, and peace

(Werito, 2014)—was also used to examine current research practices and protocols from

a decolonizing stance. I drew from the SNBH model while connecting it to existing

conversations about Critical Indigenous Research Methodologies (CIRM) (Brayboy et

al., 2012; Kovach, 2009; Smith, 2012). The latter comprises a theoretical, philosophical

methodological foundation for research based on the "4Rs"—relationality, respect,

reciprocity, and responsibility—with the ultimate goal of implementing research of

benefit to Indigenous communities.

In the past, Western theories have been used to study Indigenous peoples; there is

limited qualitative research on protecting elders and Indigenous knowledge systems that

uses Diné culturally specific models. By developing a Diné research protection model,

Nihoką́ą́' Diné Nidoolkah Bindii'ą' (Earth People Research Framework), Diné people are

better positioned to support existing NNHRRB and Diné human protection organizations

such as the Navajo Nation Human Rights Commission and the Office of Navajo Historic

Preservation which both serves as a forum to preserve and protect the Diné people and

their way of life.

The potential benefits for individual participants involved in this study was to

document historical Indigenous knowledge for Diné community members and families.

Diné traditional gifting/offering protocols were utilized and included a ceremonial

tobacco, honorarium, corn pollen, and cedar for smudging. Personal funds were used to

compensate participants. Due to the history of researchers taking Indigenous knowledge

without compensation, an incentive was required. The honorarium was determined to be appropriate based on discussions with elders and is based on cost of travel and time.

CHAPTER 2

SNBH: A DINÉ FEMINIST RESEARCH METHODOLOGY

This qualitative historical research study examines role of tribal sovereignty and

self-determination in research for Diné participants and elders from 1956-1986, a critical

period for research on the Navajo Nation. The study is further centered on research

conducted in three communities located in the heart of the Navajo Nation: Chinle, Many

Farms, and Rough Rock, Arizona and explores the following research questions: What

key research studies were conducted in the three focal communities during the period

1956-1986? What are the perspectives of Diné participants on research conducted in the

three focal communities during the period 1956-1986? What can we learn from past

research and the perspectives of Diné participants on the role of sovereignty and self-

determination in research for Diné peoples? The previous chapter provided an overview

of the study. This chapter presents a research methodology that is intersectional and

tribally specific for Diné Bikéyah. In the next few sections, I discuss conceptions of

research as it applies to research practices, Indigenous epistemologies, and the role of

elders as cultural knowledge keepers. Also discussed is the importance of gender, age,

and cultural protocols in conducting tribally specific, appropriate, and respectful research.

Findings from this study will be presented in chapter five as recommendations for the

Navajo Nation Human Research Review Board (NNHRRB) in advancing sovereignty

and self-determination for the Diné people.

Introduction

In the past, Western theories have been used to study Indigenous peoples. Yet

there is limited qualitative research on protecting elders and Indigenous knowledge

systems that uses Diné culturally specific models. Although I did not initially set out to do this, over the course of this study it became clear there is a need to develop a Diné research protection model to engage in research with Indigenous elders. In the next sections, I present the epistemological and methodological orientation used in the study including information regarding the methods, data collection, analysis procedures, as well as study significance.

First, I define the epistemological stance used, including considerations for the moral influence (axiology) of the study. This includes a discussion on understanding Western ontology as opposed to tribal worldviews and cosmos and presents considerations for understanding how the Diné episteme influences and guides this study and why that influence is necessary given the focus of the study. The discussion presented in this chapter aligns with existing conversations within the American Indian studies paradigm, Indigenous studies paradigm, and Western academic paradigm and how that shapes the selection of research methodology used when working with Indigenous peoples. Understanding colonialism and how colonization works is important for understanding my choice of using Indigenous research methods and approaches.

History of research with Native communities

Epistemology refers to the nature of knowledge (what you know) while ontology refers to how knowledge is acquired (how you know what you know). For Indigenous people, epistemology is generally grounded in the belief that all things are related, there is a strong connection between history and the universe, and a commitment to what Barnhardt and Kawagley (1995) refer to as the four R's: reciprocity, responsibility, respect, and relationships. I have already covered relationships (the idea everything is

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connected, both physical world and non-physical world). Respect refers to honoring

community protocols, the rights of people, land, and animals. Responsibility recognizes

that the researcher is not operating as an individual but should be accountable to the

community and all their relations – living and those that have passed on. Finally,

reciprocity states that a researcher is responsible for sharing the information taken and

has to give something back (they can't take without giving). Lastly, Indigenous

epistemology is place-based, can be language-based, and focused on honoring cultural

known systems. Figure 1 below shows how the four R's align with Diné concepts and

epistemology.

Figure 1
Four R's: Reciprocity, Responsibility, Respect, and Relationships. I have already covered
relationships (the idea everything is connected, both physical world and non-physical
world).
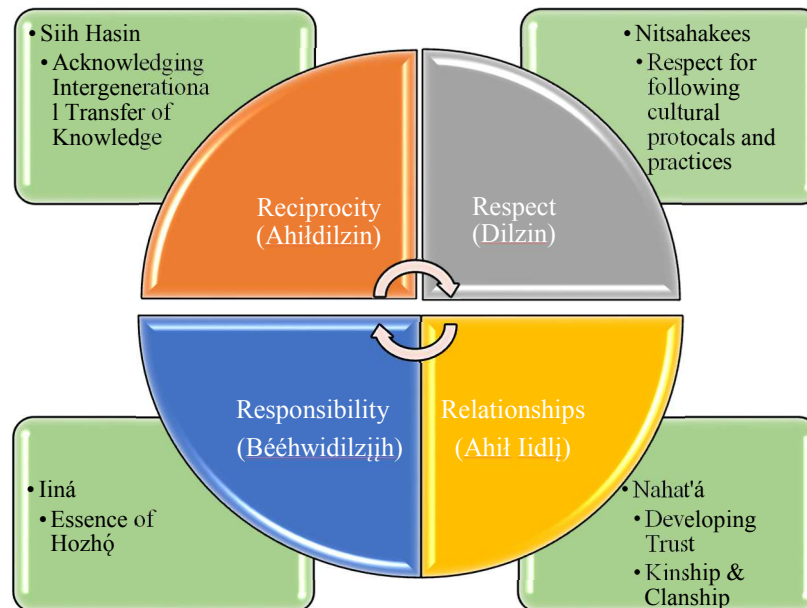
In many Indigenous communities, cultural knowledge keepers are the catalyst for

historical knowledge, cultural traditions, and traditional storytelling. For most Indigenous

communities, elders are the cultural and spiritual advisors. From an Indigenous perspective ontology requires the researcher to engage and develop relationships with elders, the community, land, and people.

Both Western and Indigenous research methodologies have their own respective methods. Popular methods from the Western approach include, observing data quantitatively and qualitatively. Measuring variables, manipulating conditions, interviewing, and collecting written documents. Some of these data collection methods are also used in Indigenous research. However, Indigenous research may focus more on storytelling, songs, stories, talking circles, art, music, spiritual ceremonies, even dreams can serve as sources of data (e.g. vision quests). Elders also play an important role in Indigenous ontology as they are not only the cultural knowledge keepers within Indigenous communities, they provide the voice for historical knowledge and traditions and facilitate the ceremonies, songs, stories, and protocols necessary to transfer that knowledge.

The core values, beliefs, practices and protocols of Indigenous people need to be discussed from an Indigenous perspective to provide validity of knowledge systems for the simple purpose of documenting history and understanding the true past of Native people. Smith (2012) and Barnhardt (2008) offer an Indigenous methodology framework for developing and strengthening Indigenous knowledge systems in the realm of research based on Indigenous epistemologies and values. More importantly, scholars such as Brayboy (2005), Smith (2012), Barnhardt (2008), Lyons (2000), and Deloria (2008) have set the "terms of the debate" for discussing the importance of Indigenous research in the context of rhetorical sovereignty. These scholars have accomplished this by illustrating

how Western epistemologies and pedagogies regularly silence Native voices and promote colonization through methods that dismiss and devalue the knowledges of Indigenous peoples.

To combat this, they present frameworks and rhetoric, to be used by Indigenous scholars, for ways to reassert and reclaim our voices, practices, and power in research and the academy. More importantly their work provides recommendations for how to centralize a voice for Indigenous communities and defy social injustices that seek to marginalize our "silent" cultural keepers of knowledge. Noted Indigenous scholars such as Linda Tuhiwai Smith (2012) support research as an important aspect of academic investigation as a process and points to the need to conduct research in an effort that decolonizes our way of thinking in a colonized world.

Theoretical and Philosophical Foundation

In order to engage in Indigenous research, a culturally and place-specific research protocol and methodology may be needed. To date, no universal Diné research methodology exists. However, Diné peoples have a wealth of theoretical frameworks that can inform a research methodology, including, focus on Sa'ąh Naaghái Bik'eh Hózhǫ́ (SNBH)—a Navajo theory of long-life happiness (seLee, 2014, 2017) —and related Diné philosophical/theoretical models. Before explaining the SNBH framework, it is important to examine, first, the concept of Hozhǫ́—beauty, harmony, and peace (Werito, 2014). I draw from the SNBH model while connecting Critical Indigenous Research Methodologies (CIRM) (Brayboy et al., 2012; Kovach, 2009; Smith, 2012). The latter comprise a theoretical, philosophical methodological foundation for research based on

the "4Rs"—relationality, respect, reciprocity, and responsibility—with the ultimate goal of implementing research of benefit to Indigenous communities.

Critical Indigenous Research Methodologies (CIRM) is an approach to conducting research that emphasizes the Indigenous way of life that is interconnected with all living beings in the universe (Steinhauer, 2002). Critical Indigenous Research Methodologies "can be defined as research by and for Indigenous people" (p. 2). The definition ensures CIRM includes historical knowledge systems with a focus on "relating and of sharing knowledge" (Denzin, Lincoln, & Smith, 2008). It is the intention to critically document Indigenous-based research and practices for future generations.

This study was designed from a CIRM approach using an Indigenous Knowledges, specifically a Diné Knowledges, Paradigm. The paradigmatic approach in relation to Indigenous methodologies means that particular research approaches must flow from an Indigenous belief system that at its core centers a relational understanding and accountability to the world (Kovach, 2010; Wilson, 2001). In this Indigenous Research Methodologies Framework, relationality, respect, reciprocity and responsibility are the guiding principles to promote the Indigenous people's right to self-determination and their inherent sovereignty rights (Smith, 2012). The overall research will reveal an Indigenous commitment to research for the community and by the community from a Diné woman's perspective.

Indigenous Knowledge Systems

Indigenous Knowledge Systems (IKS) are traditional systems to help researchers organize traditional knowledge in research practices. IKS is Indigenous cultural traditional knowledge, or ways of knowing, that is based upon life-long learning of

Indigenous culture, language, and values and, in many cases, is tribally specific. IKS is

acquired intergenerationally and interpersonally through storytelling, ceremonies, and

creation stories. While IKS is pan-Indigenous, and rightfully so, as many Indigenous

communities may share similar values and beliefs, a tribally specific set of knowledges

must also be acknowledged.

Diné Knowledge Systems.

Diné Knowledge Systems (DKS) is a way of life, balance and harmony for the

Diné people with the universe. DKS consists of values, traditions and teachings from

elders from previous generations through hane', tsodizin, and náhaghá. The Diné

language is key to acquiring and maintaining DKS. In the following sections, Critical

Indigenous Research Methodologies will be used, in combination with DKS, to discuss

how Diné peoples acquire knowledge through an epistemological process.

Figure 2
The terms Diné ontology, epistemology, axiology and methodology refer and correlate to
the four cardinal directions of SNBH. Together these concepts form a sophisticated and
unifying way of thinking that requires the presence of an individual's entire body (mind,
spirit, physical) *and* the community's body (people, environment, spirit).
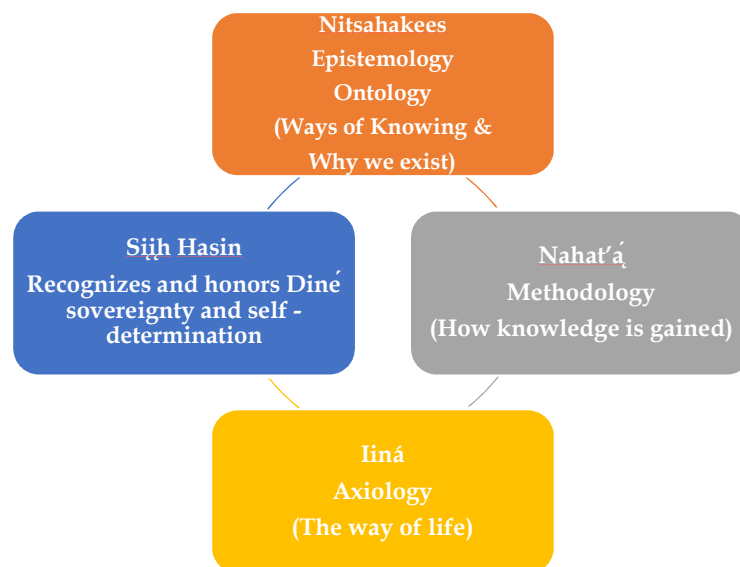
Indigenous research

While IKS and DKS inform ways of knowing and understanding the world,

Indigenous research is a way of *investigating*, *engaging*, *analyzing*, and *reporting*

research through the lens of culturally appropriate values, knowledges, goals, and

practices. In order to accomplish this, much of Indigenous research necessitates the

participation of elders or cultural knowledge keepers. Indigenous ways of understanding

the world in which Indigenous people exist explains a thought process and relationship to

the universe. Indigenous research methodologies encompass four elements: ontology

(nature of reality), epistemology (nature of thinking or thought), methodology (how

knowledge is gained) and axiology (ethics and morals) which guide the research process

(Diab & Wilson, 2008). It is the intention of CIRM to honor past cultural practices and

historical knowledge through interviews and stories of local elders. Diné Knowledge

Systems also inform research methodology while aligning to cultural protocols and

practices in a Diné specific manner. In a broad sense, Indigenous people have an

interconnectedness to the universe and the framework of Sa'ąh Naaghái Bik'eh Hózhǫ́ǫ́n

will further define the concept of Hozhǫ́ as a research model and inform appropriate

research practices and protocols.

Figure 3
Indigenous research is a way of *investigating*, *engaging*, *analyzing*, and *reporting*
research through the lens of culturally appropriate values, knowledges, goals, and
practices.

Investigating

Reporting

Engaging

Analyzing

Cultural Values

Practices

Knowledge

Goals
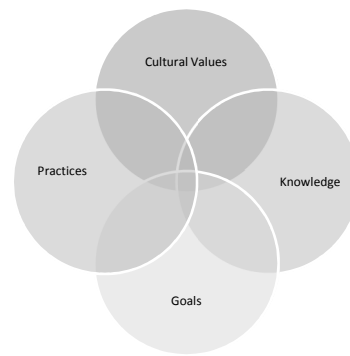
How SNBH helps shape Diné worldview, sense of wonder, and investigation?

Sa'ąh Naaghái Bik'eh Hózhóón exemplifies the way Diné people live their lives (Lee, 2014). Rex Lee Jim (2000) stated that the term literally means, "May I walk, being the omnipresent beauty created by the one that moves beyond old age" (p. 232), and provides a breakdown of each word: "Sa means old age, ah means beyond, naa means environment, ghai means movement, bi means to it, K'eh means according, ho means self and that sense of an ever-presence of something greater, zhóón means beauty" (p. 232). In short, Sa'ąh Naaghái Bik'eh Hózhóón serves as both an epistemology, ontology, axiology, and methodology.

Werito (2014) expressed that Sa'ąh Naaghái Bik'eh Hózhóón is part of who you are, and it becomes a way of life.

> For Diné people or Nihoką́ą' Diyin Diné'é (five-fingered Earth-surface spiritual beings) Sa'ąh Naaghái Bik'eh Hózhóón is who we are: it is part of our thought processes and everyday lives. Sa'ąh Naaghái Bik'eh Hózhóón is what we strive for, hope for and pray for, because we believe that its essence and meaning lie at the base of our language and cultural identity and traditional cultural knowledge and teachings (p. 26).

SNBH does not treat epistemology, ontology, axiology, and methodology as separate and discrete things but sees them all in relation and as interrelated; SNBH is more than methodology it is also an analytical lens.

Intersectionality in research methodology

Of import, is acknowledging and understanding the gendered aspects of knowledge and knowing. According to the Diné Creation Story, Antes Hasting (First Man) and Antes Asdzą́ą́n (First Woman) were made from male and female corn and eagle plumes. Thus, the philosophy of Są'áh Naagháí Bik'eh Hózhóón has male and female constructs within the phrase (Benally, 1994). Sa'ą́h Naagháí has the male characteristics of "indestructible and eternal being," and Bik'eh Hózhǫ́ǫ́n exhibits female characteristics of "the director and cause of all that is good" (Benally, 1994, p. 24). The principle is the Diné traditional living system that positions the Navajo within the natural world and universe (House, 2005). Sa'ą́h Naagháí Bik'eh Hózhǫ́ǫ́n is a framework that puts the Diné universe in the center of our way of knowing about the world and is a natural process that established the four sacred mountains (Sisnáajini, Tsoodził, Dóók'o'oosłííd, and Dibé Ntsáá), four cardinal directions (Ha'á'ą́ą́h, Shadí'ą́ą́h, E'é'ą́ą́h, Náhookǫs), and all symbolic elements.

Sa'ą́h Naagháí Bik'eh Hózhǫ́ǫ́n also embodies the four planning and learning approaches to life (Lee, 2014). It is a process consisting of Nitsahakees (thinking), Nahat'á (planning), Iiná (life), and Sįįh hasin (assurance) that are applied to the individual and community in keeping balance with the traditional way of life (Lee, 2014). The process of (nitsahakees, nahat'á, iiná, and sįįh hasin) are approaches that will be applied to both the Western and Diné research process, which are further explained

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throughout this dissertation. SNBH will frame the narrative for establishing a research protocol that is sensitive to the protection of elders and to the cultural knowledge systems.

The terms Diné ontology, epistemology, axiology and methodology refer and correlate to the four cardinal directions of SNBH in the following manner. Nitsahakees refers to ontology and epistemology; nahat'á refers to methodology; and iiná refers to axiology. However, sįih hasin adds something more. Sįih hasin reminds us of the importance of "giving back" and recognizes and honors Diné sovereignty, self-determination, and nation-building. Together these concepts form a sophisticated and unifying way of thinking that requires the presence of an individual's entire body (mind, spirit, physical) *and* the community's body (people, environment, spirit).

Hozhǫ́ is a term often used by Diné people and means a state of harmony. Depending on the context, Hozhǫ́ can be applied to Diné critical theory and thought by explaining the interpretation of hozhǫ́ as a key philosophical aspect of Diné philosophy (Werito, 2014). In the Navajo thought process, Hozhǫ́ is part of daily life, and the state of harmony is what the Diné people seek for holistic thought and life (Werito, 2014). SNBH guides the Navajo thought and philosophical process of life and balance, resulting in a state of Hozhǫ́. A Diné critical theory model is rooted from an ontological and epistemological realm of Diné philosophy, Diné intellectual traditions, and Tribal Critical Race Theory. The interconnectedness of the three principles guide a model that offers Diné research methodology from a Diné paradigm that acknowledges both the history of colonialism and a Diné philosophical framework.

Defining and exercising appropriate cultural research protocols involves establishing relationships with members of the community and knowing the ways of the people and the community. Maintaining Hozhǫ́ throughout the process of research is critical in understanding the community and traditions of Indigenous people. In the Diné belief system, the practice of Hozhǫ́ is not only essential, but an important aspect of understanding and establishing relationships with the people and the universe. Diab & Wilson (2008) suggest research methodologies go beyond oriented ways of engaging the world and recognize the importance of relational protocols and responsibilities as researchers.

The present study supports Critical Indigenous Research Methodologies (CIRM) through the validation of the Diné knowledge system of SNBH. CIRM is also used to establish a framework for a Diné Research Protection Model, Nihookáá' Diné Nidoolkah Bindii'ą' (Earth People Research Framework). The important principles of Navajo epistemology and ontology in regard to the Diné belief systems will be utilized as a guide for discussions and recommendations for a research protocol that protects Diné knowledge systems. The use of CIRM supports the decolonization of Western research practices by learning from past research and the perspectives of Diné participants on the role of sovereignty and self-determination in research for Diné peoples. It is the intention of the dissertation to use Diné philosophy to inform a research methodology that aligns with cultural protocols and practices. More importantly, Indigenous research, specifically Diné research inspires the need for Tribal Institutional Review Boards to protect elders and their knowledge systems.

Figure 4

Findings of this study inform an Indigenous elder knowledge protection model (i.e. Nihooką́ą́' Diné Nidoolkah Bindii'ą') to support existing Diné tribal IRB protocols and policies and provides additional insight for tribal cultural protection organizations.

