Research is a Pebble in my Shoe: Considerations for Research From a Pueblo Indian Standpoint

by

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ABSTRACT

The overarching purpose of my dissertation is to offer one Pueblo perspective about research and health education to contribute to critical dialogue among Pueblo people so that relevant research and health education approaches grounded in Pueblo thinking can emerge. Research was a pebble in my shoe that caused me great discomfort as I walked within academia during the many years I worked as a health educator at a university, and continues to bother me. The purpose of my journal article is to discuss why much mainstream research is problematic from a Pueblo Indian standpoint and to explore considerations for research with Pueblo people. The purpose of my book chapter is to reflect on my experiences as a Pueblo Indian health educator to add to the discussion about the importance of grounding Pueblo health education in local Pueblo knowledge systems and to discuss the limitations of delivering health education primarily grounded in a western biomedical disease model. Finally, my policy brief is an urgent call to action for tribal leaders regarding a recent change to the New Mexico Department of Health's race and ethnicity presentation in health data standard. This change resulted in 39,636 American Indians and Alaska Natives in New Mexico being reclassified as Hispanic. It is my intention to connect my ideas about research and health education with the work of other Pueblo scholars to add to the growing body of Pueblo informed writing to contribute to current and future scholarship that will ultimately benefit Pueblo people.

DEDICATION

I dedicate my dissertation to my beloved family: my daughter Sydney, my parents Lorraine and Henry, and my sisters and brother – Lisa, Tina, Kim, and Jeff. I will forever be grateful for their love, support, and prayers as I journeyed through my doctoral studies. I also would like to acknowledge the support given by my nieces, nephews, aunts, uncles, and cousins as well as my community throughout this academic adventure. I am a composite of my family and my community. Both have inspired the work that I do to benefit Indigenous people. My family and my community have taught me the importance of belonging and generosity. I also dedicate my writing to all the Native cancer survivors that I have been blessed to meet and work with. They have taught me to be strong and to live a good life filled with love, laughter, and joy – even when it is difficult to do. For this important life lesson and healing I am forever grateful.

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CHAPTER 1

JOURNAL ARTICLE - JOURNAL ARTICLE - RESEARCH IS A PEBBLE IN MY SHOE: CONSIDERATIONS FOR RESEARCH FROM A PUEBLO INDIAN STANDPOINT

Introduction

Changing the research practices of others and how they do research is a hard task for anyone to undertake. Changing an enterprise, the enterprise of research, with its roots in imperialism and colonization is an even harder task. It means dismantling an entire system of privilege and indoctrination. Thinking about what my contribution will be to Pueblo research and how I can contribute with the gifts that I have been blessed with is a much more realistic task for me to devote my energy. The overarching purpose for research that I will be in relationship with must contribute to Pueblo healing and wellness. Making change by starting with myself makes more sense by removing the "research pebble" in my shoe.

Imagine you have a small pebble in your shoe. While it is possible to walk with a pebble in your shoe it creates imbalance and discomfort with every step you take until it can no longer be ignored. Balance and comfort can only be restored when the pebble is removed. Imagine not being able to remove the pebble and having to walk every step off balance and in discomfort with no relief in sight. This is what working in an academic research institution felt like for me as a Pueblo Indian health educator during the thirteen years I worked for a university. For me, research was that pebble in my shoe that created great discomfort as I walked within academia, because it often went against what Pueblo Indian people say about how research needs to be approached with our communities

(Cajete, 2008; Dozier Enos, 1999; Dozier Enos, 2002; Romero, 1994; Suina, 2004) There was rarely a day that went by that I did not think about and problematize research.

I spent a lot of time thinking about research during my years employed by the university because researchers who were looking for an American Indian community to do *their* research or to discuss *their* research ideas often approached me. For the record, I am not anti-research, but I do have problems with how research is discussed and conducted with American Indian communities. The following excerpt from my autoethnography best describes the discomfort the "research pebble" created:

> I sat in my car in the middle of a packed university parking lot and cried; frustrated again. I just returned from an auditorium full of scientific researchers and physicians discussing genetic mapping and their interest in the state's genetic diversity to conduct research. Yet, I was only one of a few individuals in the audience who possessed the "prized DNA" that represented the very diversity being discussed. Equally frustrating was my ever more noticeable hearing impairment which obscured the details of research ideas being pitched. I knew I had to speak. I said a prayer as my parents have taught me and asked the spirits of my ancestors for courage. I stood up and I began to cry as I spoke, but I spoke because it is what I needed to do.

That day in front of research scientists was not the first or last time that I was situated between two realities in which I had felt compelled to speak up about research ethics. Research and scientific discovery brings recognition, prestige, and monetary gain for research institutions and researchers. Yet, for Pueblo peoples, who are often the subject of research, it has brought little or no direct benefit (Romero, 1994). Instead, research has brought skepticism (Romero, 1994) and broken trust due to exploitation of Pueblo knowledge (Suina, 1992).