Indigenous Feminism

Diné Research Practices and Protocols

Indigenous Research Methodologies

Indigenous Knowledge Systems
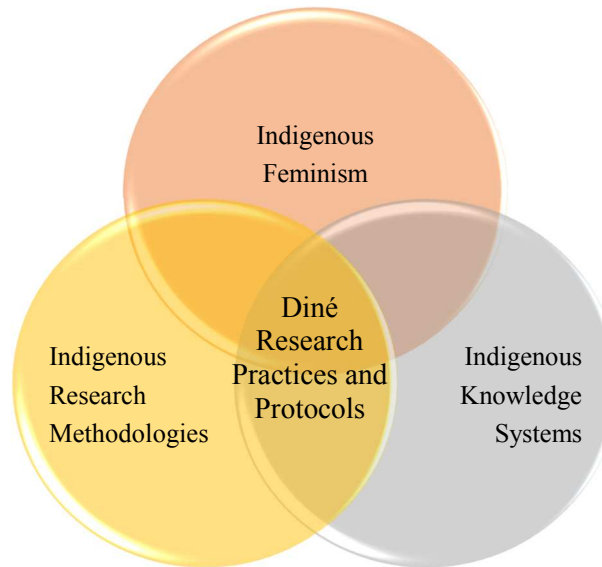
Need for this study

This research process flows from a sense of place that provides a protocol (a framework) to build respect and relationship with the community that is being researched (Lambert, 2014). The data are acquired through observations, dreams, life experiences, storytelling, and traditional rituals which inform the researcher memos. The researcher becomes part of the study because the data that is collected includes some of the researcher's most personal experiences, and the work created from the research is used to help the community. When relationships are established with an Indigenous community and the researcher acquires certain tribal knowledge he or she is seeking, it is crucial that the researcher is held accountable by advocating for the community.

Critical Indigenous research methodologies guide this research. Tribal race theories work on the ethic that methodology is working toward social change and

improving current reality through understanding of a phenomena. It is important to understand Indigenous knowledge systems address the interconnectedness of all things and are premised on relational and accountability concepts. Approaching research from this perspective necessitates asking yourself: what are my obligations in this study? How am I fulfilling my role in this relationship? How will I be accountable to all my relations and stakeholders?

Why does this research use so much of the Diné language?

As Nihooką́ą́' Diné'é, we were given the gift of our language from our holy deities. Through generations, the Diné have prospered as a people. "A language is, in fact, the repository of the intellectual wealth of a culture, the product of intellectual labor on the part of a people who speak those languages" (Arnold, 1989, p.46). More recently, in the last century, our Indigenous languages have protected our lands and democracy. We have won world wars with our sacred Diné language. The Navajo Code Talkers were instrumental in developing an unbreakable code that resulted in United States victory during WWII.

Colonization has plagued our Indigenous nations for hundreds of years and our nations continue to be oppressed from White society. For decades, colonial education has sought to mitigate the survival of Indigenous languages and cultures. As a result of colonization, particularly after the turn of the century, Diné people were forced to confront assimilation practices, resulting in language loss. The boarding and off-reservation vocational schools prohibited Diné children the usage of their mother tongue. Today the remnants of fluent Diné speakers is scarce. As a researcher I witnessed significant language barriers between generations in the three communities I worked

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with. The elders involved in this study were willing to share their stories and experiences for future generations. It was evident there was a need to share stories of their life experiences while attempting to revitalize and maintain the Diné language.

"Indigenous inquiry involves specific multi-layered preparations, clarifying the inquiry purpose, requiring attention to culture in an active, grounded way" (Kovach, 2009). As I reflect on my personal educational research journey, I first, embrace the opportunity to be taught and supported by a prestigious group of scholars. As a Diné woman, mother, grandmother and researcher, I am grounded. At a young age, I was taught the value of respect. I respect who I am and where I come from. For example, acknowledging my existence through my four clans' grounds me as a member of my people by honoring my ancestors and those who came before me.

In order to engage in research, I must acknowledge my journey begins with who I am…a Diné asdzaan from the Kinyaa'áanii clan and born for the Ta'neeszahnii clan, maternal grandparents from the To'áhaní and paternal grandparent of the Ma'iideeshgiizhníí clan. Raised in remote and rural communities of Fort Defiance, Rough Rock, and Kits'ilii, Arizona on the Navajo Nation. Nearly half a century ago, I was brought into a world with two English speaking parents whom were both survivors of the Boarding School era. My mother attended a Catholic Boarding School and my father attended an off-reservation boarding school in Anadarko, Oklahoma; creating an English-only learning and home environment.

The historical traumatic experiences of the religious and boarding schools set the overall educational values for their children including harsh disciplinary practices, language acquisition, and the assimilation to Christianity and dominant culture while at

the same time perpetuating the denial of Diné language and culture. This history of linguistic colonization has been exploited by Western researchers who choose to communicate with confusing jargon and in English to communities who are still struggling with the results of this language colonization.

At the earliest age of development, my first environment was living in a three-bedroom mobile home with all the modern amenities such as a television, stereo, washer/driver, telephone, electricity and running water. My daily routine was watching television shows such as *Mister Roger's Neighborhood*, *Captain Kangaroo* and world news with Walter Cronkite. Unlike many children my age, I was gifted my own encyclopedia collection, *Child Craft*, along with the *Highlights* magazine. My parents' decision to expose their children to an English-only environment was the best decision at the time.

My formative years were spent at a local Presbyterian mission pre-school and, from kindergarten to third grade at St. Michael Indian School. With a white shirt and red, black and white plaid skirt, ponytail, and black 'Mary-Jane' shoes, I was immersed into an English-only, Catholic school learning environment. My first books were the *Dick and Jane* series, penmanship, reciting the Lord's Prayer and attending Church services every morning and learning the Ten Commandments was a part of my everyday routine. Much like those who came before me and survived the boarding school experience, corporal punishment was a form of discipline with the Sisters of the Blessed Sacrament. The English language was the only language I heard or used for the first eight years of my childhood.

At the age of eight years, my first few weeks in the fourth grade, I had a sudden life changing experience, my family was about to relocate to a remote area of the Navajo Nation, Rough Rock, Arizona. I was to be enrolled at a local bilingual-bicultural community school – Rough Rock Demonstration School. I recall my first day of school as feeling different and foreign. I understood I was about to be immersed into a community and school that I was unfamiliar with. I felt like a stranger in a strange community.

Reflecting on my educational experience, I realize now that I was a second language learner of my own native language which was a reversal of my parents learning experiences. The initial goal for me at this age was to quickly learn the Diné language and culture, so I could communicate with my classmates and community members. Adjusting to this new world of language and culture was difficult and challenging

My first years at Rough Rock Demonstration School were spent listening and observing instruction in the Diné language. Soon after, I realized, I learned language, and in turn, more deeply about Diné epistemology, through experiences using movement with my five senses. I acquired the Navajo language through a Total Physical Response (TPR) approach to second language learning (Asher, 1969). An important aspect of surviving has been the ability for Indigenous people to listen with more than just our ears; we engage in listening through sight, touch and smell (Brayboy, Gough, Leonard, Roehl II, & Solyom, 2012).

Learning a new language also meant living in a different environment with no amenities, including no plumbing or electricity. Meals were prepared on a wood-burning stove, water was pumped from the local well, and heat was obtained from a firewood

stove. Our primary source of food was locally grown corn, potatoes, and melons. Mutton and beef were the main source of protein along with tortilla, frybread, and an array of blue corn dishes.

My responsibilities as a member of the household soon took shape into farming, raising sheep and goats, and maintaining household chores. I was soon to be transformed into a Diné woman learning an Indigenous way of life which ultimately defies who I was training to be as an Indigenous researcher through my Western education. In some ways, this upbringing also helped me establish rapport with study participants as I was able to demonstrate intimate knowledge of their living conditions and life philosophies. This personal story offers authenticity and is integral to understanding my approach to knowledge construction (Kovach, 2009).

Reflecting on these experiences during this research process made me realize I needed a methodological research approach that addressed some of these complexities. I slowly came to realize these experiences inform my research approach when working with elders from this community. I began to ask myself, for those interested in conducting research with and for members of my community, how does not knowing about the protocols and lessons I was exposed to potentially harm or limit research? How might it harm or limit the collection of data and its analysis? I remembered how important it was for my grandmother to bring food – and particular types of food – when visiting research participants and began to realize that the acquisition of knowledge sometimes happens when we break bread. When we follow protocol. When we are home.

Speaking and writing in Diné is an act of defiance. It is an act of survival. It is an act of survivance. As history demonstrates colonial education schooling for Indigenous

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peoples came in two basic forms: missionary or religious schooling (Smith, 2012). In a previous discussion, I shared my religious schooling experiences. Acquiring Indigenous knowledge from any formal schooling was excluded in my early formative years of language and culture development.

Although subtle, the intent of religious schools was to extinguish and remove the Indigenous roots from a people who roamed the lands for centuries. Forms of discipline were mandated by a colonized and paternalistic society. Unfortunately, the established religious schools had detrimental effects on the Diné people; especially linguistically and culturally. The generations that preceded me were forced to contend with a colonialized and assimilative form of education denying my family of their original place in Diné society, a life of tradition, culture and language.

Smith, (2012), acknowledges the suppression of Indigenous knowledge systems and offers recommendations of reclaiming and reconnecting one's place in Indigenous society. It is critically important for researchers, community leaders, and community elders to reclaim Diné Knowledge Systems as a research methodology to guide our practices and to honor the past and those who have gone before us; and for our future children. If cultural and language connections are not made with the elders, communities such as Rough Rock, Many Farms and Chinle will be at risk of forfeiting their culture to a colonized way of life.

A recent statistical analysis was documented among young children in the Navajo Head Start program. The results are stark and unparallel. In 1966, 99% of Navajo Head Start children spoke the Dine language. In 2016, only .009 % of Navajo Head Start children speak the Diné language (Home Language Survey, NHS 2016). In other words,

within a 50-year time period, the Diné language has become an endangered language on the Navajo Nation. The statistics are concerning since, according to recent linguistic scholars, "communities who have two generations of non-language speakers are at risk of losing their community language system" (Hinton, 2001). Most importantly, in this research, I learned how important the role of language is for knowledge acquisition. Were it not for my own ability to speak the Navajo language and understand the ceremonies, cultural teachings, and references to land and life the elders shared during their interviews, important context and meaning could have been lost or overseen. If we are to document the history of our people and use their teachings and experiences to guide future generations, it is important to understand and speak their language. To feel what they feel and know what the know.

SNBH as a research paradigm

Incorporating a Diné philosophy in research allows for a research methodology that aligns with cultural protocols and practices through a theoretical framework that is relevant for Indigenous communities. I further recommend research in, with, and for Indigenous people, specifically, the Diné people be driven by the concept of Sạ'áh Naagháí Bik'eh Hózhǫ́ǫn. Robert McPherson (2012) discusses how "Diné bigarade (Navajo language) establishes the epistemologies and conveys the knowledge of the people." In order to understand the framework of SNBH, one must understand the cultural oral history and tradition of Diné people.

As retold by traditional medicine people and "cultural knowledge keepers" the Navajo Creation Story provides a foundation of the origin of Sạ'áh Naagháí Bik'eh Hózhóón and how "supernatural beings" emerged from First Man's medicine bundle. The

two "Beings" emerged were: a male known as Sạ'áh Naagháí literally translates to "long life' in which thought was embedded. The next "Being" to emerge was the female, Bike'h Hozhó, literally translated as "happiness." Sạ'áh Naagháí undergirds the Navajo conceptualization of place and earth knowledge (Lee, 2014). In order to understand the lives, wellbeing, values, and goals of the Diné peoples one must understand that the goal of Navajo life is to live to maturity in *Hozhó* and to die of old age, the end result, incorporating one into universal beauty of harmony and happiness (Iverson, 1998).

These Diné principles help us to rethink or reframe research methodology and methods through honoring our history, language, cultural practices and protocols. By acknowledging our elders and those who have come before (supernatural beings or our holy deities) our Diné people can regain and protect our Diné knowledge systems and carry them forward for future generations in ways that are respectful and appropriate. Researchers in general can benefit from Indigenous research and knowledges through first being accountable to the community, the People, the land, and universe. SNBH reminds us it is important to honor all of these by making offerings to these entities. Moreover, researchers need to formally ask for permission to conduct their studies. However, permissions should not be limited to formal organizations such as IRBs but rather to the environment, the community, elders, and the holy deities.

Second, SNBH suggests it is important to participate in a culturally responsive training that includes understanding the community, the People, and their way of life. Allowing the community to review and understand the purpose of the study and how the data will be used is important. Because elders may speak the traditional language, having

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appropriate, experienced, and trusted language translators is necessary so that they can understand the context and full meaning, as well as implications, of the study.

Lastly, the benefits of the study need to be determined by the community. The oral histories of Diné people rely on historical and philosophical perspectives to build on established frameworks such as Sạ'áh Naagháí Bik'eh Hozhǫ́ and incorporate Diné thought process in the structure and approach of academic research, more specifically, in protecting the elders and "cultural knowledge keepers" of the Diné Nation. Guided by Critical Indigenous Research Methodologies, a body of research largely by Indigenous scholars that outlines culturally respectful and responsive research practices for working with/in Indigenous communities, an SNBH methodology could help to "reclaim research and knowledge-making practices driven by Indigenous people, knowledge, beliefs and practices, rooted in recognition of the impact of Eurocentric culture on history, belief and practice of Indigenous people and communities and guided by the intention of promoting anticolonial or emancipatory interests of Indigenous people" (Brayboy, 2005).

For over a hundred years, Native Americans led the fight to justice. However, history of Indian people has always been told from a "Eurocentric" perspective. Diné people, specifically our "cultural and historical keepers of knowledge," have been silenced for over a century and used to promote the interests of researchers who do not belong or stay in our communities. It is the intention of this research study to reclaim our history and stories of our Diné people and to acknowledge and learn from past failures and establish a research protocol that embraces our history and stories from elders and our keepers of history of knowledge.

Toward a Diné feminist research methodology

An intersectional theory and practice of feminism that focuses on decolonization and Indigenous sovereignty is an important component of this study. Understanding decolonization is a space for aspiration, recalibration of how we think, and what we know, is key. Exercising and embracing our Indigenous sovereignty as researchers provides the context to center cultural values and the empowerment of Indigenous women in the research process.

"Indigenous feminism aims to maintain Indigenous equality of status, self-determination and sovereignty" (Waters, 2000). The role of feminism within Indigenous communities empowers Indigenous women in the context of cultural values, encompassing their voices and perspectives from an Indigenous theoretical and practical paradigm that connects gender to decolonization and sovereignty in an Indigenous context. More specifically, within a Diné Knowledge System framework of SNBH, I define feminism from a Diné paradigm known as Bik'eh Hózhóón Nitsahakees Bindii'a'.

Diné oral traditions, including creation stories, have survived 500 years of conquest. Diné traditional oral traditions inform a Diné paradigm. Jennifer Denetdale (2007) explains "decolonizing research is about centering Indigenous worldviews and articulating theory about research from our own perspectives and for our own purposes" a (p.45). A Diné paradigm of BHNB acknowledges and honors Diné worldviews and acknowledges patriarchy as a form of lateral oppression – a patriarchal belief system that condemns Indigenous women as not enough or less than our male counterparts. Again, the history of colonization has shifted the dynamics of leadership and the acknowledgement of who holds and can create knowledge in some communities.

After colonial contact, the Diné people transformed from a matriarchal society to a patriarchal society. The changes in organizational systems created systemic norms for many Indigenous nations, including the Diné Nation, that silenced or demoted the powerful voices, minds, spirits, and potential of women. It is time to hold patriarchy accountable both inside and outside Indian Nations. As we go through the process of accountability, Indigenous women will be validated as sacred and reclaim the honor, respect and authority that is instilled in the many kinship systems and creation stories, and philosophical frameworks such as SNBH.

Conclusion

Because research from the Western perspective has been conducted in the past without much input from the People, research has disproportionately benefitted the individual researcher and/or organization (i.e. funding agency) more than Native peoples. The Navajo Nation has not been immune to this. Generations of forced colonized education and research plague Diné communities, denying our people their right to express original voice and knowledge systems in research. Currently in research, the role of tribal sovereignty and self-determination research is limited. The body of research on the role of Diné epistemologies and protocol in research is small but growing and only four studies have examined the role of Diné elders in research (Arolnith, 1994; Clemmer, 2011; Lee, 2014; Schrag, 2006).

For Diné research and Indigenous research more generally the intention is to produce research knowledge that "documents social injustice, that recovers subjugated knowledges, that helps create spaces for the voices of the silenced to be expressed and 'listened to,' and that challenges racism, colonialism and oppression..." (Smith, 2012, p.

198). Therefore, Indigenous research encompasses a political focus or political outcomes. At this stage, Smith (2012), acknowledges the significance of Indigenous perspectives on research and attempts to account for how, and why, such perspectives may have developed. As an Indigenous researcher, the use of a decolonization framework can allow elders to reclaim Indigenous thought, knowledge, and identity. Research for and by Indigenous researchers allow for Native people to accurately depict historical knowledge, cultural traditions and practices.

The next chapter applies this methodology in an exploration of the following research questions: What key research studies were conducted in the three focal communities during the period 1956-1986? What was the purpose of these studies? How did Diné participate in the studies? What was the researchers' role in relation to Diné participants? Whose interests did the studies represent. Who benefited from the research?

CHAPTER 3 (BOOK CHAPTER)

RESEARCH ON DINÉ BIKÉYAH FROM 1956-1986

The History of Research of Indigenous Peoples

This chapter explores the following research questions: What key research studies were conducted in the three focal communities during the period 1956-1986? What was the purpose of these studies? How did Diné participate in the studies? What was the researchers' role in relation to Diné participants? Whose interests did the studies represent. (Who benefited from the research?)

Introduction

Research is defined as the systematic investigation into and study of materials and sources in order to establish facts and reach new conclusions (Oxford Dictionary, 2017). From a Western perspective, when it comes to Indigenous people, research has been undertaken in a way that promotes colonial beliefs about Native people. Deloria (1969) perpetrates the discussion on Indigenous research and argues the way in which Native research has been addressed to, with, and by anthropologists. For decades, Indigenous people have been the object of stereotypes and prejudicial observations. "The fundamental thesis of the anthropologist is that people are objects for observations, people are the considered objects for experimentation, for manipulation, and for the eventual extinction" (Deloria, 1969, p. 82). Research conducted among Native people have been superficial and negate from telling the true history of the people, land and knowledge. "Over the years anthropologists have succeeded in burying Indian communities so completely beneath the mass of irrelevant information that the total

impact of the scholarly community on Indian people has become one of simple authority" (Deloria, 1969, p.82).

According to Deloria (1999), "race has been the primary criteria in gathering and determining data about Indians" (p. 19). Western research has pushed the belief that only White scholars can observe phenomena objectively. In other words, data was observed through "culturally prescribed categories that restrict the possible answers and understandings to a predetermined few selections" (p. 18). This helped perpetuate racist beliefs about Native Americans and limited Western knowledge, placing White scientists as the expert on Native people rather than Native people themselves.

Colonization is a practice of domination, which involves the subjugation of one people to another. Western research promotes intellectual and physical colonization by allowing white researchers that enter Indigenous communities and considering them an expert on those communities once they leave. This practice leads to cultural imperialism in research and threatens the livelihood of Indigenous people by exploiting them, their lands, and their knowledge systems.

Both Deloria (1969) and Smith (2012) have highlighted three main concerns regarding Western research. First, research has been conducted in a way that is culturally irrelevant or disrespectful to Native communities. Second, the methodology used in research is not 'Native friendly' and is almost impossible for an average Native person or participant to understand research terminology or the results of research. Third, the topics under investigation may not be of interest or desire for the community to have the research conducted. Therefore, research is limited in how useful it is for Indigenous communities. Nevertheless, Smith (2012), acknowledges the suppression of Indigenous

knowledge systems and offers recommendation for Indigenous scholars to reclaim, reconnect, and realign their research practices within Indigenous societies. Smith argues that by following research practices that are informed by cultural protocols, academic research can be made useful for Indigenous people.

Cook-Lynn (2018) brings forth the concept "history, myth, identity," the power of storytelling. This dissertation will weave traditional Diné teachings throughout the explanation and philosophical formulations of Diné research. The purpose of storytelling especially that storytelling that tells one generation of listeners what the previous generation has come to know through the long tenancy of the tribe in a specific geography. In the case, Indigenous storytelling is a powerful tool of translating traditional/philosophical teachings.

Research Site 1: The Navajo-Cornell Field Health Project (1957-1962)

The Navajo-Cornell Field Health Research Project was initiated in 1955, by a contractual agreement between the Department of Public Health and preventive medicine, Cornell University Medical College and the Division of Indian Health, United States Public Health Service (Young,1961). According to a socioeconomic survey of the Many Farms and Rough Rock Navajos, an area serviced by the Cornell Field Health Research project indicated that from 1958-1959, 354 families earned $586 per annum which was significantly lower than the Navajo reservation as a whole (Sasaki, 1961). The economic situation in the Many Farms area depended on environmental changes and influences. A drought in 1956 added to the reduction of livestock and farming operations which resulted in economic strain. The clinic was opened to a population of 2,371 persons, approximately 809 participants.

This section discusses the use of elders and intergenerational oral history of the Health Care Experiment at Many Farms from 1957-1962 from a Diné perspective. This study illustrates the following important considerations the effects of historical trauma caused by Western researcher practices, understanding the role of health and place in Indigenous research, and, lastly, how Indigenous knowledges should inform recommendations for culturally/tribally appropriate approaches to epidemiology and biomedical models of health. In order to understand how this study was conducted and its effects on Diné peoples, a series of interviews were conducted with local Diné community members describing their experiences and perceptions of the Navajo-Cornell Field Health Project. The following research questions were investigated: 1) Was the Navajo-Cornell Field Health Project effective in delivering modern medical services to an isolated and remote community of Many Farms? 2) What was the community's response to modern health care? And; 3) As Diné people, how was modern medicine accepted to those who used traditional healing practices?

The purpose of this research study was to critically reflect on the 'Health Experiment at Many Farms' from the perspective of community members who lived during the time period of 1957-1962. As two participants explained,

> *"I remember the Cornell Clinic. It was located (over there) and the clinic was set up to help with the sicknesses in the community. We were happy with it."-Elder 1*
> *"The health visitor came one day and gave me $5.00 to eat sugar cubes and came back a month later to draw my blood."- Elder 1*
> *"My older brother worked at the Cornell Clinic and told us there were bilagáana doctors with medicine." – Elder 2*

According to these well-respected community members, the purpose of the Navajo-Cornell Field Health Project was to study discrete diseases and disease patterns in a non-technological society and to develop methods to provide delivery of modern medical services to a community where health care was limited or non-existent (McDermott, Deuschle and Barnett, 1972). However, in order to understand the complexity of the clashing cultural viewpoints presented in this study it is important to note the term for well-being in Diné is having balance – physically, mentally, spiritually and psychologically.

Being healthy means a person's whole self "T'áá Jizínigí" and to live in Hozhó in beauty and balance with mother earth. Diné people have a strong and complex traditional way of healing that is comprised of twelve different ceremonies for sickness and healing. From the creation stories of the Diné, ceremonies were given to our people for maintaining spiritual, mental, physical and psychological well-being.

Prior to European contact, diseases did not exist, if sickness occurred herbal remedies and various ceremonies were held to cure illnesses. After Hwééldi, the Long Walk of the Navajo to Fort Sumner (another government effort to eradicate Indigenous peoples by removing them from their ancestral homelands), the Diné were exposed to many infectious diseases and sicknesses. The diet of the Diné also changed drastically from natural plants, berries, small game and large game to government processed rations of flour and canned foods. The time spent at Hwééldi was difficult for the Diné as they were brutally treated and herded like cows. Living in a desert with no contact with the outside environment, the Diné remained imprisoned for four years, similar to a Jewish concentration camp, nearly dying of starvation and heat exposure.

In 1868, the federal government officials and Headsmen of the Navajo signed the Treaty of 1868, "Naaltsoos Saní," which included provisions, allowances, conditions, appropriations and the approval to return to an area known today as the Navajo reservation. The establishment of new lands and a new of life in confinement was to begin for the Diné. After much failed assimilation and acculturation practices and experiments, the Department of the Interior began an effort to provide rights back to Indian people. Sixty years later The Indian Reorganization Act of 1934 was passed by Congress and provided rights and sovereign opportunities for Native peoples. In particular, one of the government's responsibility was to provide and improve health care for Indian people. By the 1950's, health research projects such as the "Many Farms Experiment" initiated health care services to highly populated and rural communities on Diné bikéyah. Soon after, Indian Health Services systems were developed (these would become places where Indigenous peoples could access Treaty-guaranteed health provisions).

Historical Trauma

Understanding place and origin are essential to understanding the historical context of the topic under study when or while researching in Indigenous communities. The paragraphs above help to contextualize the health experiences and conditions of the Diné prior to the arrival of non-Diné health researchers. Had the non-Diné researchers studied and understood the history of health treatment of the Diné as a result of oppressive colonizing practices, perhaps their treatment and engagement with Diné peoples may have gone differently.

Kirmayer and colleagues describes historical trauma as a construct to describe the impact of colonization, cultural suppression, and historical oppression of Indigenous peoples in North America (Kirmayer, Gone, & Moses, 2014). In addition, historical trauma offers an explanation for continuing inequities in health and well-being and a focus for social, cultural, and psychological interventions (Gone, 2014). In the case of the Navajo-Cornell Field Health Project, the impact of colonization affected the rural community of Many Farms and Rough Rock. According to elders who lived and received health care made the following statements:

> "*It was good to get the medicine for our sickness, the health visitors who came to our home told us we need to find better ways to drink and use our water. One thing they told us was that we needed windows and there were too many people in living in our hogan. The health worker helped us get help from the chapter house to get a sink installed to wash our hands and pots."- Elder 1*

The forced assimilation of civilizing Diné people to relinquish their livelihood of caring for livestock and farming was soon to end. Many Diné community members were forced to mobilize into small community villages comprised of large families, usually averaging 7-11 family members. Families lived in a one room home with a primary diet consisting of processed foods from USDA commodity program. A diet that was transformed from natural foods, fishing, and livestock. Some have argued there may be a *chain of casualty* linking past oppression to current dysfunction based on the physical and forced relocation to a confined reservation (Kirmayer, Gone, & Moses, 2014).

"Regal Poverty" is a term used in the Experiment at Many Farms study to characterize the Diné community members as "well adapted" to the harsh circumstances

to the environment (McDermott, 1972). According to the Health Care Experiment Study, disease patterns were predictable based on the home environments of the patients served. For example, windowless homes favored airborne transmission of tubercle bacilli and other respiratory diseases. The scarcity and contamination of water was another factor.

> *"Many of our family members were exposed to Tuberculosis, at the time we didn't know what TB was, all we know was our relatives were sick and had trouble breathing. Many of our relatives were sent away for months and years to get better."* -Elder 3

Research Studies

According to the researchers, one of the goals of the Many Farms Health Experiment was to create a comprehensive system of primary health care and to organize various programs for personal medical care to a community in which only a rudimentary system existed (McDermott, 1972). The health care system from May 1956 to July 1962 was a satellite facility that included two field physicians, two nurses, one Navajo teacher and four Navajo auxiliary health workers. During an interview with a participant, who was fourteen at the time and living in Many Farms, Arizona, one community member reflected on her memories on the Navajo Cornell Health Project. Participants were asked to talk about the doctors who came in 1956, the community's response to the healthcare initiative, and some of the results of the Navajo-Cornell Health Project. One participant explained,

> *I was in high school at the time. My parents were living in Many Farms, I was attending school at St. Michaels and was a boarding student and I came home on weekends, holidays and summers. My mother was the first teacher at Many Farms*

School. She was the only one who spoke and wrote English. My mother also did a

lot of work with the clinic interpreting for and to the people. I recall my uncle

Eddie getting very sick, and we took him to see the doctor over at the boarding

school, that's where the health people were located. From there he was sent to

Fort Defiance hospital. He didn't return right away. Later, I found out he had TB

and was sent to a sanatorium in Albuquerque, New Mexico. The clinic in Many

Farms was good for us. There were many "white visitors" who worked at the

clinic. A few relatives worked for there as helpers and translators. They gave us a

lot of shots and recommended good sanitation. We were never told why we got

certain shots or medicine. We just did what we were told. -Elder 3RL

Another participant added,

Many relatives were reluctant to go to the clinic. Many were told that they came

to study us and cure us. Some didn't trust them because they were white, and

others were scared and felt obligated to participate or the government might take

away their monthly check -Elder 3

The same question was asked of a local elder in the Diné language: Ya'át'ééh

shichéi. Biniyé náaniyáhigii éí ahił nahodiilnih. Hast'adiin naahai yéedaa', azee'ił'ini

e'e'ááhdee' yikai,binaji', azee'al'í alyáa, beeniilniihish? [Good day, grandfather. I came

to visit you to talk to you about doctors who came here about 60 years who started the

health clinic here in Many Farms.][3]

Yes, that's a long time ago. I was young and living here at this same place. At the

time, I was traveling with my uncle and grandfathers to various healing

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[3] The following transcription is in the Diné language and has been translated for the purpose of this study.

ceremonies. I was their helper. When the 'White doctors' came, we were curious

of their healing practices. I never went to the clinic, but the health people would

come by our homes and ask us questions about the ceremonies. The (Bilagáana)

always had many questions. We weren't sure of their purpose. The last time,

Bilagáana come by was when John Collier reduced our livestock. 'What will they

take now?' were my thoughts"-Elder2

Elders responded to the health care experiment:

We went to the Chapter House one day, and they told us they were given out Polio

vaccines. They gave us sugar cubes and dropped red fluid on it, no explanation

and then 5 years later we were given a $5.00 check for our participation. -Elder2

From these responses, it is evident that community members did not trust nor

understand the bilagáana, however, many of the elders were compliant and did as they

were told out of fear of government retaliation. At any time, no one explained the

purpose of the "Many Farms Experiment," and translators were used solely to instruct

Diné peoples on what to do (i.e. not to obtain informed consent nor to explain the purpose

or results of the study). For some, participating in the study did not seem optional or

voluntary and they participated in fear or what more would be taken from them (with or

without their study participation).

Lack of trust was the common theme of both community members interviewed.

Kirmayer (2014) discusses "dispersed communities negotiating invasion by diverse but

technologically advanced and vicarious settlers" in different times and places. Obviously,

the negative experiences affected the way the community would accept outsiders,

specifically non-Natives. Although negative past experiences with the Diné people and

non-Natives happened decades prior, the lasting impact still remained in later generations. "Resulting in a kind of community resilience, defined as how people overcome stress, trauma and other life challenges by drawing from the social and cultural networks and practices that constitute communities," (Kirmayer, 2014). Resiliency also means strength, adaptability and hardiness, as Native peoples have done for hundreds of years.

Community resilience is important to determine and validate how the community of Many Farms used traditional medicine, community health workers, and other resources to embrace the Navajo-Cornell health project. The responses from the participants describe how a resilient community can be mobilized and adapt new community infrastructures and relationships for a healthy community. In addition, the study revealed the development of a relationship between Diné practitioners and medical staff with Cornell University health project.

The elders in this study had the following to say about the Many Farms Health Experiment:

> *The Cornell Clinic was our first health clinic in Many Farms and later in Rough Rock, Arizona. The study brought attention to health care for our community. - Elder 1*
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> *I believe the clinic got more funding from the government, not long after the Cornell Clinic closed, a bigger clinic opened in Chinle. Today, we have a large IHS hospital in Chinle. Many Farms started it all. - Elder 1*

In a historical and cultural context, Native peoples have lived a strong and healthy lifestyle. Before colonization, Native people survived from their environment land, water

and animals. Adelson (2000) tells the story of the Cree of Northern Quebec and the cultural parameters of health and the history of a people pre-to post colonization as told by the elders of the community. 'Being alive well' is a means by which adult Cree can articulate their distinct status in opposition to the persistent encroachment of Whiteman upon themselves and their land." (p. 110).

Native people were wealthy prior to colonization. Rich in land, resources, and culture. The food and people were generally free from chronic illness. Natives roamed their lands freely and respected mother earth and thus, mother earth provided them with natural foods from hunting, gathering and fishing. Water was life. Diseases were non-existent, illnesses were common, but treated. As Native people became exposed to New World contacts, lifestyles were changed, resulting with today's health disparities. "The oppressive factors caused severe inequities in Indigenous health status, unsatisfactory disease and vital statistics impaired emotional and social wellbeing, and poor prospects for future generations" (Gracey & King, 2009). What seemed missing from the research conducted during the Many Farms experiment was an acknowledgement on behalf of the researchers of the role of forced colonization, racism, European migration and history on the effects of Native peoples' health and well-being. Because the definition of health and well-being did not align with how the Navajo define it, it was unclear how or why the methods used by non-Navajo researchers involved in this study were connected to the health and well-being of study participants. Because researchers did not continuously inform participants about the purpose of each research act, nor did they openly invite questions or establish rapport with the participants, many of the participants appeared fearful to ask questions or were uncomfortable asking questions in a context that was not

culturally welcoming nor appropriate. Rather than supportive of community practices, the researchers were critical of their living situations and their water use and dwellings. For this reason, many past participants have mixed feelings about the study.

I don't think our community knew we were a part of a research study. -Elder 1

Sometimes I wonder if our blood stream was introduced to diabetes, when the sugar cubes and red liquid were given to us to eat. -Elder 1

The Cornell clinic was good while it was here. One day, it was gone. - Elder 2

The following section explores the following question: what are the connections between various forms of sovereignty and justice as it relates to research? The next section explores what federal, state, and local protections have been devised to protect Native peoples in research as well as how tribes have sought to protect their cultural knowledges and practices from harmful research. Lastly, I discuss what role, if any, elders have in participating and guiding local research practices.

Sovereignty and Justice in Research

Adapting and actively incorporating Indigenous research practices, protocols, and researchers in research design and execution allows for community healing and a rebalance of injustices of misinformation of the past. Because I discussed past injustice in research in detail earlier in this chapter, I won't elaborate too much on this topic in this section. One important finding from this research is the point that research undertaken from an Indigenous perspective and protocols is more likely to incorporate tribal history, as written and understood by Indigenous peoples themselves, rather than rely on research about the people that have been written by non-Natives and that may espouse incorrect history, information, and stereotypes about the people (what Deloria in 1969 argued is the

problem with historic anthropological research). In order to correct for past injustices, adapting Indigenous research practices and protocols may mean ensuring that research is designed and driven by Indigenous peoples themselves or those who have a sense of accountability and duty to the people. Which is accomplished through the assertion of sovereignty and self-determination in research practices.

The Cornell-Navajo Study in Many Farms, Arizona conducted from 1958-1963 serves as an example of colonial research approaches that have had a damaging effect on Indigenous peoples in the state of Arizona. The Navajo-Cornell Field Health Project played an important part in promoting colonial practices and beliefs about the rural community of Many Farms and Rough Rock, Arizona. It was about this time, the Diné people were forced to assimilate and relinquish their livelihood of caring for livestock, farming, hunting and continuing their traditional way of life as Diné. Instead, the Diné were forced to mobilize into small community villages comprised of large families, usually averaging 7-11 family members living in one home with a primary diet consisting of processed foods from the USDA commodity program. This was the direct result of colonization and the legacy of hostile and destructive government practices against Indigenous peoples. As evidenced with much research conducted amongst Indigenous communities, researchers believed grouping Native peoples, contrary to their "scattered" placement, would allow them to assimilate and thrive in a modern context (McDermott, 1972).

Early approaches to American Indian research were conducted as health experiments and through observation without regard for respect, justice, and beneficence (these principles will be discussed in greater detail in part 2). For example, the Health

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Care Experiment Study on the Navajo Nation (1959-1963) was completed without any regard for the local people and their cultural way of life. Instead the experiment concluded disease patterns were predictable based on the home environments of the patients served (McDermott, 1972). Researchers documented their findings only through observations. They analyzed data and concluded findings through a colonized lens and disregarded Indigenous livelihoods, perspectives, histories, and voices.

McDermott's research concluded, "windowless homes favored airborne transmission of tubercle bacilli and other respiratory diseases" (p. 24). The scarcity and contamination of water was another factor in determining local illnesses. At no time were the local people orientated or personally interviewed for the study. Many assumptions were made by both the researchers and the local community about the research being conducted. The researchers entered into the community without explaining why they were there and instructed members of the community to carry certain actions without proper explanation or consultation.

> *I remember one day, a local community relative who worked for the clinic came by to talk to us about washing our hands and making sure we use a separate container for drinking water. -Elder 1*
>
> *One time, I got very sick with stomach pains and they told me not to drink the water at home. They told me to only drink water from the large jugs. They came by to check on me and gave me more good water. -Elder 2*
>
> *They gave us a paper to sign to get new windows and doors. -Elder 2*

These quotes illustrate several important points. First, they highlight the lack of consultation with the community in terms of why, how, and when the study would be

administered. Second, they demonstrate lack of respect for the sovereignty and self-determination of the Diné people, their bodies, and their lands as members of the community were observed without their consent and/or asked to provide biological samples or agree to medical treatment they were unfamiliar with. Third, they demonstrate confusion shared among the People themselves as to why the researchers were there and why they were recommending the solutions they had presented.

Many studies like the "Many Farms Experiment" were conducted by non-Indigenous researchers to help "Save the Indian" (Troutman, 2009). In other words, White researchers undertook a patriarchal attitude that sent the message that when it comes to health, social structures, and governance, they knew best. They imposed their European practices and knowledge for healing without taking into consideration that Native peoples have their own type of medicine. They voided the traditional knowledges and ways in favor of ways that were unfamiliar to the people they were targeting.

Concluding thoughts

"Socioeconomic status is a major determinant of disparities in Indigenous health, irrespective of ethnicity" (Gracey & King, 1990). This is evident in the Many Farms Health Experiment. The study was chosen for the very reason of the disparities in health among the Diné people on the Navajo reservation. Access to adequate health care, clean water, and lack of nutritional foods are caused by poverty and is worsened by living conditions as evident in this study. Moreover, the history of removal and forced relocation directly affected the access Diné people had to clean water, game, and other historical traditional sources of sustainment. Substandard nutrition of infants and children, as a result of colonization, affected pregnancy and inadequate child

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development such as low birth rate, high risk pregnancy, infectious and other childhood related illnesses. In contrast, middle class affluent non-Native communities had access to nutritional foods, adequate prenatal care, and pediatric services. The accessibility to homes that have adequate ventilation and heating fixtures would decrease breathing issues in adults and elders. Unfortunately, the Diné continue to live in hogans or one room homes using coal and firewood for heat with minimal doors and windows for proper ventilation.

The qualitative data indicates the resistance to embrace health care initiatives by non-Natives based on historical traumatic experiences. However, in time, trust and relationships were developed to improve health care for the community of Many Farms. Toward the end of the project, the Many Farms health clinic became a safe place to go and receive medical attention because traditional practitioners and doctors began a dialogue of bringing together Navajo healing practices with modern medicine.

Toward the end of the project, we started to share our healing and herbal

medicine techniques. -Elder 2.

The building of trust, communication, and relationships were key factors in later establishing a health clinic in the community of Rough Rock and a dental clinic in Many Farms.

A glimpse on Diné perspectives from Many Farms community members on the Navajo-Cornell Field Study from 1957-1962 was fascinating. Although there are many interviews of transcripts available, I attempted to provide an introduction of memoirs from a time period of adjustment and acculturation to a community who was now confined to a new way of life. The inevitable change for a healthier way of living for the

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Diné people. In a broader context, to close the gaps in health and disease among Native peoples, society would need to address the socio-economic inequities within the communities in which they live. Although, health standards remain poor among Native peoples, remedies need to be found to support healthy native communities. Government entities must be culturally responsive to the needs of indigenous people while improving resources and services to the people in which they serve.

In this section, I provided an example of research conducted on the Navajo reservation from 1958-1962 that demonstrates the lack of cultural understanding and community involvement referenced by Deloria and Smith above. Gone (2013) describes historical trauma as a construct to describe the impact of colonization, cultural suppression, and historical oppression of Indigenous peoples in North America (Kirmayer, Gone, & Moses, 2014). Historic research practices have contributed to and perpetuated historic trauma. Moreover, the outcomes of Western research have been used to exploit Indigenous peoples, displace them from their lands and resources, place limitations on their ability to practice their spiritual practices, and destroy their well-being (Lomawaima, 2013). Historical trauma offers an explanation for understanding continuing inequities in health and well-being and provide a focus for social, cultural, and psychological interventions (Gone, 2013). In retrospect, health experiments were the most obvious of this type of research occurring with Indigenous Nations, specifically, on the Navajo reservation. The Navajo-Cornell Field Health Project is one such study. The study was to observe discrete diseases and disease patterns in a non-technological society, and to develop methods to provide delivery of modern medical services to a

community where health care was limited or non-existent (McDermott, Deuschle and Barnett, 1972).

Research Site 2: Rough Rock Demonstration School (1966-1976)

For Indian Nations, the 1960's era was significant in the development of Indian Self-Determination. National leaders including Richard Boone, the founder of Community Action Programs (CAP) under the Office of Economic Opportunity (OEO), Sandy Kravitz, Director of Demonstration and Research Projects under CAP, and Sargeant Shriver from OEO took the lead in establishing the birth of demonstration schools on Diné Bikéyah (Johnson, 1968). Robert F. Kennedy, Chairman of the Indian Sub-committee fostered a national agenda for improving the education and welfare of Indian children (Roessel, 1975). Prominent national and local leaders would become the stronghold for Rough Rock Demonstration School (RRDS).

Rough Rock School (Tsé Chizhí biolta') had been initially established in 1935 as a Bureau of Indian Affairs School. For nearly 30 years, (1935-1966), Rough Rock Day School was led by a principal, teacher, and maintenance man. In the early 1960's, however, about the same time President Lyndon Johnson declared "War on Poverty" and the inception of the Office of Economic Opportunity to improve the health, education and welfare for disadvantaged and underrepresented people, funds were provided to start the *demonstration school (Roessel, 1977)*. In 1964, the OEO Act was passed to provide funding for demonstration projects in poverty-stricken areas. The Navajo tribe applied for a three-year demonstration grant for a tribally controlled school. A few years later, three local leaders developed a non-profit corporation known as DINÉ, Inc. The local corporation was comprised of a Board of Directors featuring local community leaders.

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Soon after, DINÉ, Inc. was awarded $3 million to build a school on the most remote area of Diné bikéyah, Rough Rock, Arizona (Roessel, 1977).

Rough Rock Demonstration School officially opened its doors on July 1, 1966 by a locally elected five-member school board. The school remained funded from two sources: OEO and the Bureau of Indian Affairs. This funding brought in federal funds from OEO (as opposed to the BIA which provided monies to the tribe to run the school while schooling was provided by local missionaries and non-Native instructors). In the past, the BIA had provided education to children, by Treaty, however, OEO funding allowed for expansion of services for the school including allowing for higher student enrollment, funding for a dormitory, funds for building a new school, incorporating culture and language in school instruction, and creating parent/community involvement. RRDS would serve as a catalyst for self-determination and local control of education. However, the educational changes ushered in research-related behaviors that were unfamiliar for many of the students (Johnson, 1968).