The purpose of this paper is to discuss why research that goes against the grain of Pueblo thinking is the pebble in my shoe, and to provide considerations for more

appropriate research from a Pueblo Indian standpoint. I would like to contribute what Linda T. Smith (2012) would call an "alternative story" of Western research but instead of "through the eyes of the colonized," my story is through the eyes of a Pueblo person with a colonial history because I do not consider Pueblo people to be colonized. With this paper I hope to connect my ideas about research and health education with the work of other Pueblo scholars and add to the growing body of Pueblo-informed writing, with the ultimate goal of contributing to current and future scholarship whose end will benefit Pueblo people. I also would like to personalize the challenges that Pueblo people face through the use of stories and autoethnography. My writing, influenced by the writing style of my father, Pueblo scholar, Joseph Suina, incorporates history, storytelling, and personal reflection to provide a historical snapshot of Pueblo life experiences, resiliencies, and challenges.

My primary audience here includes Pueblo and other Indigenous scholars, educators, health professionals, and tribal leaders. I am aware that my writing will also reach a broader audience of non-Indigenous scholars, and I have written about my experiences within academia with this in mind, to provide insight into how research that is typically carried out has alienated Indigenous people, including me. My long-term scholarly career goal is to inform an alternative approach to health research with Pueblo communities so that structural inequities in research can be minimized and, ideally, eliminated. This article is a step toward creating balance and comfort without the research pebble in my shoe.

Positionality Matters

Indigenous scholars remind us that place and where we come from matters when conducting research (Cajete, 2008; Dozier Enos, 1999; Dozier Enos, 2002; Smith, 2012; Walter & Andersen, 2013; Weber-Pillwax, 2001; Wilson, 2008). My views about research have been informed by who I am and where I come from. I am a composite of those who physically surrounded me growing up in my Pueblo and those who surrounded me in spirit and I know of by way of stories because I was too young to remember when they left this earth. I was raised in my small Pueblo of Cochiti in New Mexico; a community comprised of about 700 people living on the reservation, with the nearest city, Santa Fe, located thirty-five miles away.

I grew up at a time when formal education for the advancement of Pueblo people and the predominant use of the English language among community members was not questioned as much as it is today, so I grew up speaking English like most of my peers instead of the Keres language of my ancestors. At the same time, I was encouraged as a youth and expected to participate in our traditional ways, which one could do without proficiency in Keres. As a non-Keres speaker, participating in traditional activities that are conducted in my heritage language is difficult because language is critical for understanding Pueblo worldview that is embedded in cultural practice.

As a college student, I learned that my disconnection from my heritage language was the result of calculated moves by the federal government through U.S. Federal Indian Policy to educate and assimilate us into mainstream American society to get rid of “the Indian problem” and to usurp our land and resources (SFIS Leadership Institute, Pueblo Convocation, 2012). I can say I am not completely assimilated into mainstream society,

because my Pueblo core values and identity have been ingrained in me. Unfortunately, my understanding of critical Pueblo knowledge that is embedded in our Keres language has been disrupted. As a result, I resist attempts from the outside to homogenize my community, or me, and that devalue our own Pueblo systems of knowledge. In my opinion, western research is one such offender.

I embarked on my doctoral studies so I could gain a deeper understanding of research ethics and to better understand Pueblo perspectives regarding research to effectively participate in dialogue within the academic institution where I previously worked. I wanted to acquire this knowledge to help Pueblo people become well informed about research and know what questions to ask to engage in a more strategic dialogue with researchers because I have seen what happens when tribal representatives are invited to a university and are far outnumbered by medical researchers using research jargon. This type of imbalanced power dynamic makes it challenging to ask questions and to direct research in the best interest of Pueblo people.

Tribal nations, as sovereign entities, have the power to choose whether to engage with research or to disengage, altogether putting a stop to potentially beneficial research. Researchers are short sighted if they do not recognize this imbalance and continue to move forward without being transparent about their research agendas or rethinking their research practices. They must begin by listening to tribal concerns about research and their research needs. Santa Clara Pueblo scholar Enya Dozier Enos (1999) stresses that listening with respect to understand the perspective of an individual rather than to question or challenge what that person is saying as is typical of western research methodology, is a critical part of conducting qualitative research working with Pueblo

people. I would add that listening with respect to Pueblo people is critical for establishing research partnerships and establishing accountability of the researcher before research even begins.

Research and Indigenous People

Linda T. Smith's seminal book *Decolonizing Methodologies: Research and Indigenous People,* second edition (2012) is often quoted because she clearly articulates what many Indigenous scholars discuss on campuses in trusted circles. Smith reminds us that research is not neutral and cannot be separated from imperialism when she states,

> Research 'through imperial eyes' describes an approach which assumes that western ideas about the most fundamental things are the only ideas possible to hold, certainly the only rational ideas, and the only ideas which can make sense of the world, of reality, of social life and of human beings. It is an approach to indigenous peoples which still conveys a sense of innate superiority and an overabundance of desire to bring progress into the lives of indigenous peoples – spiritually, intellectually, socially, and economically (p. 58).