Researchers and government officials would come in to observe the students and the implementation of OEO funds.

> *I started school back in 1966, I saw a lot of "bilagáana" men and women. I didn't know who they were. They watched us in the classroom, cafeteria and playground. They always took picture of us. Our teacher made us listen to nursery rhymes and recite them every day. I liked making animal sounds. - Elder 5*
> *Sometimes the White visitors would visit my house and watch us herd sheep. They liked to watch my family do things…my mom carding and spinning wool. They always had a camera. – Elder 4*

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The students became icons for observation without being informed of why they were being observed nor solicitation of parental assent and student consent in research. For many students at the time, it was unclear what would become the result of the photographs and observations.

The philosophy of RRDS encompassed many local empowerment initiatives including locally elected school board, school-community education, incorporation of Navajo language and culture in the classroom, parent involvement activities, and dormitory living. The first graduating class was in 1976.

> *I began school at Rough Rock and graduated from there. Back then, schools were different, I wasn't aware that RRDS was a big deal. It's the only school I ever went to, I thought all schools were like that. – Elder 4*
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> *There were so many White teachers and visitors, I remember one time when I was at the trading post, a lady with yellow hair wanted to take a picture of me. She gave me $1 and bought my silver and turquoise hair pin for $5. She asked me many questions. Years later, I saw my picture in the National Geographic magazine. – Elder 5*

Again, while the OEO ushered in new lines of funding and the opportunity to incorporate some tribally relevant practices (such as heritage language instruction), this era also brought an abundance of non-Native researchers and policy-makers that interacted with the children without fully explaining why they were there, the proposed outcomes of their visit, nor brokering permission from parents to interact with and informally interview students.

Despite the introduction of vigilant researchers to Diné children and their

schooling practices, the education in the small community of Rough Rock from 1966-

1976 was progressive, unlike other local community schools. RRDS was unique and

offered many innovative programs. Most importantly, RRDS was a community-

controlled school, the first of its kind in America. During the first ten years of RRDS,

over 12,000 visitors came to the rural school in Rough Rock, Arizona to see for

themselves a community school that received much national attention that fostered

legislation such as and the Bilingual Education Act of 1968 and the Indian Education Act

of 1972. As a demonstration school, the research for this study presents concerns similar

to the previous research site #2. However, what separates this study from the previous

study are the extremely biased and flawed external evaluations at RRDS. A counter-

evaluation of the Erickson Study, 1968-1969 will be examined below. Erickson and

Schwartz led the research evaluation of RRDS (Roessel, 1977).

The Erickson Study was an evaluative study of RRDS and was initiated by the

Office of Economic Opportunity (OEO). Donald Erickson, a researcher from the

University of Chicago, conducted a six-month study which consisted of interviews of

Rough Rock students, parents, and school staff. Other sources of data included board

minutes, school documents, analysis of standardized test scores, staff questionnaires, and

an "anxiety scale." RRDS standardized test scores were compared to three other schools:

Rock Point Community School, Chinle Boarding School, and Chinle Public School. The

external evaluation included a 30-day residence at RRDS dorm and an "anthropological

live-in" on campus; 11 days in Rock Point, and 14 day in Chinle and 4 visitations at the

tribal fair. Observational notes were taken and RRDS was to be only assessed in terms of

its own objectives (McCarty, 2002). The Erickson Report was a massive document that included nine chapters and four appendices.

This evaluation process was not only tainted, but inappropriately completed. While the evaluation report consisted of many photos and observational notes, protocols of research were absent from the report (Erickson & Schwartz, 1969). No formal consent for observation nor formal interviews appears to have been obtained from students nor community members. The observational notes of Schwartz "in-residency" was not approved by the RRDS School Board, but her residency at Rough Rock was forced without following proper protocols and demonstrating respect for the Diné community. Little or no explanation was given to the community by OEO but that RRDS would be evaluated.

Had the federal funding agency collaborated with local leaders and the community, had they provided a cultural workshop and dialogue about the Diné structure of leadership and history, the external evaluators may have developed a different, and richer, interpretation of the Diné way of life. As a result, the external evaluation was completed without the knowledge or consent of the child, their parents, and their community members, was a violation of trust, and may have contributed to negative or inaccurate perceptions of Diné peoples. The report revealed the following: disparities with California Achievement Tests (CAT); results of Cornell Medical Inventory "Anxiety Scale"; and acculturation photos of community members (Erickson & Schwartz, 1969).

In 1969 Erickson and Schwartz submitted their report to OEO. Soon after, the University of Chicago released a public statement which indicated "Rough Rock failed to demonstrate any superiority to other schools in the study" (McCarty, 2002). The Erickson

Report revealed invalidity and racial overtones. The assumptions evaluators made and what counted as appropriate and adequate evaluation evidence was recorded as invalid. Erickson and Schwartz, (1969) state, vilified the depth of relationships the community had developed with the school stating, "relationships between the school and community were unusually even phenomenally rich and well developed."

Erickson & Schwartz's report (1969) disregard for school programs and personnel was evident throughout the report. The report indicated the patronage system is "badly out of control" with nepotism and patronage (p.3.54). Relating to the hiring of relatives and hiring of close relatives hindering the work environment and the rotations of short-term employment. The researchers suggest that the "Arts and Crafts" program participants also continued their employment beyond the length of their original work contract and "developed skills they need" to pursue a craft independently. In commenting on the school Board stipends of $118 for each meeting, Erickson stated this "made board members very wealthy" and encouraged them to spend a large amount of time on personnel matters rather than classroom or dormitory affairs (Erickson & Schwartz, p.327). These type of remarks and accusations lack objectivity. The remarks appear extrapolated without evidence of accuracy or truth. In summary, the evaluators dismiss the demonstration school project altogether.

The patronizing attitude by the external evaluators presented were naïve, mean-spirited and prejudiced. Not only did the study fail to account for moral and ethical considerations in research, the Erickson Study was filled with western concepts and lack of scientific "objectivity." When the report was shared with the community, it was rejected (McCarty, 2002, p.107).

The aftermath of the Erickson Study brought forth responses from other external evaluations by prominent anthropologists, psychiatrists, and researchers including Wax (1970) who argued that, "instituting a system of local control through elected school board does not eliminate the potential for conflict, it merely establishes a new framework within which the struggles…to occur" (p.85). Robert Bergman, a psychiatrist for the U.S. Public Health Service Mental Health program also cites, "culture shock as a cause of bias." Dillon Platero, RRDS Director responded to Erickson and Schwartz assertion that RRDS was necessary. Platero responded to the Erickson report that RR does matter and suggested that it may even serve as an exemplar for other tribes to attempt to realize greater control (McCarty, 2002). Rough Rock School Board's telegram to OEO responded with the words "slanted interpretation" (McCarty 2002).

The federal funded evaluation of a federal funded program used normative criteria and measures that legitimized the larger power structure within which both the evaluation and RRDS coexisted. The evaluation process lacked in objectivity screening from scrutiny any critical considerations of evaluative norms and ignored implications and considerations for how Indigenous self-determination might be achieved. The Erickson Report suggests the genuine Indigenous Self-Determination was not appropriate.

As a result of the scandal, the RRDS School Board hired an all-Navajo evaluation team to reassess the demonstration project and voted to forbid future external evaluations. The evaluation process remained in effect until 1975 when federal legislation made external evaluation a requirement of all Bureau of Indian Affairs Schools contracting requirements.

As far as self-determination, the 1960 and early 1970's were eras of increased interest in bilingual and bicultural education. It was President Kennedy and President Johnson who laid the foundation for the 1969 Bilingual Education Act, later to become Title VII. The BIA fostered bilingual and bicultural as "most promising approaches" (McCarty 2002). Robert Kennedy couldn't have said it best, "Rough Rock has proven it's point," it should serve as a model for a comprehensive "new national Indian policy" (1969. U.S. Congress, p.1055). Kennedy's seven volume testimony (Kennedy Report) led to the legislation of the Federal Policy of Self-Determination Act of 1975 PL (93-638). The policy allowed for operation of social and educational services and legitimizing the experimental procedures at Rough Rock. PL (93-638) paved the way for Indigenous communities to operate their own education system.

This study raised important implications for research. First, it added a historically underdiscussed element of research into the conversation: the role of research evaluations. RRDS and the Erickson study not only supported the implications of the Cornell study in that all research participants deserve to be informed, and continually informed, about what research practices are occurring, why, and how the data will be used. It also raised awareness that consent for participants, minors and adults, was not being properly obtained. Lastly, it raised awareness of the importance of collaborating with the local community and ensuring there are community members who are part of the analytical process to assist in properly contextualizing the data so that findings would not be skewed due to ethnocentric ignorance of non-Native researchers.

Most important, however, was the progress the RRDS context shows in shaping research protocols. With community members rejecting the Erickson study, informing the

federal government of their concerns, and implementing processes that require evaluation studies to include researchers who are familiar with the Indigenous context, history, and community the Diné peoples of Rough Rock demonstrated what self-determination and sovereignty in research practices could look like. This would serve as foreshadowing to the implementation of the nation's own research protocols, practices, and Internal Review Board criteria.

Research Site 3: Navajo Mental Health Project (1976-1985)

McCarty (2002), clearly defines the purpose of the Navajo Mental Health Project (NMHP) as "a school committed to promoting the community's mental health and spiritual life" (p.88). Navajo Mental Health was established in 1967 and supported by the community and elected school board members. The NMHP was initially funded by RRDS and later was funded by the National Institute for Mental Health. "Earlier in the life of the program there had been two trainees for each medicine man, later because of lack of funds, the ratio was one-to-one" (Roessel,1976). The training program allowed medicine men to directly instruct and support their trainee in ceremonial practice. The goal of NMHP was to maintain the Navajo culture and the need to address the possible disappearance of Navajo ceremonies.

In this project, we see progress in multiple areas: the active inclusion of Indigenous peoples as the leaders of research and in how Indigenous peoples are compensated for their knowledge and time. The medicine men and their trainees were compensated as part of the mental health project. Over nine different ceremonies were taught: Blessing Way, Mountain Top Way, Evil Way, Male Shooting Way, Red Ant Way, Navajo Wind Chant, Enemy Way and Feather Way. Many grants helped support

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the Navajo Mental Health for over fifteen years. In 1976, medicine men practitioners received $300 a month and trainees received $200 a month. According to Elder 5, "T'áá náhidizííd bik'égoo,naakí neeznádíín nihich'i'náada'iilyé'." Each month, each participant was required to submit a monthly report of the training they provided or received and document all ceremonies completed or in progress (personal interview).

This study was also unique in that its focus aligned with Diné interests, prioritized DKS in healing ceremonies, and responded to the desires of Indigenous peoples. World renowned psychiatrists including Karl Menninger were strong supporters of the program. Menniger worked directly with local medicine men to assist with patient wellness. "Navajo religion is around the relatedness of the mind and body" (McCarty, 2002). Menniger further states, "far more advanced than their white brothers." Like many local elders of the community believed, mental health was of high importance. Even more important was the salvation of a culture and spiritual way of life.

The NMHP was of high importance to the Rough Rock community. Many medicine men from local and distant communities took part in the program learning the traditional ways of healing. Other local medical officers like Dr. Bock worked with Public Health Services for 10 years supported the NMHP. He believed that Navajo sickness is caused by a violation of some order, harmony is temporarily destroyed and comes out in physical sickness, headache, stomach, and in other physical forms. Dr. Brock suggests that although he can cure physical ailment, but if not treated with a traditional ceremony to restore harmony the healing process is incomplete, and traditional medicine should be seen as cooperation (McCarty, 2002).

Over forty years ago, medicine men were increasing because of the urgency to reclaim traditional ways of healing, now 40 years later, there are a scarce amount of Diné traditional healers. NMHP was a priority for Rough Rock and the School Board, it's been documented that from 1966-1976, 131 separate times the NMHP was discussed (Roessel p.54). Although funding was acquired by the National Institute of Mental Health, Rough Rock School Board took a personal interest into the continuation of funding for the NMHP.

The directors of the NMHP were local Indigenous leaders: John Dick and Linda Hadley. Hadley was hired because of her English fluency and effective communication skills. In a personal memoir, Hadley writes, "we want to save our traditions, ceremonies and language-how can we do this, but through the recording of our stories using the bilagáana tapes and machines. This would be the way to save our culture, our history, our knowledge and our language" (Memoirs, 1980). This was the first major research study initiative that was co-led by a local Indigenous woman. Including Indigenous community members to lead the study ensured tribal and cultural protocols were taken and that consent and knowledge of the study, its aims and outcomes, were properly understand as Hadley was a speaker of the Diné language. The change in rapport, trust, and willingness to participate in the research is evident in research participant responses.

> *Linda took care of us and explained the purpose of the NMHP. She came every two weeks with a happy greeting. She would start by asking about my well-being and then we went to talk about my work. I gave her a verbal report. Shinalí (Linda) in return gave me program and school updates. She always shared information, I told her of the small ceremonies I participated in. I liked that she*

spoke both Navajo and English. She always wrote down everything. I wish I could read English. At a young age, I tried to learn the White man's language, but it didn't want me, so I never learned English. My mom and uncle were traditional practitioners of Red Ant Way and Enemy Way, I followed them all over the lands to heal people. I learned the ceremonies and now I only advise. -Elder 5

Mrs. Hadley personally chose me to be in the NMHP as a trainee, I was a naughty kid. Mrs. Hadley talked to me and made sure I was part of the program. My parents were both traditional practitioners. My mom was an herbalist and practiced the Blessing Way. My dad was a well-known medicine man. He conducted small and big ceremonies. Mrs. Hadley believed in me and mentored me. I was assigned to my dad and became his apprentice. I spent most of my life learning the ceremonies and traditional ways. I learned the history and stories. My family had great respect for Mrs. Hadley, we trusted her. We invited her to our ceremonies. The medicine man training program was a very good program, it made me who I am today, that's how I made a living for my family. I am the only Navajo practitioner for 8 ceremonies. I learned all of it from my mother and father.

NMHP research included exploratory interviews, audio and video recordings of traditional ceremonies, interviews of history, process of Diné ceremonies and 1:1 interviews. In the case of NMHP, the Diné woman researcher ushered in positive change by leading the research and establishing the following cultural protocols: developing relationships, greeting each participant by clan, informing participants of the purpose of visit, getting verbal and written consent from the participants, and building trust. She

additionally went a step further and made sure that study participants were aware of study findings and constantly reminded of the study aims and processes.

This Diné woman would change the narrative regarding self-determination, sovereignty and the role of Diné Knowledge Systems in research by ensuring protection of Diné participants, acknowledging and respecting traditional protocols of SNBH, and providing historical documentation for future generations. Hadley demonstrates and supports, Linda Smith's conceptual framework of reclaiming, reconnecting and realigning research practices within the community so that research is no longer a "dirty" word among Indigenous peoples. As a researcher, she helped ensure the research aims were aligned with community needs. Her work validated Smith's argument of the importance of research practices that are informed by cultural protocols, academic research can be made useful for Indigenous people. Furthermore, Hadley brings voice to her research as she continues to co-author a book on the *Blessing Way, Hózhǫ́ǫ́jí Hane'* (1988), and shared origin stories, chants, and prayers from a woman's perspective. Hadley demonstrated a research protocol that ensured DKS are protected from harmful, exploitative or irrelevant research by establishing cultural research practices allowing Diné people to be respected and acknowledged for their historical knowledges and cultural practices.

Implications

This chapter began by stating that for decades, Indigenous people have been the object of stereotypes and prejudicial observations. As Vine Deloria explained, "the fundamental thesis of the [researcher] is that people are objects for observations, people are the considered objects for experimentation, for manipulation…Over the years [researchers] have succeeded in burying Indian communities so completely beneath the mass of irrelevant information that the total impact of the scholarly community on Indian people has become one of simple authority" (Deloria, 1969, p.82). I have argued that one

of the most damaging acts of Western research has been to position the non-Indigenous researchers as an "expert" of Indigenous peoples.

As demonstrated in the Cornell study, early research failed to ensure that research concepts aligned with the definitions, epistemologies, and ontologies of Indigenous peoples. Western researchers have entered into Native communities, at times uninvited, and engaged in taking biological specimens, without ensuring the community understands for what purpose. They have also subjected Indigenous peoples to medical practices that did not make sense to them, disparaged their living conditions and blamed them for their own illnesses without recognition of the role of colonization and Western expansionism and enforcing changes in diet and living situations as impacting Indigenous health and well-being.

According to Deloria (1999), "race has been the primary criteria in gathering and determining data about Indians" (p. 19). Western research has pushed the belief that only White scholars can observe phenomena objectively. In the Rough Rock Demonstration School project further perpetuated confusion, lack of understanding, and potentially, trust in the Western research process. Although researchers in this study were not collecting biological specimens, they engaged in observations without explaining to the children, their parents, or community members what the focus, purpose, or goals were of the study. Study participants were shocked to find their photos appear in popular magazines such as *National Geographic* without their knowledge or consent. These types of research practices further the notion that data was observed through "culturally prescribed categories that restrict the possible answers and understandings to a predetermined few selections" (p. 18) and may have helped perpetuate racist beliefs about Native Americans

and limited Western knowledge, placing White scientists as the expert on Native people rather than Native people themselves. By the 1970s further progress is seen in research conducted in Diné Bikéyah as the Navajo Mental Health project was more aligned with the interests, values, and concerns of Diné peoples.

This chapter has explored the following questions: What key research studies were conducted in the three focal communities during the period 1956-1986? What was the purpose of these studies? How did Diné participate in the studies? What was the researchers' role in relation to Diné participants? Whose interests did the studies represent. (Who benefited from the research?) Although the history of research in Diné Bikeyah has not always aligned with the interests and values of Diné peoples, subtle changes have taken place. However, more work is needed. The next chapter presents findings from in-depth interviews with Diné elders who participated in the studies listed in this chapter. The elders offer recommendations for how to improve research in, with, and for Diné peoples and Diné Bikéyah.

CHAPTER 4

DINÉ PEOPLES AND ELDERS PARTICIPATION IN RESEARCH FROM 1956-1986

*Níhizáád iilį is a Diné phrase meaning "our words are sacred": Recommendations for
Diné Research Policies*

Abstract

This study explores the role of language, elders, sovereignty, and self-determination in research on and with Diné peoples over the critical 30-year time period of 1956-1986. This historical research qualitative study is guided by the following questions: What are the perspectives of Diné participants on research conducted in the focal communities of Rough Rock, Many Farms, and Chinle Arizona during the period 1956-1986? And, what recommendations do Diné elders have for how to engage in culturally appropriate research practices for research conducted in or on Diné Bikeyah? To answer these questions Five Diné elders participated in in-depth interviews about their research experiences during the stated time period. Participants completed three 90-minute in-depth interviews. Seven themes related to cultural protocols, language, research policies and protocols emerged. Findings from this study present implications for how Indigenous IRBs can create policies that protect the role of language, elders, and cultural knowledge systems.

Introduction

The topic of Indigenous research and sovereignty has been of increasing concern in recent years, as reflected in the work of numerous Indigenous scholars (e.g., Brayboy et al., 2011; Denzin, Lincoln, & Smith, 2008; Grande, 2008. 2014; Lee, 2014; Lomawaima, 2000; Kovach, 2009, Smith, 2012). Research for Indigenous populations remain especially limited for Indigenous peoples in the U.S. Southwest, home to more than forty-four Native American nations. This study focuses on the role of tribal sovereignty and self-determination in research for Diné participants and elders from 1956-1986.

The following research study is committed to honoring Indigenous knowledge systems; to heal from past injustices and acknowledge past failures committed by western researchers; and to become accountable researchers for the sacred people and land of

Indigenous communities and to be able to conquer, defeat and bring about social change. The focus on elders in research is important. In the past, Western theories have been used to study Indigenous peoples in a broad spectrum; however, there is limited qualitative research on protecting elders and Indigenous knowledge systems that use Diné traditional or culturally specific models.

Only four studies have examined the role of Native elders in research (Arolnith, 1994; Clemmer, 2011; Lee, 2014; NN HRRB, 2003; Schrag, 2006). Elders also known as cultural knowledge keepers are defined as those who are recognized by the community as Niháhastóí dóó Nihizáanii (our male and female elders), cultural stewards, and possessors of community, cultural, and tribal memory. All participants (elders) in the study are over the age of 60 and, since epistemology can be intimately tied with heritage language, are fluent speakers of the Diné language and practitioners of traditional ceremonies and protocols. Elders have served important roles in research from serving as interpreters, to assisting with data collection, and even data analysis. Yet, few studies have explored the role of Indigenous epistemologies and protocol in research while almost no studies in the U.S. have examined the role of Native elders and cultural knowledge keepers in research. This research is needed as findings from such explorations can present important implications for research methodology and IRB processes and add important insight into discussions on protecting the well-being and cultural knowledge of Indigenous communities – which remains to be explored.

The negative legacy of Western research

Research is defined as the act of gathering, organizing, and interpreting information with the intention of using data as a guide to make informed decisions or

understand the world around us (First Nations Information Governance Committee, 2007). Research is about "ideas in motion" (Red Pedagogy the Un-methodology, 2008). This definition of research "in motion" suggests research is a process of active and close observation. Grande (2004) also suggests that research methodology and protocols are meaningful through people and communities, events, practices, ceremonies and rituals. *Red Pedagogy*, an Indigenous research lens, allows us to reinvent ourselves while we as Native people examine our own communities, policies and practices. For Indigenous peoples, research is important to investigate, validate, contest, and enhance Indigenous knowledges and practices.

Research is also about understanding phenomena related to a variety of cultural and environmental concerns including better understanding of health practices and challenges, the role of cultural and spiritual practices, the impact of climate change, and concerns with water and land, to name a few examples. From an Indigenous research perspective, research is generally focused on finding asset-based or culturally responsive solutions to pressing challenges and concerns. Yet for hundreds of years, proponents of Western European and Euro-American imperialism and colonization have dismissed the ways of thinking and practices of Indigenous people. When conducted from the Western perspective, research within Indigenous communities has always been one sided and explored by non-Indigenous researchers.

In the Diné communities of Many Farms and Rough Rock, Arizona, this has manifested as *"Bilágáanás and others come to our land to study us as if we were animals or foreign objects. They come here with their backpacks, tape recorders and notebooks with no other intention, but to take our way of life,"* (personal interview with Elder 1,

2019). Because research has been undertaken without regard for Indigenous people, Indigenous scholars have argued historic academic research practices have relegated Indigenous voices and ancestral knowledge to the periphery while continuing to oppress society and peoples of Indigenous nations (Deloria, 1969; Smith, 2012).

This study presents findings from a series of in-depth interviews and archival records related to research. The following studies were selected for analysis, all conducted on the Navajo Nation during the years of 1956-1986: the Cornell Study (1957-1962), the "Many Farms Experiment" (1966-1976), and the Rough Rock/Navajo Education Evaluation Study and Navajo Mental Health Case Studies (1975-1985). Specific studies analyzed were the "Health Experiment at Many Farms" in which the purpose of the *Navajo-Cornell Field Health Project* was to study discrete diseases and disease patterns in a non-technological society and to develop methods to provide delivery of modern medical services to a community where health care was limited or non-existent (McDermott, Deuschle &Barnett, 1972). *Rough Rock/Navajo Education Evaluation Study* such as Roessel's (1970, 1980) work on Navajo education, and Linda Hadley's *Rough Rock Navajo Mental Health Project: Medicine Man Training Program* (1982-1985).

Study Purpose

Since research has historically been undertaken in a manner that is unresponsive to the needs, interests and desires of Indigenous peoples, many Native peoples believe research is not relevant or useful to their communities and have developed a deep distrust of research and researchers. The result is that for many Indigenous communities "research is probably one of the dirtiest words in the Indigenous world's vocabulary"

(Smith, 2012, p.1). Deloria (1969) has also stated that, "research has been a practice difficult to digest and devoid of any meaningful application for Native peoples." Deloria (1969) argues that anthropological studies conducted on Native Americans were done only for the benefit of the researchers and did not address Native community values, needs, or desires.

"Researchers like anthropologists and different White people come to our communities to get information from us. (They) steal our words and our way of life. Later, we see our words and culture in city museums, in books and magazines." (personal interview with Elder 4, 2019). This elder raises concerns for the historic confusion or ownership of data and the lack of consultation with Indigenous peoples as to how data will be collected and when, where, how, and why findings will be disseminated. During this study another elder commented, "People who come into our lands don't explain their studies or research. We only see them once and never again." This elder raises concerns about the lack of long-lasting relationships and rapport non-Indigenous researchers present to research with Indigenous peoples. This sentiment was echoed by another elder who stated, "We watched people come and go. People outside the community bring new buildings and programs only to last a few years. They bring sickness and our die. They try to heal, but the fail." While another elder commented, "Bilágáaná nihítá niyáadóó nihizááad dóó nihí ǫ'ol'įįł béedee'sįį'ná. Bilágáaná bizááád k'ad éí niha'ałchiní k'ad t'áá éí ałchiní yéeyádaałt̨į'. Dóó ya'áshóodah."

Theoretical Framework

The purpose of this historical research qualitative study was to interview Diné elders and ask them: 1) To describe the role of sovereignty and self-determination in

research on/with Diné elders; 2) To outline a research philosophy informed by Diné epistemology that promotes protections for the well-being and cultural knowledge of Diné participants, and; 3) To learn from past research how the perspectives of Diné participants on the role of sovereignty and self-determination in research for Diné peoples can inform a research methodology, policies, and protocols.

At least two conceptual bodies of work inform the foundation of this proposed project: Tribal Critical Race Theory (TribalCrit) and the field of work known as Critical Indigenous Research Methodologies (CIRM). TribalCrit addresses the complicated relationship between American Indian tribes and the United States' federal government and attempts to value indigenous and experimental knowledge as a way to inform thinking and research (Brayboy, 2006). This work draws upon two of the nine tenants presented in the Tribal Critical Race Theory framework: (1) Indigenous peoples have a desire to obtain and forge tribal sovereignty, tribal autonomy, self-determination and self-identification, and (2) governmental policies toward Indigenous peoples are intimately linked around the problematic goal of assimilation (Brayboy, 2006). The purpose of this research study is to outline recommendations for how Indigenous communities can further assert their self-determination and sovereignty through the implementation of policies, procedures, protocols, and guidelines in research with/for Indigenous elders, their cultural knowledges, and their communities.

Research Questions

This study focused on the following research questions:

RQ1: What are the perspectives of Diné participants on research conducted in the three focal communities during the period 1956-1986?

RQ2: How was Diné sovereignty and self-determination reflected, if at all, in these studies?

RQ3: What recommendations do Diné elders have for how to engage in culturally appropriate research practices for research conducted in or on Diné Bikeyah?

Sampling

Given the historic nature of this project, it was difficult to identify living participants for this study. Moreover, many participants in this age group may not have regular access to telephones or technology making communication difficult – especially in terms of setting up interview times and locations. Therefore, the researcher used convenience sampling (and some snowball sampling) to identify study participants. The researcher began by reaching out to elders in Rough Rock, Chinle, and Many Farms area verbally during social gatherings and community social ceremonies. The Beauty Way Ceremony was targeted because they are specifically open to community elders and ceremonial practitioners. The researcher described the study and invited Navajo researcher elders who participated in research from 1956-1986 to participate in the study.

One of limitations associated with these sampling techniques relate to confirmation bias. Researchers tend to remember points that support their own hypothesis and points that disprove other hypotheses. Confirmation bias is deeply seated in the natural tendencies people use to understand and filter information, which often lead to focusing on one hypothesis at a time (Sarniak, 2015). To minimize confirmation bias, as a researcher I sought to continually reevaluate impressions of participant's respondents and challenge preexisting assumptions and hypotheses. Asking quality questions at the

right time and remaining focused on sources of bias enabled me to ensure a high-quality historical research-qualitative analysis.

Participants

Prior to collecting data, I spoke with local community elders and inquired about possible participants for my research study and spent time establishing rapport. Based upon recommendations, I visited each possible participant and initiated a relationship to gently probe their interest in participating in further research study. Next, I established rapport and relationships with each of the interested and prospective participants. During our formal introductions we exchanged information about our clans, family origin, and purpose of the research study. Establishing kinship and clanship is essential to building relationships among the Diné people (Lynch, 1998). Multiple visitations to each prospective elder prior to conducting the interviews was of critical importance to establish rapport before any data was collected for this study.

Participants were selected from the communities of Rough Rock, Many Farms and Chinle, Arizona. Six participants from each community who participated in research during the time period of 1956-1986 were interviewed. Three women and three men were selected based on their experiences with research during the time period from 1956-1986. At least two of six elders were identified as a Diné ceremonial practitioner. A traditional introduction which includes an emphasis on shared relationships between the researcher and participants through the Diné kinship system was established and practiced with each participant prior to the formal interviews. The interviewees ranged in age from 60 to 91 years of age. All participants spoke the Diné language and all, but one elder completed the interview in the English language with a few Diné phrases. It is important to note that

during the course of the study, one elder passed away and his wife of 55 years completed the final stages of the interview.

Data Collection

This historical research qualitative study was conducted during the Spring and Summer of 2019 and relied primarily on archival records of the research studies and analysis as well as in-depth interviews with former study participants. Data collection occurred during a 10-month time period. All interviews took place off reservation in Gallup, New Mexico. Modest travel stipends were provided to participants to defray travel costs. At each stage of the interviews, participants spoke in their preferred languages of Diné or English.

A series of individual interviews were administered to research participants. An interview protocol for case studies using I.E. Seidman (2013), *Interviewing as Qualitative Research* (4th edition) was used as part of a three-part interview consisting of 90-minute interviews. The questions selected were designed to allow participants to freely share their experiences. The interview protocol contained questions examining their personal experiences with research in their respective communities. The interviews followed Diné protocols in combination with I.E. Seidman's three-part, 180-minute interview format that includes the following: A *focused life history, details of experience, and reflections on meaning* (see Appendix 1). Interview questions allowed participants to freely share their experiences and were conducted in Navajo and/or English, based on the participants' preference, and audiotaped. As a native Navajo speaker, I initially transcribed and translated the interviews. The final transcriptions were completed by a Navajo linguist.

Part one of the interview protocol centered on eliciting a *focused life history.* The interview probed into the participant's personal history as it relates to the study focus and research questions. During this interview, participants/elders were asked to share their personal stories, including their experiences with research studies. The second interview focused on *details of experience.* The purpose of this interview was to ask questions that elicit more detailed experiences with the topic of research. During this interview, I solicited participants' experiences with research in terms of research benefits, Diné sovereignty, and self-determination. The final interview was focused on *reflections on meaning.* During this interview, I asked participants to reflect on what their experiences mean to them personally in terms of the research questions (Appendix 1)

Interviews were conducted in Gallup, New Mexico. The consent process took place in Gallup, New Mexico and consent forms were obtained in person. At each stage participants were spoken to in their preferred language. For those participants who do not speak English, but preferred a written copy, a Navajo language form was provided. However, participants who were fluent Navajo speakers and did not read the Navajo language received an oral translation in the Diné (Navajo) language.

Data Analysis

Hsieh and Shannon (2005) indicate, "qualitative content analysis is defined as a research method for the subjective interpretation of the content of text data through a systematic classification process of coding and identifying themes or patterns" (p. 128). The analysis of research participants' interviews was designed in a series of a three-part interview process. The approach allowed the interviewer and participant to plumb the experience and to place it in context. The first interview established the context of the

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participants' experience. The second allowed participants to reconstruct the details of their experience within the context in which it occurs. And the third encouraged the participants to reflect on the meaning their experience holds for them (Schuman, 1982). The process of analysis included re-reading and analyzing, first, responses related to establishing rapport through introductions, family origin and purpose of the study. The second part was analyzing and assigning codes to interview responses as well as anecdotal memos and researcher journal entries. Third, themes were created from the codes drawn from transcription and memos.

Data analysis was accomplished, in part, through the use of MAXQDA, a qualitative analysis software which allowed me to record audio of the interviews, develop themes, and code key words in the Diné language. This process provided me the opportunity to use key Diné terms as codes and identify each participant's experiences and cultural knowledge systems. MAXQDA was used to transcribe and code interviews, journal entries and anecdotal notes. As I completed this process, I began developing themes and codes and sub-coded areas that were closely related to each theme. "Emergent categories were used to organize and group codes into meaningful clusters" (Hsieh & Shannon, 2005, p.1279). A descriptive coding method was used to analyze data (Saldaña, 2016). All coding was completed via MAXQDA in the Diné language.

Findings

A total of seven themes were identified. Interviewees spoke about lack of awareness of the nature and purpose of research studies, trouble understanding the spoken language used in research, concern researchers did not have approval for the

study and did not indicate what would happen to findings, lack of follow up, and lack of awareness of the scope of the study.

Table 1

Responses from Research Participants to Questions

	Elder 1	Elder 2	Elder 3	Elder 4	Elder 5	Elder 6
Theme 1 Lack of Knowledge	X	X	X	X		
Theme 2 No protocols identified	X	X	X	X	X	
Theme 3 No formal explanation given	X	X	X	X	X	
Theme 4 No follow-up	X	X	X	X	X	
Theme 5 Research not approved by NN government	X	X	X	X		
Theme 6 Not aligned with Diné epistemology or ontology	X	X	X	X		
Theme 7 Diné language not acknowledged	X	X	X	X		

Four out of six interviewees indicated they were not aware they were part of a research study. Although researchers may have indicated they had funding from an external agency to conduct the study, these participants were not aware they were part of a study nor why the study was being conducted. Second, no protocols identified. Participants indicated no clear understanding of methodology was shared with them thus participants did not know what to expect nor what was happening nor why. Third, no

formal explanations were given. Participants expressed feeling exploited or violated.

Many felt obligated to participate for fear of government retaliation and/or losing access

to treaty-guaranteed services. Fourth, the participants shared that no follow up was

conducted after studies were concluded making it difficult for them to discern what the

results/findings were and where, when, why, and how findings would be disseminated.

Fifth, participants expressed concern that the research study was not approved by local or

Navajo Nation government. Because of this lack of tribal oversight, participants felt that

researchers did not understand the role of history, the local context, nor cultural protocols

and how this might affect their findings and their interactions with local research

participants. Sixth, participants in two of the three studies expressed concern that the

research did not align with Diné epistemologies or ontologies. There was no concept of

k'é or hozhǫ which made participants uncomfortable. However, participants in Linda

Hadley's *Rough Rock Navajo Mental Health Project: Medicine Man Training Program*

felt differently. Lastly, four of six participants expressed that the importance and role of

Diné language was ignored or unincorporated. Several participants indicated limited

translation was offered during their participation in research. Participants are fluent Diné

speakers. Explanations by interpreters were vague.

Interesting to note was that for the older elders, those that had participated in

research during 1956-1966, expressed concerns with lack of consent, Diné language and

representation in research, lack of fully explaining what was being done and why, and

lack of awareness of what the purpose and outcomes of the research would be. Some of

these concerns were echoed by participants in research during 1966-1976. However,

these participants shared stories of getting access to research reports of findings and the

overall community rejection of the report findings, how research was conducted which began a conversation for the need for Indigenous evaluators in research and tribal approval for research studies. Lastly, participants in research from 1976-1986 expressed the highest approval for research practices. This was due to the fact that the research study was initially co-lead by a local Indigenous woman researcher, Linda Hadley, who spoke the Navajo language fluently, maintained constant communication with study participants, incorporated Diné practices and customs in research, and informed participants of the purpose, aims, scope, process, findings, and dissemination of the research. Hadley would later go on to become the exclusive director and leader for this research and gain the respect, trust, rapport, and favor of study participants.

Recommendations

In order to ensure research is culturally respectful, responsive, and relevant the research(ed) community participants offered several recommendations. The following chart demonstrates the recommendations provided.

Table 2

Recommendations from Participants

PARTICIPANTS	GENDER	RECOMMENDATIONS
Elder 1	M	"Nihí o'ool'įįh bahaadánosin." Preserve our culture with respect.
Elder 2	F	"Hazho'ó naalkah beenihiłldaholne' dóó biniyé ahát'inígii." Tell us specifically the purpose of the research.

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Elder 3	M	"Nanit'ą́ą́' beenisolkaa'igíí ni'hichi'iishjanií adádooleeł."
		Return and inform us of research findings.
Elder 4	F	"K'é béénihitaákai."
		Develop relationships with us.
Elder 5	M	"Táá dinék'éjii'nihich'į' yadaaltį.'"
		Speak or translate in Navajo when interviewing elders.
Elder 6	F	"Níhihane' nihił da'iilį"
		Be appreciative of our stories.

Discussion

Initially, participants indicated researchers had little knowledge or regard of Diné way of life. Their questions and recommendations felt judgmental, misinformed, and had a lack of overall direction. As years progressed, participants indicated researchers were more respectful and eager to learn ceremonies. However, even in the 1970s, when researchers indicated more interest in understanding Diné practices and ceremonies, participants indicated researchers invaded cultural spaces via photography and recordings without proper permission or following cultural protocols. Lastly, participants indicated researchers did not appear to understand the importance of prayers and ceremonies.

This study is guided by the following questions: What are the perspectives of Diné participants on research conducted in the three focal communities during the period 1956-1986? How was Diné sovereignty and self-determination reflected, if at all, in these

studies? What recommendations do Diné elders have for how to engage in culturally appropriate research practices for research conducted in or on Diné Bikéyah?

To answer the first question, Diné participants indicated that initially researchers at the beginning of the time period appeared judgmental, exhibited belief they were "experts" who knew what was ideal for participants' health, families, community, and livelihood even though they knew little to nothing about Navajo language and culture. Over time, researchers gradually began to demonstrate cultural humility and interest in Diné ways of life but Diné participants were still treated as the objects of study. Images and information about Diné people were taken without their permission and shared on a national scale without their knowledge. Second, this study asked: how, if at all, was Diné sovereignty and self-determination reflected in these studies? Participants did not appear to believe sovereignty and self-determination was evident in these studies. Several participants indicated concern that research was taking place without express approval from a Navajo IRB nor from the community.

Third, this research study asked: What recommendations do Diné elders have for how to engage in culturally appropriate research practices for research conducted in or on Diné Bikeyah? Study participants overwhelmingly support the creation of a body of Diné peoples to oversee and approve research in Diné Bikeyah and with Diné.

Although the NNHRRB has a vision statement, to date, no mission statement for the organization has been stated. Findings from this study suggest a mission statement should be created to guide this body. Elders recommend research boards prioritize the education, well-being, and health of its members, staff, community leaders, elders, administrators, and community partners. Participants believed research can benefit and

address modern day Diné health, environmental, education and other concerns and challenges. However, elders believe researchers should enter the community with the intention of engaging in mutually respectful and beneficial partnerships with community members. Community members should benefit from the research. Not just researchers.

Moreover, elders believe research should promote self-determination and sovereignty by allowing Indigenous peoples to take control of their information and should focus on the promotion of healthy lifestyles, practices, and effective program planning. Furthermore, participants recommended that researchers interested in conducting research in, with, for, or on the Navajo Nation or with Diné people to be culturally respectful, appropriate, and, mindful of the ceremonies and protocols of the Navajo people. Thus, research should follow appropriate cultural, spiritual, linguistic, and spiritual regulations and protocols.

Since it is unclear if the NNHRRB (the Navajo Nation IRB) is based on Western research practices or Diné epistemological values and protocols, it is necessary to review NNHRRB procedures and make recommendations, informed by Diné elders and past research participants, for procedures that prioritize the well-being and cultural knowledges of participants, especially Diné elders, cultural advisors, and keepers of sacred and cultural knowledges in research.

Elders further recommended and validated the following cultural research protocols: research should observe spiritual, cultural and ceremonial protocols. Researchers should be expected to engage in appropriate practices of *honoring and acknowledging the land* through song or prayer since this is critical to our Indigenous epistemologies and ontologies. Establishing relationships with the land, environment and

all living things are important aspects of Indigenous cultural protocols. This process demonstrates a form of respect and acceptance of Indigenous peoples cultural value systems. Depending on what type of research is being conducted, and where, the NNHRRB should require researchers to partner with a local medicine man, elder who is a practitioner of traditional practices, or spiritual leader from the area to ensure the proper ceremonies, prayers, and protocols are taking place *before* any data is collected or removed from the area. This includes but is not limited to prayers for the fauna, plants, and spirits of the area as well as any relevant offerings.

Next, elders recommended establishing protocols for creating rapport with community elders. Establishing relationships with community elders and *gifting* are important in the initial steps of establishing relationships with community members. The act of gifting demonstrates a form of respect and the importance of reciprocity. The process allows for all parties to acknowledge each other's presence and honor those participating in research (as primary or secondary participants) with the acceptance of gifts. An important protocol for researchers is to make proper introductions using a Diné standard form of introduction. Affirm who you are, who your parents and grandparents, and where you come from. Next, establish your purpose and intention for your visit. Establish yourself as a part of the community and focus on other roles you have other than a researcher.

Moreover, the elders recommend that researchers be required to seek permission before disseminating study findings involving the participation or efforts of elders and should require researchers to formally acknowledge the participation of elders in any publications or public presentations of the research. Additionally, the researchers are

strongly encouraged to follow up and report back to the community and elders and community members who have participated or assisted in the research post-study (after the research has been completed), especially in the case of any publications or other tangible outcomes related to data collected with, on, in, or for Diné and Diné Bikéyah.

Lastly, elders stressed that language is an important protocol for research within Indigenous communities, particularly for the Diné people. Researchers who conduct research with Diné speaking elders offer Diné knowledge and experiences within the context of Diné epistemologies, ontologies, axiology and methodology. Researchers who complete research on Diné Bikéyah are recommended to have a fluent Diné speakers as a member of their research team.

Conclusion

This article explored the role of sovereignty and self-determination in research and research methodology for Diné peoples and recommendations for improving research protocols and outcomes by Diné elders who served as research participants from 1957-1987. Research on elder protection and the role of tribal sovereignty and self-determination in research with Indigenous peoples is limited—especially research by Indigenous/Diné scholars. The present study is needed because research practices and protocols have historically had negative effects on Indigenous peoples, including Diné. As Māori scholar Linda Tuhiwai Smith (2012) writes, "the word itself, 'research,' is probably one of the dirtiest words in the Indigenous world's vocabulary" (p. 1). This is because research has been conducted in a manner that is not culturally respectful or congruent of Native communities, the jargon researchers use is almost impossible for the average Native person to understand, and the topics under investigation may not be

relevant to tribal communities. Thus, research has been conducted with little or no input from Indigenous peoples.

The NNHRRB, initiated in 1996, is a positive step forward in redressing these issues. Yet there is much to be accomplished. It is time to reclaim rhetorical and research sovereignty to guide research from a Diné philosophical perspective. This research has implications for developing a Diné conceptual model for elder knowledge protection and for tribal nations seeking to prioritize tribal sovereignty and self-determination in research. This study will also positively impact elders within Indigenous communities through policy amendments for the protection of elders and Indigenous knowledge systems. Lastly, this research is important to avoid repeating past protocol failures.

The next chapter applies these findings from to address the following questions: What can we learn from past research and the perspectives of Diné participants on the role of sovereignty and self-determination in research for Diné peoples? How can Diné philosophy inform a research methodology that aligns with cultural protocols and practices? How can this research contribute to Nihookáá' Diné Nidoolkah Bindii'a' (Earth Peoples Research Framework) as a potential research model?

CHAPTER 5

POLICY BRIEF AND RESEARCH IMPLICATIONS FOR RESEARCH ON DINÉ

BIKÉYAH

Sovereignty is defined as the fundamental right of a state to self-government and independence (Morris, 1975). The underlying definition of sovereignty in an Indigenous research context is the guiding story in pursuit of self-determination. Although sovereignty has not always been considered or engaged in Western research practices, recognizing sovereignty in research allows Indigenous people to protect how their lands, language, knowledges, cultural practices and protocols are engaged and studied. Sovereignty allows Indigenous peoples to exercise their power through acts of self-determination that allow for the regulation and enactment of policy, legislation, restrictions and protocol about research (Lyons, 2000). The following policy brief explores the role of sovereignty and self-determination in advancing justice and proposes policy changes for the protection of Indigenous peoples in academic research for the Navajo Nation.

Nihookáá' Diné Nidoolkah Bindii'ą' (Earth Dwellers Protection Research Framework) is proposed to support existing NNHRRB and Diné human protection organizations such as the Navajo Nation Human Rights Commission and the Office of Navajo Historic Preservation which both serve as a forum to preserve and protect the Diné people and their way of life. This policy brief applies findings from a study conducted with six Diné elders who participated in research activities on the Navajo Nation between 1956-1986 to address the following questions: What can we learn from past research and the perspectives of Diné participants on the role of sovereignty and self-

determination in research for Diné peoples? How can Diné philosophy inform a research methodology that aligns with cultural protocols and practices? How can this research contribute to Nihooką́ą́' Diné Nidoolkah Bindii'ą' (Earth Dwellers Protection Research Framework) as a potential research model?

The perspective from community members affected by this research remains to be told and, most importantly, underscores the lack of regard or understanding for Indigenous self-determination as it applies to health practices, medicine, research, the bodies of Indigenous peoples, and the reasons for why/how non-Native peoples come to be on sovereign Indigenous lands. Testimonials of community elders and members, which could inform Indigenous or Diné research methods/methodology, are almost non-existent. The importance of documenting research initiatives from an Indigenous perspective and examining the dynamics of Indigenous knowledge is crucial (though it is not the scope or focus of this paper). More importantly, reviewing the two bodies of knowledge about research (both Indigenous and Western), how it has been conducted, and how Indigenous peoples wish for it to be conducted can create a valid depiction of the history and allow for strengthening current and future research initiatives of Indigenous communities (Barnhardt & Kawagley, 2005).

The adaptation of Indigenous practices, protocols, and researchers in research design and execution can be accomplished through federal, state, local, and institutional recognition of sovereignty and through acts of Indigenous self-determination in research. This will allow research to minimize the cultural, spiritual, social, and health related harms to Indigenous peoples. The following section examines the role of sovereignty and

self-determination in research related to, involving, or impacting Indigenous peoples, lands, knowledges, and cultural artifacts in the United States.

Sovereignty and self-determination in research

Sovereignty, as it applies to Indigenous peoples, is a term that has a long and complex legal history in the United States. For instance, the Supreme Court reaffirmed the legal standing of Indian nations as sovereign nations in the Marshall Trilogy cases. The Marshall Trilogy serves as a foundation to understanding Indian sovereignty for Indian Nations which means having distinct political entities that acknowledge their rights as a people. The resultant Marshall Trilogy reaffirmed tribal Indian sovereignty and acknowledged the existence of sovereignty prior to European contact.

The three cases that comprise the Marshall Trilogy are *Johnson v. McIntosh* (1823); *Cherokee Nation v. Georgia* (1831); and *Worcester v. Georgia* (1832). In *Johnson v. McIntosh* (1823), the Supreme Court acknowledged that tribal sovereignty, despite European migration, cannot be ignored. The *Cherokee Nation v. Georgia* (1831) ruled that Indian tribes were a "a distinct political society, separated from others, capable of managing [their] own affairs and governing [themselves]" (Getchens et al. 1993, 162). *Worcester v. Georgia* (1832), declares that tribal sovereignty is not relinquished when Indian tribes exchange land for peace or protection. These cases provide a foundation for the U.S. and states to recognize that Indigenous people have rights that precede the arrival of non-Natives. This allows Indian nations to drive research practices and have political influence to set guidelines and restrictions for how research with/for their nations is undertaken, when, why, how, and by whom. Indigenous based policies should focus on protecting, prioritizing, and respecting the rights of the People, their lands, and

their culture and not focus on prioritizing the rights of non-Indigenous researchers and research institutions. Lastly, this means that researchers do not have any inherent right to enter into Indigenous spaces and conduct research without the approval or acknowledgement of the People who live on those lands.

As previously stated, tribal sovereignty remains a nationally recognized but legally contested concept regarding the inherent power of a nation to govern itself since states may resist recognizing sovereignty. As further evidence of efforts underway to honor Native American sovereignty, the Native American Language Act (NALA), Public Law 101-477 was enacted by Congress in 1990 so that Native Americans may preserve their native languages. NALA encourages and supports the use of Native American languages in school as a medium of instruction to enhance the survival and educational opportunity for Native Americans (25 United States Code, Chapter 31). This Act recognizes that traditional languages of Native Americans are an integral part of their cultures and identities and form the basic medium for the transmission and thus survival of Native American culture, literature, history, religion, political institutions, values, and thought systems. Although this Act is not specifically focused on research, it does present implications for research policy as recognition of the importance of traditional languages of Native peoples could mean that research needs to be conducted in a language that is understood and accessible to the participants of the study. In other words, this may present implications not only for speaking to research participants in easily understood terms (for example, avoiding the use of jargon or other confusing academic language that may not be easily understood by community members outside the field of research study or outside of academia). It may present an additional implication for the onus of

researchers to ensure that research practices, policies, and protocols align with the spoken or understood language of the tribal community they are working with. Regretfully, state and local education agencies continue to struggle with honoring the tribal special relationship with the U.S. government, but I will discuss this more shortly.

The enactment of federal mandates relating to research and human subjects were initiated about the same time as the adoption of Indian policies and significant cases. The inception of self-determination has been the basis for strengthening Federal Indian Policy for Indigenous peoples. It is also equally important to understand the impact of research from a historical context. The next section will discuss the complex history of colonized research practices.

An important aspect of tribal sovereignty is the trust relationship between the United States and Indian Nations. Although the special trust relationship was established to execute treaty obligations, advocate, and protect the best interest of Indian tribes, Native people continue to struggle with sovereignty and protection of their special trust relationship with the Federal government. The federal government's obligation to honor this trust relationship and to fulfill its treaty commitments is known as its trust responsibility (Pevar, 1992). In 2004, the President signed an executive order reconfirming the United States' commitment to work with federally recognized tribal governments on a government-to-government basis and to support tribal sovereignty and self-determination (Executive Order 13336, 2004). Contrary, threats to tribal sovereignty and states jurisdictional battles arose in 2001 when English-only legislation was proposed in Arizona. For Indigenous peoples, this type of legislation did not recognize the previous legislation related to NALA. In other words, although NALA was introduced first, this

English-only legislation would prohibit schools to incorporate non-English practices into the classroom. This legislation introduced a threat that Indigenous language and culture could not be taught in the schools which would not allow Indigenous people to convey their values, knowledges, and important historical and cultural lessons through their mother language. This law meant that research conducted in schools did not have to be adapted into the language of the People nor protocols that reflect Native beliefs. This would not be the first and only failed attempt by the federal government to protect the rights of Indigenous people.

In short, it is important to understand sovereignty, self-determination, and the trust relationship in order to understand how these concepts shape the current state of research with/for/among Indigenous peoples in the U.S. Although this section has focused mostly on examples of research that occurred on tribal lands, this paper extends sovereignty in research beyond research that takes place on tribal lands. This is because, as the Marshall Trilogy recognizes, Indigenous peoples were on U.S. lands prior to the arrival of Europeans so research that occurs anywhere on the U.S. *is* taking place on Indigenous lands. Sovereignty in research extends beyond tribal boundaries to research that involves *any* Indigenous participants, lands, language, cultural practices, and protocols – regardless of where the physical research takes place. This means non-Native researchers and research institutions need to work with Indigenous people to ensure their research practices, protocols, and policies are culturally appropriate and that Native scholars need to work with their nations to ensure that tribal nations have policies in place that align with their cultural traditions and protocols to protect the land, people, and traditional and cultural knowledges.

The ensuing policy recommendations argue for the recognition of sovereignty in research while promoting social justice. Sovereignty allows Indigenous peoples to exercise the power to take ownership of who they are, where they are, and what has rightfully been given to them from their ancestors. This means their lives, bodies, lands, traditions, and practices are not open for non-Native researchers to come in and take, exploit, negate, or explore at their leisure and from their racist, western perspectives. Sovereignty in research is about acknowledging past harm, recognizing past research failures, and taking the necessary steps to promote Indigenous rights and restorative justice. The next sections present a review of the history of research and the evolution of Federal Research Protections for Indigenous people.

Federal Research Protections

Many landmark cases attempted to resolve the controversies associated with tribal sovereignty. Moreover, the adoption of national research guidelines that resulted from international research violations during World War II have also shaped the research policy landscape for Indigenous peoples. The following section includes court cases and legislation that have been significant to tribal sovereignty and have had ethical and legal implications for how research is conducted. In this section, I briefly review the history and evolution of colonized research practices as well as federal mandates relating to research and human subjects.

Historical inequalities and past research injustices in American Indian history have been evident since at least the 1800's. The result of such a violent and oppressive education history is that American Indians have struggled adapting to a long series of new federal policies and mandates. The initial intrusion of federal policies on Indigenous

peoples in the U.S. began with the Civilization Act of 1819 (De Jong, p. 57-59). While this Act directly applied to education, the disregard for Indigenous peoples, their languages, knowledges, protocols, and values were evident in research practices as well. During this early colonial era, colonizers failed to acknowledge any form of Indian culture or traditional practices as a form of belief or religion.

One historical example was the Ghost Dance of 1890, where American soldiers massacred hundreds of Plains Indian tribes while participating in a dance to worship the American God. Although this form of dance was a form of Christianity, the act of dancing was perceived as an Indian ceremonial dance. The outlawing of religious ceremonies continued throughout the 1930's, the most controversial was the Sun Dance, an alleged "sacrilegious" ceremony performed by Native Plains Indians from the perspectives of Whites. The enactment represented early federal efforts to assimilate Indian nations into mainstream society. Although this example is not overtly related to research it serves as an example of how non-Native peoples – many who "studied" Indians, including anthropologists, and documented their practices for academic, historic, and research purposes (Deloria, 1969) – did not understand, respect, or recognize the history, significance, and meaning of Indigenous practices or the effects of assimilation. The result was that policies and actions were taken that led to one of the biggest massacres of American history.

For the next 150 years, Congress continued to create legislation that directly changed the direction, vision, and lived context for American Indian Nations. After nearly a century of the signing of treaties, the United States government continued to make slow shifts in recognizing their treaty obligations, which included the protection of

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Native lands. This meant that research on Indigenous lands proliferated and exploitation of natural resources, desecration of burial sites, and the ransacking of historically and culturally significant sites and artifacts ensued (such as the case of Chaco Canyon and Canyon de Chelly).

The Meriam Report was a critical analysis of the Dawes Act and the overall poverty conditions of reservations. The data from the report was used as a means to begin a reform effort for tribal sovereignty and self-determination for improvements to Indian Nations; reversing the assimilation and Christianization of Indian people. This era provided the basis for self-governance, and empowered state and tribal governments to begin local government control. During this period of time, Indian tribes started to (re)govern their own processes and were educated to realize what was happening with non-Natives invading their communities. Thus, guidelines and boundaries were set with who could enter and work in reservations. For instance, the Navajo Nation set their own local laws to protect their lands from outside harm.

This monumental movement has set the foundation for significant federal mandates, such as Congress passing the Johnson O'Malley Act to "provide education, medical and welfare programs to Indians" (Meriam Report, 1928). Followed by the passing of the Indian Reorganization Act, of four major reforms was to "provide special education for Indians: Indian cultures would be encouraged through support for arts and crafts, traditional activities, and teaching schools attended by Indian children, and scholarships would be given to Indian students for college or vocational training" (Meriam Report, 1928). New American Indian policy, known as the Indian Reorganization Act (IRA) of 1934, and the Johnson O'Malley Act of 1934 was

established as a subpart to the IRA and recognized the importance of American Indian language and culture. These Acts, although not focused on research explicitly, help to illustrate how the federal government was starting to support Indian education and respect language and culture. Native people started to feel like their language, culture, and traditions were finally being validated. However positive it was that their voices were now being heard, this did not lead to tangible federal research policies that benefitted Indian tribes until the next decade.

As time passed, the international landscape began to influence research policy. The Nuremberg Code, which resulted from research violations that occurred during World War II, is the most important document in the history of ethics in medical research. The Nuremberg Code would commence research protections for human subjects. In 1946, as a result of the Nuremberg War Crimes Trial, 23 Nazi doctors were charged with brutal crimes while medical experiments were performed on inmates in concentration camps without any consent from the participants. The Nuremberg Code established two important principles: voluntary consent and the right for human subjects to terminate participation at any time.

Voluntary consent, an important aspect of the Nuremberg Code, gave subjects the legal authority to exercise their free power of choice without force or coercion. This was important for Indigenous peoples as it gave them the right to decide who, what, and where research could be conducted rather than being the guinea pigs for non-Native researchers that they had been in the past (as was the case with research aimed at civilizing and assimilating Indian children through boarding schools, see Carlisle Indian School from 1879-1950's). The second important principle was the ability to end

participation in an experiment at any time. Prior to the Nuremberg Code, human subjects had no rights. The result of the Nuremberg Code gave research subjects as much authority as the researcher (Grodin, 1996). Although the Nuremberg Code initiated some protection for human subjects, including Native peoples, unethical research practices aimed at Native communities continued unabated until the 1970's (see for example, the Cornell-Navajo study). Medical, archeological and anthropology studies on Native American reservations continued with little regard for Indigenous peoples.

The era between 1970-1990 ushered in another evolution of research protection. The National Research Act of 1974 set the foundation for Federal regulations and the formation of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, also known as the Belmont Report, a document of ethical principles which encompasses the following principles: respect for persons, beneficence, and justice. Respect for persons means that every individual has the right to decide what happens to their body and when/how they engage in research. Beneficence refers to the recognition that the researcher has a moral obligation to "do the right thing." In other words, research should be kind and do well rather than exploit, harm, or injure those targeted by the research. Lastly, justice refers to the idea that the risks of engaging in research should not outweigh the benefits. While this last tenet presents some protection to Indigenous people, the aspect of justice does not immediately correlate with notions of Indigenous justice and harm. For instance, Western definitions of harm can be limited to physical harm but may not recognize spiritual or cultural harm Indigenous participants may face if they are subjected to research practices and protocols that do not align with cultural protocols. For example, conducting and engaging in research that

explores topics that are culturally sensitive or conducted during an inappropriate time of year.

The basic ethical principles further protect human subjects. For Indigenous communities, respect for persons stresses the importance of the subject to understand the study and know it is voluntary. This principle may mean research needs to be explained and/or conducted in Indigenous languages. In some ways, the policy could be used to support tribal sovereignty and/or self-determination through ensuring research is conducted in the appropriate language. Respecting the subject while protecting them from harm is also important because this means Native peoples will no longer be subjected to research on their bodies without understanding the full risks and benefits associated with the study. And finally, ensuring fair procedures and outcomes allows Native peoples to make the choice of whether they want to participate in a study and potentially benefit from its findings.

In terms of social justice, the Belmont Report emphasizes equity and fairness. As it relates to Native people, research on Native lands continues to be conducted disproportionately without respect of the people, land, culture and sovereignty. For decades, colonized researchers manipulated, desecrated and invaded the lands of the Indigenous people. Although federal laws were enacted, laws on Indian nations were not fully enforced to the extent of providing local protection of the rights of their people and resources.

The exploitation and unethical representation of Native Americans was at its peak from 1960-1975, through various media, including movies, such as "A Man Called Horse," "Little Big Man." "Lone Ranger," and other Classic Western Movies. Television

portrayed feathered Indians with tomahawks and other Indian stereotypes including tepees, war paint, and the use of bow and arrows as forms of weapons. This presentation of Indigenous peoples as savage and lawless may have contributed to the impression and understanding of Western researchers that it is not important to honor the knowledge systems, protocols, lands, and bodies of Indigenous peoples through the observation of culturally/tribally appropriate research policy and guidelines. Even more common was the invasion of sacred Indian lands throughout Indian country. Archaeologists, researchers from various colleges and universities, and medical personnel targeted Indian people for studying a group of people they oppressed hundreds of years. The act of unethical research would evolve to extreme practices of the removal, impugning Indigenous people's bodily sovereignty by subjecting them to unclear medical research practices without their full understanding and consent, and the desecration of ceremonial and sacred sites while removing human remains from sacred burial sites and ancestral objects for the purpose of investigating and exploiting American's First People.

Even more common was the removal of human remains and cultural items from Native American graves lands and communities without proper consent or protocol and without regard to how that may affect the emotional, spiritual, psychological, and physical health and wellbeing of those living around the area. These acts of injustice provided a strong influence for the creation of the Native American Graves Protection and Repatriation Act (NAGPRA), Pub. L. 101-601, 25 U.S.C. 3001 et seq., 104 Stat. 3048. NAGPRA is a United States federal law enacted on 16 November 1990 which provided protection of anthropological, archaeological, and other related research on

Indian land. In 1970, the Native American Religious Freedom Act (NAFRA) was enacted to recognize Native American religions.

The NARFA gave Indian Nations the right to freely express their beliefs and religions without any legal repercussions. After centuries of failed attempts to Americanize the Indian, general society began to rethink colonization and Native Americans began a movement for sovereignty and cultural preservation and sustainability. This legislation demonstrates federal recognition of the need to protect Native Americans from cultural exploitation and desecration of their lands and human remains. This fundamentally presents implications for past research that did not respect or honor the rights of Indigenous peoples and their lands. Following were other pieces of legislation which supported Indian rights and sovereignty of Indian people, including the Indian Self Determination Act of 1975, which for some tribes, ushered in a desire to establish their own research Internal Review Boards (which I describe in more detail below).

Another significant legislation was the Indian Arts and Crafts Act of 1990, a law prohibiting misrepresentation of marketing of Indian Arts & Crafts. The law finds it illegal to offer or display, any artifact or craft falsely suggesting it is Indian produced. This legislation, although not specifically related to research, provides protection for Indian people from the exploitation of researchers who may seek to take their art or artifacts without attributing ownership or credit to the Indigenous people or artist.

As colonizers continued to exploit Indian cultures, Native people began to advocate and defend their nations. Internationally, countries with highly populated Indigenous peoples such as United States, Canada, New Zealand, and Australia oppressed

their indigenous peoples and community, making a public statement of continuous oppression and lack of protection for their Indigenous nations. Nonetheless, the Declaration of Indigenous on the Rights of Indigenous Peoples establishes a universal framework of minimum standards for the survival, dignity, well-being and rights of Indigenous people. It argues that "Indigenous peoples have the right to maintain, control, protect, and develop their cultural heritage, traditional knowledge, and traditional cultural expressions… they also have the right to maintain, control, and develop their own intellectual property over such cultural heritage, traditional knowledge, and cultural expressions" (UNDRIP, p. 11). The declaration further out laws discrimination against Indigenous peoples and promotes their full and effective participation in all that concern; ensures their right to remain distinct and to pursue their own priorities in economic, social and cultural development. This legislation, although it was not signed by the U.S., helps support and establish dignity in research for Indigenous peoples.

State Policies

This section explores state devised research policies in the state of Arizona – where part of the Navajo Nation resides. The most recent, public, and significant act of legislation regarding research protections for the state involved the abuse of Indigenous peoples in the state.

In 1989, the Havasupai tribe and Arizona State University (ASU) began a research study partnership known as the Diabetic Project. The purpose of the research was to collect biological samples from members of the tribe in order to explore whether a genetic link to Type II Diabetes existed. However, the researchers, who were non-Native individuals who did not have a cultural or personal relationship with the Havasupai,

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departed from the original study and used the collected biological samples to conduct research that fell outside the scope and focus of the initial study. This research departure occurred without the knowledge or consent of the tribe, its members, or the research participants and violated an important principle outlined by both the Belmont Report, the Nuremberg Trials, and the UN DRIP.

Shortly thereafter a participant of the research study learned the original genetic samples were used for other studies without proper participant consent. The alterations made by the non-Native Western researchers, utilizing Western research practices, to the "Diabetic Project" study was culturally unacceptable and presented the potential to discredit sacred cultural knowledge and cause far-reaching spiritual damage. In 2004, a lawsuit was filed against the Arizona Board of Regents and ASU researchers for violating participant and tribal rights. The issues cited included using genetic samples without proper and informed consent from Havasupai tribal members, violation of civil rights for the improper use of blood samples, unapproved use of data, and violation of medical confidentiality (2004). This case illustrates a strong example of the need for strong research protections for tribal sovereignty and tribal self-determination.

Prior to 2004, research among Arizona Universities lacked state protection for human research subjects and had little or no respect for Indian tribes as previously discussed with ASU and Havasupai Tribe. The impact of the 2004 lawsuit between the Havasupai Tribes and Arizona State University established Arizona Board of Regents adoption of ABOR Policy 1-118 On Tribal Consultation. Since the inception of the ABOR Policy 1-118, the three public state universities (Northern Arizona University, Arizona State University, and the University of Arizona) have been required to adopt

research protocols and ethical practices for conducting research with, for, about, and/or among the Indian tribes of the state whom geographically make up 2/3 of the State of Arizona.

The Arizona Board of Regents Policy 1-118 on Tribal consultation was developed as a result of an unethical research study conducted on Indian lands. The policy was also created to reaffirm the commitment of support to the government-to-government relationships with the 23 Indian Nations in Arizona. Specifically, the policy recognizes the inherent sovereignty rights and the importance of trust relationships to tribes by requiring researchers to demonstrate permission from the tribe or community to conduct their research. The policy further acknowledges Native culture, traditions, beliefs, tribal law codes, regulations and protocols in relation to research on with or by Native people or lands. This policy forefronts the rights of Indigenous peoples in shaping or controlling research policy, practices, and protocols because receiving IRB permission and protection from the research institution depends upon whether the tribal community agrees to the research that is proposed, how it is designed, and its stated goals and objectives.

Tribal Policies: Research in and with Diné Bikéyah

While the state of Arizona has now adapted some form of recognition for tribal sovereignty rights in research, it was not until the winter of 1995, the Navajo Nation, the largest tribe in the state, through its Navajo Area Indian Health Service, acquired direct oversight of its tribal Institutional Review Boards (IRB). The goal of the IRB was to protect the rights and welfare of human subjects recruited to participated in research activities and to protect communities in which research was to be conducted. On October 10, 1995, the Navajo Nation Tribal Council approved the Navajo Nation Health Research

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Code which called for the creation of a Navajo Nation Health Research Review Board that would oversee any research that is conducted on the Navajo Nation.

In March 1996, the Navajo Nation Health Research Review Board (NNHRRB) was developed to guarantee ethical research for the Diné people. (13 N.N.C.§3205, Health & Welfare). The creation of the NNHRRB was established to review all proposals (notwithstanding other IRB approvals from outside research institutions) for human research which will occur within the territorial jurisdiction of the Navajo Nation, subsections of the Navajo Nation Tribal Code (N.N.C.§3206-3271) include *Informed Consent, Progress on Research, Continuing Review of Research Activities, Publication Review Procedures, Permit Appeal Procedures, and Enforcement*. The Navajo Nation would be the first nation to establish and exercise their sovereignty rights through establishing research guidelines for their people and Nation. Their policies go beyond federal, state, and institutional policies and include protocols that require researchers to provide regular updates on their research, require researchers to apply for ongoing permission to continue the study, outlines requirements that must be met for any data to be published, and outlines penalties for any violation of research procedures. This provides an example of tribal sovereignty and self-determination in enacting research requirements and policies that align with the nation's understanding and protection of justice in research.

University/Institutional Policies: ASU as one example and the role of CITI Training

After the adoption of the ABOR policy, Arizona State University established an effective research protocol that institutes the highest ethical process to protect human subjects. The Research Conduct of Research is committed to ethics training for

researchers. All research dealing with human subjects and ethics is completed through an on-line system known as the Collaborative Institutional Training Initiative (CITI) which provides modules to ensure every student and faculty researcher understands and comprehends research ethics and responsibilities. CITI training provides an overview of information privacy and security training as well as conflicts of interest and human subjects research training.

The Office of Research Integrity and Assurance is a resource for researchers to support ethical principles and compliance with federal, state, and university regulations governing research. When dealing with human subjects, and prior to gathering data and research, the Institutional Review Board must approve all research. Researchers affiliated with this state university must apply to the ASU IRB and gain its approval to gather and complete data collection to complete any research studies. The ASU policies are an example of how research protection for human subjects has evolved to policy and mandated protocols at the local college and university level for an improved protection system for all human research.

The Role of Elders in Research

Tribes have sought to protect their cultural knowledge and practices from harmful research through implementing policies and ordinances. Two of the tribes who have developed tribal policy include the Navajo Nation as previously discussed. The other tribal group is the Hopi Nation which has developed local policies such as the Protocol for Research, Publication and Recordings: Motion, Visual, Sound, Multimedia and other Mechanical Devices. The policy allows protection for the Hopi rights and Intellectual Property by outlining protocols for the appropriate use and permission of media. The

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policy prevents from Hopi traditions from further misrepresentation and exploitation. The protocol allows for all research on the Hopi Nation to be guided and protected. Other resolutions including H-10-94 provides support to the implementation of NAGPRA.

More recently, research elders have been the subject of discussions on research participation as they may shape and guide local research practices. Elders and cultural knowledge keepers. For the purposes of this paper they are defined as those who have participated in past research and are recognized by the community as traditional knowledge keepers, cultural stewards, and possessors of community, cultural, and tribal memory. In research, elders may provide important translation services, cultural stories and oral history, serve as liaisons between the community and non-Native researchers, can lead local ceremonies and protocols, inform researchers of appropriate behaviors and expectations, and help interpret cultural history and traditions.

In Alaska, elders are cultural navigators and assist as cultural knowledge keepers. Alaskan elders are utilized to support native healing practices and provide key information about Indigenous knowledge systems in local communities (Burhansstiapnov, 2014). Elders are key to understanding Indigenous views and help put research studies into cultural perspective. Elders can also draw examples to help researchers understand the community. Elders can serve as consultants and help improve the research design and identify appropriate instrumentation or connect researchers with community members who can create appropriate research instruments (Fisher & Ball, 2003). Elders can also identify ways community members can gain skills and employment through research and help minimize chances of group harm and

stigmatization from the research. Lastly, elders can help mandate how data and findings can be shared.

Currently research on elder protection as it applies to tribal sovereignty and self-determination in research and methodology is limited but needed. Some research has even begun to explore the ethics of how, when, and why elders should be compensated and recognized for their efforts in research. Additionally, elders are key to maintaining cultural knowledge and have been used in research but have not been specifically targeted by research policies for protection. Only a few articles have explored the role of Native elders in research (Arolnith, 1994; Clemmer, 2011; Lee, 2014; NN IRB, 2003; Schrag, 2006). Even though there currently exists some tribal IRB's which outline tribal policies to reclaim rhetorical and research sovereignty and guide research from a tribal philosophical perspective, little is known about how tribal and IRB procedures have been influenced by elders and how procedures prioritize the well-being and cultural knowledges of elders in research.

More and more Indian tribes are taking ownership of their land, culture and language. Community elders are engaging in more community-based research partnerships and research. After centuries of oppression, researchers are finally acknowledging and respecting Indigenous people and communities. In retrospect, Indigenous research evolved with little regard for procedures, research design and respect for Native participation. There is obviously a disconnect between the values being promoted in research. Although cultural knowledge and protocols are not always observed, the researcher seems to always benefit while the community and people do not always benefit from the research. The overall intention for Indigenous research should be

to contribute academic contributions and findings to support the rights and culture of Indigenous people.

How NNHRRB supports and/or protects Diné research participants and lands

The Navajo Nation Health Human Research Review Board (NNHRRB) supports research that promotes and enhances the interests and the visions of the Navajo people: to encourage a mutual and beneficial partnership between the Navajo people and researchers; and to create an interface where different cultures, lifestyles, disciplines, and ideologies can come together in a way that improves, promotes, and strengthens the health of the Navajo people (www.nnhrrb.navajo.gov). NNHRRB was created in 1996 to maintain, control, protect, and develop their Diné knowledge systems, culture and language. The purpose of this policy is to provide cultural research protocols for recognizing and approving beneficial research and to eliminate harmful research practices.

This following policy recommendations are informed from a study with six Diné elders from Many Farms, Rough Rock, and Chinle during 1956-1986. In a series of in-depth interviews with the paper author, the elders shared recommendations for how to align research practices with our SNBH philosophy and our Diné cultural practices. The following sections outlines policy recommendations in seven total areas. It is recommended the NNHRRB review this proposal and revise, adapt, or adjust these recommendations for future NNHRRB research provisions.

Policy recommendations

This policy seeks to improve research relevance and ensure research is moral, ethical, and respectful of the Indigenous peoples and the communities it seeks to serve. In

this section, recommendations for research policy are divided into seven areas and recommended for the following: (1) the research application process; (2) protocols for obtaining consent from research participants; (3) protocols for gathering, sharing, storage, and ownership of collected information (henceforth referred to as data); (4) researcher expectations and responsibilities including expectations for research outcomes; (5) the role and responsibilities of NNHRRB; (6) protocols for terminating research; (7) the decision appeals and dispute resolution process; and, (8) general recommendations for research. The last section of is intended to outline what researchers can/should do to improve the research process and relationships between themselves and the stakeholders of NNHHRRB.

1. Implement a mission statement

Although the NNHRRB has a vision statement, to date, no mission statement for the organization has been stated. To align with the proposals in the seven areas identified above, it is recommended the following mission statement is recommended for the NNHHRRB:

NNHRRB maintains a vision committed to promoting the education, well-being, and health of its members, staff, community leaders, elders, administrators, and community partners (hereby referred to as "Stakeholders"). NNHRRB recognizes and respects that research can serve to benefit and address modern day Diné health, environmental, education and other concerns and challenges and welcomes research that seeks to address those concerns and challenges. Additionally, NNHRRB recognizes and respects the obligation(s) of the researcher to knowledge creation in his/her discipline and seeks to enter into

mutually respectful and **beneficial partnerships** with interested researchers. In order to uphold its mission to its Stakeholders as well as honor the rights and responsibilities of independent researchers, and, NNHRRB shall approve only research that adheres to the specific research principles outlined in the following paragraph:

Research, and its concomitant goals and practices, is for the purpose of serving the purpose of asserting self-determination and sovereignty by reserving the right of Indigenous peoples to take control and NNHRB of their information and to assist in the promotion of healthy lifestyles, practices, and effective program planning. NNHRB promotes making the most of any funding or research opportunity on behalf of Indigenous peoples. "Benefits to the community as a whole and to individual community volunteers and participants should be **maximized** by the researchers. We expect researchers interested in conducting research in, with, for, or on the Navajo Nation or with Diné people to be culturally respectful, appropriate, and, if applicable, responsive to the lands and the people of Navajo. The NNHRRB is committed to ensuring any research approved by our organization follows appropriate cultural, spiritual, linguistic, and spiritual regulations and protocols. NNHHRRB reserves the right to not only judge and evaluate the merits of a proposal, but also to put forward conditions so that good research ideas can be done in a good way (First Nations Information Governance Committee, 2007).

It is time for Diné people to reclaim rhetorical and research sovereignty and guide research from an Indigenous philosophical paradigm. Although sovereignty has not always been considered or engaged in Western research practices, considering and

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applying aspects of sovereignty in research allows Indigenous people to reclaim ownership to their lands, language, cultural practices and protocols. In order to better protect Diné peoples, their knowledges, elders, and Diné Bikéyah, a few policy revisions and amendments are recommended for the NNHRRB. In a study conducted in 2019, elders recommended and validated the following cultural research protocols:

2. *Observing spiritual, cultural and ceremonial protocols*

A critical area of Indigenous research is developing a series of spiritual, cultural, and ceremonial protocols for any researcher (Indigenous or non-Indigenous) conducting research on Diné Bikéyah. Researchers should be expected to engage in appropriate practices of *honoring and acknowledging the land* through song or prayer since this is critical to our Indigenous epistemologies and ontologies. Establishing relationships with the land, environment and all living things are important aspects of Indigenous cultural protocols. This process demonstrates a form of respect and acceptance of Indigenous peoples cultural value systems. Depending on what type of research is being conducted, and where, the NNHRRB should require researchers to partner with a local medicine man, elder who is a practitioner of traditional practices, or spiritual leader from the area to ensure the proper ceremonies, prayers, and protocols are taking place *before* any data is collected or removed from the area. This includes but is not limited to prayers for the fauna, plants, and spirits of the area as well as any relevant offerings.

3. *Protocols for establishing rapport with Community Elders*

Establishing relationships with community elders and *gifting* are important in the initial steps of establishing relationships with community members. The act of gifting demonstrates a form of respect and the importance of reciprocity. The process allows for

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all parties to acknowledge each other's presence and honor those participating in research (as primary or secondary participants) with the acceptance of gifts. An important protocol for researchers is to make proper introductions using a Diné standard form of introduction. Affirm who you are, who your parents and grandparents, and where you come from. Next, establish your purpose and intention for your visit. Establish yourself as a part of the community and focus on other roles you have other than a researcher.

As much as possible, the NNHRRB should ask researchers to explicitly create a detailed plan for how they will honor elders or compensate them for their participation in research whether they are acting as translators, providing cultural context, serving as guides, or in any other capacity assisting researchers, this includes but is not limited to serving as research participants.

The NNHRRB should ask how researchers will engage in gifting. Not all gifts need to be monetary, though these should not be excluded as in the case of translation or guide services provided, but can include gifts of food items, tádidíín, compensation for any travel expenses incurred, cedar, or any other requested items. If the researcher is unsure of what is appropriate to gift in this area, the NNHRRB is encouraged to provide counsel or direct the researcher to places where they may receive guidance on the matter. e

Moreover, the NNHRRB should require researchers to seek permission before disseminating study findings involving the participation or efforts of elders and should require researchers to formally acknowledge the participation of elders in any publications or public presentations of the research. Additionally, the NNHRRB is strongly encouraged to require the researcher(s) to report back to the community and elders and community members who have participated or assisted in the research post-study (after the research

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has been completed), especially in the case of any publications or other tangible outcomes related to data collected with, on, in, or for Diné and Diné Bikéyah. If possible, the NNHRRB should request researchers to provide the NNHRRB with physical copies of relevant publications or other tangible items. These items will be used to create a research library and running record for all research work conducted in, with, on, or for Diné Bikéyah.

4. Role of Diné language in research

Language is an important protocol for research within Indigenous communities, particularly for the Diné people. Researchers who conduct research with Diné speaking elders offer Diné knowledge and experiences within the context of Diné epistemologies, ontologies, axiology and methodology. Researchers who complete research on Diné bikéyah are recommended to have a fluent Diné speakers as a member of their research team. It is further recommended NNHRB establishes a policy for Diné research to include a Diné language speaker with all research studies conducted for or by Diné people. An executive policy should then be developed with members of the Navajo Nation Council, NNHRRB, and community leaders. Once the policy has been developed and amended, NNHRRB can execute the cultural protocol requirements for Diné research participants. The policy amendment will allow for accurate and accountable language research practices by researchers on Diné Bikéyah.

Relevant applications and forms

This policy brief has outlined the process by which researchers are expected to seek provisionary and final approval for their project. It is recommended the NNHRRB clearly state that ALL applicants are required to clearly indicate not only **what** research

will be done, for **what** purpose information or data will be gathered and used, **where** the information will be physically stored, and **who** will be involved and have access to any information collected but **how** cultural protocols and practices will be observed throughout the research process. See the following appendices for recommended forms and checklists to facilitate the adoption of the policy recommendations listed above (see APPENDICES).

Conclusion

This policy brief suggests that Diné peoples can reclaim and exercise their sovereign power and ownership through federal, state, local, and tribal practices and policies through adopting research policies, protocols, and guidelines that are informed by our community members, epistemology, and elders. Sovereignty and self-determination are a topic that is important to Indigenous peoples but until recently had not been discussed in any meaningful detail. Although some work has explored the importance of Indigenous peoples in driving research policies, protocols, principles, and practices (see the work of Linda Smith, Shawn Wilson, etc.). To date, no research has examined how federal, state, and local policies influence Indigenous research policies in the southwest and, more importantly, how Indigenous peoples shape their own research policies, protocols, and guidelines to not only protect the humans, land, language, and knowledges implicated by the research.

Research is needed that examines how tribes enact their own sovereignty and self-determination to outline protocols and guidelines for research and research methodology that aligns with their own epistemology and promotes protections for the well-being and cultural knowledge of their tribal participants. Future research should examine the role of

tribal sovereignty and self-determination in research for Diné participants and elders; conceptions of research as it applies to research practices, indigenous epistemology, the role of elders and cultural knowledge keepers, and cultural protocol; as well as the implications of Internal Review Boards (IRBs) in advancing sovereignty and self-determination for Indigenous nations.

CHAPTER 6

CONCLUSION

This research study examined the perspectives of Diné participants on research conducted in the three focal communities during this period of time. A completed historical research qualitative study explored the role of sovereignty and self-determination in research on and with Diné peoples over the critical 30-year time period. How, if at all, was Diné sovereignty and self-determination reflected in these studies? What can we learn from past research and the perspectives of Diné participants on the role of sovereignty and self-determination in research for Diné peoples? This research covers conceptions of research as applied to Indigenous ways of knowing while acknowledging and respecting local cultural protocols. Findings will be used to inform the NNHRRB policy in ways that prioritize Diné sovereignty and self-determination. More broadly, I seek to use this research to inform research on, by, and for Indigenous peoples in ways that will promote social change.

This study expands knowledge on the topic under investigation by presenting knowledge on research epistemology and methodology in the following ways: how it may be used to protect Diné elders and cultural protectors and to develop a Diné theoretical model for research and elder knowledge protection. The study will fundamentally benefit the field of Justice Studies through promoting rhetorical sovereignty – allowing Indigenous peoples to frame the parameters of the research conversation, and by presenting a framework that ensures Indigenous knowledges are protected from harmful, exploitative, or irrelevant research and by presenting a vision for

tribal nations to prioritize tribal sovereignty and self-determination in research (Lyons, 2000).

I was primarily raised by my maternal grandparents, Wade and Linda Hadley. My grandmother Linda was of the Kinyaa'áanii and born for Tłashchi'í clans; my grandfather Wade was of the Tóahání and Táchii'níí clans. I was fortunate to be raised in a dual society—the Diné and White mainstream world. This research study has helped me realize my life's work has been profoundly inspired by the example of my grandmother, Linda Begay Hadley—one of the first Diné researchers.

As an indigenous researcher, this study seeks to develop a tribal policy theoretical framework to recommend governmental and educational policies for the NNHRRB. The intent of this research is to amplify discussions of the role of gender, age, and cultural status in research.

Incorporating a Diné philosophy in research allows for a research methodology that aligns with cultural protocols and practices through a theoretical framework that is relevant for Indigenous communities. I further recommend research in, with, and for Indigenous people, specifically, the Diné people be driven by the concept of Są'áh Naagháí Bik'eh Hózhóón. Robert McPherson (2012) discusses how "Diné bizáád (Navajo language) establishes the epistemologies and conveys the knowledge of the people." In order to understand the framework of SNBH, one must understand the cultural oral history and tradition of Diné people.

SNBH suggests it is important to participate in a culturally responsive training that includes understanding the community, the People, and their way of life. Allowing the community to review and understand the purpose of the study and how the data will

be used is important. Because elders may speak the traditional language, having appropriate, experienced, and trusted language translators is necessary so that they can understand the context and full meaning, as well as implications, of the study.

Recommendations for Research

The recommendations from elders in this study include rethinking or reframing research methodologies and methods through our history, language, cultural practices and protocols. Second, acknowledging elders and those who have come before us through providing a history and context of the topic under study prior to introducing new research in the area. Third, elders recommend that Diné regain and protect our Diné knowledge systems for future generations. In other words, research should be prioritized that is undertaken by Diné for Diné using Diné research methodologies, Knowledge Systems, and practices. Lastly, elders insist on researcher accountability to the community, people, land and universe.

These recommendations could be facilitated by requiring NNHHRRB to provide a culturally responsive training to all aspiring researcher that helps them understand the significance of land and past and present research that has taken place in the community the researcher has indicated interest in serving or studying. It could also be facilitated by requiring the NNHRRB to conduct a listening session every 5-10 years with community members that have participated in research to elicit their experiences and potentially identify additional adjustments to policies that would help the NNHRRB better protect the lives, rights, and wellbeing of the Diné peoples and of Diné Bikeyah.

These Diné principles help us to rethink or reframe research methodology and methods through honoring our history, language, cultural practices and protocols. By

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acknowledging our elders and those who have come before (supernatural beings or our holy deities) our Diné people can regain and protect our Diné knowledge systems and carry them forward for future generations in ways that are respectful and appropriate. Researchers in general can benefit from Indigenous research and knowledges through first being accountable to the community, the People, the land, and universe. SNBH reminds us it is important to honor all of these by making offerings to these entities. Moreover, researchers need to formally ask for permission to conduct their studies. However, permissions should not be limited to formal organizations such as IRBs but rather to the environment, the community, elders, and the holy deities.

Second, SNBH suggests it is important to participate in a culturally responsive training that includes understanding the community, the People, and their way of life. Allowing the community to review and understand the purpose of the study and how the data will be used is important. Because elders may speak the traditional language, having appropriate, experienced, and trusted language translators is necessary so that they can understand the context and full meaning, as well as implications, of the study.

Lastly, the benefits of the study need to be determined by the community. The oral histories of Diné people rely on historical and philosophical perspectives to build on established frameworks such as Sạ'áh Naagháí Bik'eh Hozhó and incorporate Diné thought process in the structure and approach of academic research, more specifically, in protecting the elders and "cultural knowledge keepers" of the Diné Nation. Guided by Critical Indigenous Research Methodologies, a body of research largely by Indigenous scholars that outlines culturally respectful and responsive research practices for working with/in Indigenous communities, an SNBH methodology could help to "reclaim research

and knowledge-making practices driven by Indigenous people, knowledge, beliefs and practices, rooted in recognition of the impact of Eurocentric culture on history, belief and practice of Indigenous people and communities and guided by the intention of promoting anticolonial or emancipatory interests of Indigenous people" (Brayboy, 2005).

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APPENDIX A

RESEARCH INTERVIEW QUESTIONS

Decolonization of Diné Research Practices and Protocols
DATA COLLECTION

Interview Protocols for Diné Elder Research Participation from 1956-1986

INFORMATION FOR INTERVIEWERS: This protocol is a modification of I.E. Seidman's (2013) 3-part interview series condensed into a single 90-minute interview for participants (Elders/Cultural Knowledge Keepers) in the study. Questions are designed to maximize a free flow of participant's experiences with research conducted in their local communities.

Participant Category	Part I: Focused Life History - Placing Participant's Experience in Context	Part II: Details of Experience - Concrete Details of Participant's Experience with research conducted in their local community	Part III: Reflections on Meaning - Personal view of research conducted
Elders and Cultural Knowledge Keepers	Please tell us about your family and community. How did you become involved with research studies in your community? • Where were you born? • Where did you grow up? • What language do you speak? • What is your education and background? • Tell me about your family. • How long have you resided in your community? • How did you obtain important community news? • What are your memories of early research conducted in the community? • What do you remember about researchers conducting studies in your community? • How did you become involved in the research project? • How did you define research?	Please tells us about how you were involved in the research project in your community? • Describe how or who influenced you to become part of the research study? • How did you hear about the research study? • Was the research explained to you in depth? • Were you informed of the benefits of the research project? • What do you remember about your experience? • Were you compensated? • Did an interpreter accompany the non-Native researcher? • Describe your role in the project. • Describe what you remember about the project and process. • Describe the level and type of community involvement you observed. • Other comments about how the research was conducted and implemented.	Given what you have said about the research study conducted in your community, do you see any benefits the study provided to your community? How does the program support student learning? • What other benefits/impacts did the research study have for your community and people? • How did you feel about the non-Native/Native researchers coming into your community? • Were the researchers respectful to the culture of your community? • Were you compensated for your participation? • Were cultural protocols followed and/or respected? • What were the benefits of the study? • Were there any challenges or barriers? • What ways would you have done the research to optimize the outcomes? • What would you want researchers to know about your community? • Do you see research as a benefit? • How might research be improved? • Other comments/questions/ideas? • Given what you have shared about your participation in these studies, did your experience change or influence the way you now define research?

APPENDIX B

RESEARCH PROTOCOLS

The Decolonization of Diné Research Practices and Protocols: Epistemologies and Ontologies from a Diné Woman's Perspective

I am a doctoral student under the direction of President's Professor, Dr. Bryan Brayboy in the School of Social Transformation, Department of Social Justice and Inquiry at Arizona State University. I am conducting a research study focusing on the role of tribal sovereignty and self-determination in research for Diné participants and elders from 1956-1986. The purpose of this historical research qualitative study will be:

1) To describe the role of sovereignty and self-determination on/with Diné elders.

2) To outline a research philosophy informed by Diné epistemology that promotes protections for the well-being and cultural knowledge of Diné participants.

3) To learn from past research and the perspectives of Diné participants on the role of sovereignty and self-determination in research for Diné peoples?

I am inviting your participation, which will contain questions examining personal experiences with research in respective communities from 1956-1986. The questions selected are designed to allow participants to freely share their research experiences. The three-interview series model involves conducting three separate interviews with each participant. You have the right not to answer any question, and to stop participation at any time.

Your participation in this study is voluntary. You may choose not to participate or to withdraw from the study at any time. An incentive of a $50 gift card will be given to you for your participation. The benefits to your participation will provide important and critical historical knowledge to Indigenous research. There are no foreseeable risks or discomforts to your participation. Your responses will be anonymous, and your participation will remain confidential. The results of this study may be used in reports, presentations, or publications but your name will not be used. I would like to audio record or video record this interview. The interview will not be recorded without your permission. Please let me know if you do not want the interview to be recorded; you also can change your mind after the interview starts, just let me know.

If you have any questions concerning the research study, please contact my dissertation co-chairs, Dr. Bryan Brayboy or Dr. Jessica Solyom at (480) 965-1000. If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788. Please let me know if you wish to be part of the study.

By signing below, you are agreeing to be part of the study.

Name:

Signature: Date:

APPENDIX C

POLICY RECOMMENDATION

APPLICATION FOR RESEARCH APPROVAL

Research is for the purpose of serving the purpose of asserting self-determination and sovereignty by reserving the right of Indigenous peoples to take control and to assist in the protection of research practices and protocols. NNHRRB will reserves the right to evaluate the merits of all proposal, but also to put forward conditions so that good research ideas can be done in a good way (First Nations Information Governance Committee, 2007). The following section outlines the process by which researchers are expected to seek provisionary and final approval for their project. All applicants are required to clearly indicate **what** research will be done, for **what** purpose information or data will be gathered and used, **where** the information will be physical stored, and **who** will be involved and have access (First Nations Information Governance Committee, 2007).

Gaining approval to research is a two-step process and includes gaining provisionary approval and final approval.

Individuals and/or institutions that are interested in conducting research on the Navajo Nation will be required to obtain approval from the NNHRRB prior to any data collection and/or research activity. An application process and a list of the required documents in the guidelines (below) can be submitted via electronic mail (or e-mail), in-person, by fax, or through postal service.

Upon submission of the application and required materials, NNHRRB 's Board of Directors will discuss the research proposal at their next scheduled board meeting. During this time, they will make a decision about the next steps, which may include a face to face presentation of your project and proposal.

Guidelines for the Principal Investigator

1. A **cover letter** (between 1-2 pages) explaining the scope of research: background, purpose, hypothesis, how you're building on previous research, how you intend to add to the existing research, and benefits to the community

2. An **abstract** for the research proposal, evaluation, or assessment must be written in plain and clear language that avoids jargon; thus keeping in mind the audience that you are addressing.

3. A **curriculum vitae** (CV) or resume for the Principal Investigator and co-investigators must be submitted to support the qualifications of the researcher(s) by education, training, and experience to conduct research.

4. A **letter of support** from the school director at NNHRRB must be obtained before protocols are initiated with the Board of Directors.

5. A copy of the approved research proposal from their **Institutional Review Board (IRB)** or granting institution must be provided to the NNHRRB Board of

Directors (along with the statements of confidentiality and copies of **consent**). In this IRB, the name(s) and contact information of the Principal Investigators' supervisor or chair must be noted.

6. A copy of the research **instrument** (including surveys, questionnaire, and/or other forms of instruments) must be attached to your application submission.

7. A copy of the **budget** (including detailed allocations) related to research expenditures must be submitted.

8. For purposes of transparency, if the Principal Investigator is receiving **external funding** or grants from a third-party agency or sponsoring organization for their project, a **copy of the approved plan and summary of the budget support(s)** must also be provided to the Board of Directors at NNHRRB.

Application Interview
(template)

Below are tentative questions to ask applicants

Name:

Title of Research:

Name of Principal Investigator:

Title/Affiliation of the PI:

Name of the Co-Principal Investigators:

Name of sponsoring Professor or Supervisor:

Address of Institution or Organization:

City: _____

State: _____

Zip Code: _____

Phone: _____

Fax: _____

Email: _____

Research Partnership Agreement

(Working checklist for researcher to initial)
The Principal Investigator is responsible for the applicable policies and protocols at NNHRRB. If for any reason the PI is unwilling or unable to serve as the principal investigator, this agreement may be terminated.

A. Research Purpose, Plan, Description, and Procedures
1. ____ Full disclosure of the purpose and nature of the research and participants' involvement

2. ____ Details of sampling methods, selection criteria, research procedures, and data analysis must be clearly stated

3. ____ Data collection instrument(s) to be used during the research

4. ____ Confidentiality parameters and ethical considerations

5. ____ Contacts for the research

6. ____ Liability

B. Research Team
1. ____ Names and qualifications of the members of the research including any evidence the team hires diverse staff members

C. Community Partnership and Involvement

1. ____ The researcher will discuss partnerships with NNHRRB 's community members and their potential role as collaborators during the research process.

2. ____ Describe the effectiveness of their research and research outcomes.

3. ____ Letter of recommendation from a community leader or governing body.

D. Risks and Benefits

1. ____ To the extent that risks and benefits exist, the researcher should design the research plan beforehand to ensure anticipated benefits outweigh the risks.

2. ____ The researcher should identify and describe the direct risk(s) and benefit(s) to the community (including, but not limited to administrators, community members, and Stakeholders) for all Stakeholders to better understand how the research may affect them. In doing so, individuals are better informed to decide whether or not they want to participate.

3. ____ If there are anticipated risks—physical, psychological, social, economic, and/or privacy—they must be provided in detail, both verbally and in writing, to research participants.

4. ____ The idea of informed consent should articulate ways to minimize risk. This may include the following: (a) assembling a research team with appropriate training including sufficient expertise and experience involving those who are collecting data; (b) implementation of safety monitoring plan(s); (c) protection of participants' privacy; (d) and efforts to secure research participants' well-being.

E. Informed Consent

1. ____ It is mandatory that consent be obtained in writing prior to the beginning of research. The researcher is responsible for ensuring that participants are informed about the reason(s) for research, the importance of their role and why their participation is sought, and the benefits are to them and to the community.

2. ____ Should the researcher decide to make any major changes to the original proposal, design, activities and/or plan, they must submit an amendment or modification in writing to the Board of Directors. The Board of Directors will, then, decide if the projected changes require full review and approval.[4]

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[4] Numbers 2, 3, & 4 are adapted from the process of conducting research on the Hualapai Reservation, Arizona:
http://www.indiancountryextension.org/sites/indiancountryextension.org/files/publications/files/u6/Hualapai%20-%20Process%20of%20Conducting%20Research%20Oct08.pdf

3. ____ Different sources of documentations including written documents, videos, audio recordings, and other media devices pertaining to the research activities must be submitted for review and approval with the Board of Directors prior to any public distribution. The Board of Directors requires the approval of research products and all materials.

4. ____ The researcher should request approval of conference presentations, manuscripts and research outcomes for publication through a presentation to the Board of Directors.

5. ____ When it is necessary, a researcher must translate the consent form in the participants' Indigenous language to ensure they understand what they're consenting to.

6. ____ In the event that research involves the participation of minors under age 18, the researcher must obtain consent from the parent or guardian. If permission is granted, the researcher must also attain consent from the minor through an age appropriate process.

7. ____ If participants are unable to read the document, oral consent must be audio-recorded as a confirmation.

8. ____ The researcher is required to provide a copy of the consent form. If participants have questions after consent is given, the researcher must respond to them in a timely manner (no longer than 1-week).

9. ____ Consent is an ongoing and continual process during the life of the project. It is NOT a one-time event that occurs when research participants sign a form. Therefore, consent can be withdrawn or negotiated at any time during the research.

E. Publications

NNHRRB recognizes that the results of their research findings and outcomes may be publishable. We are also aware that researchers intend to present at symposia, national, or regional professional meetings, and to publish in journals, or otherwise of their own choosing, and methods. However, NNHRRB shall be provided copies of any proposed publication or presentation at least one month in advance of the submission of such proposed publication or presentation to a journal, editor, or other third party. The Board of Directors shall have one month after receipt of said copies, to object to such proposed presentation or proposed publication because there may be patentable subject matter or intellectual properties which needs protection including proprietary confidential information. It is understood that NNHRRB may wish to be credited in the publication or co-publish as a research-partner, as it is appropriate. No such publication shall contain any confidential information of NNHRRB.

F. Intellectual Property
1. ____ Ownership

2. ____ Control
3. ____ Access
4. ____ Possession

G. Research Effectiveness & Enduring Relationships

H. Term and Termination[5]
This Agreement shall become effective upon the date first written above and shall continue in effect for the full duration of the Partnership Period. Thereafter, the term of this Agreement shall automatically renew for successive one-year periods unless either party provides prior written notice to the other party of its desire not to renew the term hereof, which notice must be given at least 60 days prior to the then current term of this Agreement. Company may terminate this Agreement or any Project upon 60 days prior written notice at any time within the partnership period.

In the event that either party commits any breach of or default in any of the terms or conditions of this Agreement, and fails to remedy such default or breach within thirty days after receipt of written notice thereof from the other party, the party giving notice may, at its option and in addition to any other remedies which it may have at law or in equity, terminate this Agreement by sending notice of termination in writing to the other party. Such termination shall be effective as of the date of the receipt of such notice.

No termination of this Agreement, however effectuated, shall release the parties from their rights and obligations accrued prior to the effective date of termination.

Upon termination of this Agreement or any Project, other than for breach of the terms hereof, Sponsor shall reimburse Recipient for any amounts Sponsor is otherwise obligated to provide Recipient under the terms hereof, for work on each terminated Project performed by Recipient up to the effective date of termination and for non-cancellable pre-paid expenses reasonably incurred by Recipient in anticipation of its work on each Project.

If any of the clauses (above) are determined to be breached, then the NNHRRB reserves the right to contact the researchers' education and/or funding institution to report the violation as well as consider taking any other legal measures to protect their stakeholders.

NNHRRB and the Navajo Nation Tribal Council may change these guidelines at any time and is not required to reveal the reasons for the change. If at any time individual participants wish to withdraw, retract, or reclaim their personal properties (including but not limited to physical artifacts, narratives, or other possessions of material value) from the research study, they reserve every right to so.

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[5] http://www.1000ventures.com/doc/legal/agr_sample_research_byum.html

RESEARCH CONSENT FORM[6]
CONSENT FORM TEMPLATE
For MINIMAL RISK Human Subject Research
e.g., data collection, leftover specimens, interviews, surveys, behavioral interventions.

– Instructional text is in red *and should be removed prior to submission to the IRB*
– Red text in parentheses ( ) should be replaced by information for your study, e.g., (*your name here*)
– Consider using large font if you anticipate recruiting participants with visual impairments, e.g., older populations, or for eye studies

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OPTIONAL FORMAT to use when there are BOTH adults and children in the same study; otherwise remove this box.

When there are both adults and children in the same study, you may use one consent form for both the adult participants and for the parents or guardians granting permission for a participant who is a minor. If you choose to use this format, please insert the information below into your consent form.

Please check one of the following:

_____ You are an adult participant in this study.

_____ You are the parent or guardian granting permission for a child in this study.

Print child's name here:

_____

The following information applies to the adult participant or to the child or ward. If the participant is a child or ward, the use of "you" refers to "your child" or "your ward."

For studies that ONLY involve children, revise the consent form to refer to the participant as "your child...."

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FOR QUESTIONS ABOUT THE STUDY, CONTACT: (Protocol Director Name, address and phone number). Only protocol directors or academic sponsors whose names appear on application cover page may be listed here.

DESCRIPTION: You are invited to participate in **a research study** on (*describe project in non-technical language; include types of questions that will be asked, if applicable; explain* ***purpose of the research***). You will be asked to *(describe* ***procedures***; *mention video/audio taping, if*

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[6] Stanford University consent form

applicable, and what will become of tapes after use, e.g., shown at scientific meetings; describe the final disposition of the tapes).

TIME INVOLVEMENT: Your participation will take approximately *(insert* **duration***).*

RISKS AND BENEFITS: The risks associated with this study are *(describe* **foreseeable risks** *to participants; if none, state as such).* The benefits which may reasonably be expected to result from this study are *(describe any* **benefits***; if none, state as such).* **We cannot and do not guarantee or promise that you will receive any benefits from this study.** *(If applicable)* Your decision whether or not to participate in this study will not affect your *(choose as appropriate): employment; medical care; grades in school.*

PAYMENTS: You will receive *(describe reimbursement; where there is none, state as such)* as payment for your participation.

PARTICIPANT'S RIGHTS: If you have read this form and have decided to participate in this project, please understand your **participation is voluntary** and you have the **right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled**. **The alternative is not to participate.** You have the right to refuse to answer particular questions. The results of this research study may be presented at scientific or professional meetings or published in scientific journals.
 (If identities will be disclosed, provide details: With your permission, your identity will be made known in written materials resulting from the study).

CONTACT INFORMATION:
Questions: If you have any questions, concerns or complaints about this research, its procedures, risks and benefits, contact the Protocol Director, *(name and phone number of Protocol Director).*

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the (IRB) to speak to someone independent of the research team at (000)-000-0000 or toll free at 1-000-000-0000. You can also write to the NNHHRB, Navajo Nation, Window Rock, Arizona.
(If applicable) **Appointment Contact:** If you need to change your appointment, please contact (*name*) at (*phone number*).

Indicate *Yes* or *No*:
(If applicable) I give consent to be audiotaped during this study.
     ___Yes   ___No
(If applicable) I give consent to be videotaped during this study:
     ___Yes   ___No
(If applicable) I give consent for tapes resulting from this study to be used for *(describe proposed use of tapes)*:
     ___Yes   ___No
(If applicable) I give consent for my identity to be revealed in written materials resulting from this study:

___Yes   ___No

The extra copy of this signed and dated consent form is for you to keep.

Signature _____   Date _____

SAMPLE CONSENT for USE OF PHOTO, AUDIO, or VIDEO RECORDINGS[7]
[ADAPT AS APPROPRIATE – ALSO SEE ATTACHED INSTRUCTIONS RE: MAIN
CONSENT FORM]

Research Media Records Release Form

As part of this project we will make photographic, audio, and/or video recordings of you while you participate in the research. Please indicate below by initialing what uses of these records you consent to. This is completely up to you. We will only use the records in the way(s) that you agree to. In any use of these records, your name will not be identified.
1. The records can be used by the research team for use in the research project.

   Photo _____ Audio _____ Video _____

2. The records can be shown to participants in other experiments.

   Photo _____ Audio _____ Video _____

3. The records can be used for scientific publications.

   Photo _____ Audio _____ Video _____

 4. The records can be shown at meetings of scientists interested in the study of
   _____.

   Photo _____ Audio _____ Video _____
5. The records can be shown in classrooms to students.

   Photo _____ Audio _____ Video _____

6. The records can be shown in public presentations to non-scientific groups.

   Photo _____ Audio _____ Video _____

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[7] UC Berkeley

7. The records can be used on television and radio.

Photo _____ Audio _____ Video _____

I have read this form and give my consent for use of the records as indicated above.

Signature _____ Date _____

BIOGRAPHICAL SKETCH

Sharon Henderson Singer is Diné from the Navajo Nation. She comes originally from Black Mesa, Arizona. Her clans are Kinyáá'áanii (Towering House), Ta'neeszahnii (Tangle People), maternal grandparents are Tó'áhaní (Near the Water), and, paternal grandparents are Ma'íídeeshgiizhníí (Coyote Pass People). Ms. Henderson Singer is a doctoral candidate in the School of Social Transformation at Arizona State University. She holds a double master's in Education Administration and Supervision and in Bilingual Education and Multicultural Education.

A member of the Navajo Nation, she is fluent in Navajo language and has over 30 years' experience in teaching, consulting, and program/curriculum evaluation ranging from early childhood education through postsecondary education. She has worked successfully with Indigenous, Latinx, and other diverse communities. Ms. Henderson Singer brings over 12 years' experience developing and implementing complete organizational restructuring plans to improve equity and inclusion for education-oriented organizations. She has designed restructuring plans for Head Start and Early Childhood efforts for the entire Navajo Nation, which serve over 2,000 students and families, as well as grant and contract schools. Ms. Henderson Singer has also deployed strategies that effectively address the education and governance needs of tribal nations and education organizations. As a consultant, Ms. Henderson Singer has spent the past five years developing strategic development plans for tribal governments and organizations, including the American Indian Alaska Native Early Childhood research project, providing a process for culturally responsive and inclusive leadership and governance. Her most recent work for Navajo local governments, which include 110 local communities within the Navajo Nation, co-created a model for Navajo leadership and decision-making that informed by tribal philosophies and ensure leadership policies and initiatives foster self-empowerment and transparent organizational practices. This work is culturally responsive and inclusive of Navajo beliefs and gender diversity.

Ms. Henderson Singer holds professional teaching and administration licensing and is an experienced qualitative researcher and educator. She has organized and led focus groups and interviews with program leaders and participants. Her professional, administrative and teaching background focuses on equity and inclusion in science and technology, STEM, and program design and evaluation. She has experience conducting environmental scans and literature reviews, and, although she is a strong qualitative researcher, has extensive experience in mixed-methods research. Currently, Ms. Henderson-Singer serves as a pre-doctoral research scholar at the Center for Gender Equity in Science and Technology (CGEST), where she assists in research design and implementation for social justice-oriented youth technology programs. Her research focuses on equity, inclusion, and culturally responsive practices for Indigenous, Latinx, and other historically underserved student populations. Her work draws from Tribal Critical Race Theory, Indigenous Knowledge Systems, and Critical Indigenous Research Methodologies to inform culturally responsive schooling, pedagogy, curriculum and practices, and Institutional Review Board's as tools to promote education equity and enhance the mental, social, and intellectual wellbeing of diverse communities.