Western science and research have served as tools for the violent processes of imperialism and colonialism. Entangled with governmental polices, science and research has justified disconnecting Indigenous peoples from their lands to benefit colonial settlers. (Smith, 2012). For example, the federal government established the1883 Religious Crimes Code, a law prohibiting Native ceremonies because lawmakers considered American Indian religions barriers to the process of civilizing and assimilating American Indians into mainstream American society (Irwin, 1997; Prucha, 1984; Prucha, 1990; Sando, 1992). One of the goals of assimilationist policies was to seize land occupied by American Indians to open up for use and ownership by white colonial American settlers.

Jemez Pueblo scholar Joe Sando (1992) recounts how the Pueblos of the Southwest responded to Bureau of Indian Affairs (BIA) Commissioner Charles H. Burke's use of propaganda against Pueblo religion in the early 1920's to support the Religious Crimes Code and to turn public opinion against Pueblo Indians. Burke believed that "native religion was a crutch preventing the useful assimilation of the Indian into white society" (p. 92). The response made by the Council of All the New Mexico Pueblos regarding Burke's attacks on Pueblo religion implicates the role researchers played in religious persecution towards the Pueblo people:

> We specify the first order issued by the Commissioner of Indian Affairs to Indian Superintendents, dated April 26th, 1921. In that lengthy order, the Commissioner gives a list of "Indian Offenses for which Congress penalties are provided." He places upon local Superintendents the duty of determining whether Indian religious observances "cause the reckless giving away of property," are "excessive," promote "idleness, danger to health, and shiftless indifference to family welfare." And one of our present Superintendents of the Pueblos thus states his attitude in a printed Government report: "Until the old customs and Indian practices are broken up among this people, we cannot hope for a great amount of progress. The secret dance is perhaps one of the greatest evils. What goes on I will not attempt to say, but I firmly believe it is little less than a ribald system of debauchery.
>
> We denounce as untrue, shamefully untrue and without any basis of fact or appearance, and contrary to the abundant testimony of White scholars who have recorded our religious customs, this statement, and we point out that the Commissioner's order, quoted here, to be interpreted and enforced by the local Superintendents, is an instrument of religious persecution. (p. 93)

Research conducted a decade earlier by the anthropologist Matilda Cox Stevenson (1914) characterized Tewa religious rites and practices as "strange" and involving human sacrifice. It is unclear if Stevenson was among the white scholars that the Council of All the New Mexico Pueblos referred to in their statement, but her scholarship represents the type of research conducted during the early 1900's in the Southwest.

BIA Commissioner Burke's and Stevenson's views about American Indian religion were not innovative or solely created by American systems of thought. Ideas put forth in U.S. Federal Indian Policy and academic understandings about American Indians mirror earlier Spanish colonial narratives of Indigenous people. For example, Spanish colonists viewed Indigenous people as barbarians, a condition that justified the process of civilization (Spicer, 1962):

> …prevailing Spanish opinion, especially among officials at a distance from the Indians, was that the barbarians lacked law and real authority, that they had either no religion at all or a species of worship which was called idolatry and was wholly evil (usually regarded as worship of the Devil), that their settlements were not organized communities, that their sexual lives were unregulated, that their forms of body covering were not clothing properly so called, and that they lacked houses worthy of human beings (p. 282).

Spanish viewpoints regarding American Indians provided the rationale for their unjust and inhumane treatment by the Spanish colonizers that went hand-in-hand with the process of civilization.

Taiaiake Alfred and Jeff Corntassel (2005) caution Indigenous people of the danger of allowing the story of colonization to be the only story told of our lives as Indigenous people, "It must be recognized that colonialism is a narrative in which the Settler's power is the fundamental reference and assumption, inherently limiting Indigenous freedom and imposing a view of the world that is but an outcome or perspective of this power" (p. 601).

Health Research and Representation of American Indians

Health research about Indigenous people is situated within a historical backdrop of imperialism and colonialism. Bryan Brayboy (2005) defines colonization as the domination of "European American thought, knowledge, and power structures" (p. 430)

in U.S. society. Using Brayboy's definition of colonization is helpful in questioning and thinking about how European American *thought*, *knowledge*, and *power structures* produce narratives of Indigenous people, the purposes for producing these narratives, and how research played a complicit role.

Research has served as a mechanism for representing Indigenous people as deficient, authoritatively providing "evidence" for prevailing notions about Indigenous people, which often seems to go unquestioned by the non-Indigenous. When research is questioned, it is usually by those that are being represented and essentialized by research findings like when the Council of All the New Mexico Pueblos vehemently denounced white scholarly portrayals of Pueblo people and their religion.

My interest in and questioning of research and statistical representations of Indigenous people began as an undergraduate health education student because I was concerned with how this population that I belonged to seemed to be pathologized and stereotyped by health data. I delivered an American Indian health presentation as an undergraduate and asked my mostly non-Indigenous classmates to describe the top two health issues for American Indians in New Mexico and they immediately responded alcoholism and diabetes. The data I presented showed that heart disease and accidents were the two leading causes of mortality. My classmates rationalized the data assuming that accidents occurred probably due to alcohol. They even went so far as to question if I grew up on the reservation after I presented anecdotal information about areas of employment among tribal members because it probably challenged ideas that American Indians are mostly uneducated and unemployed.

I was not surprised by my classmates' response because Indigenous people are often portrayed and treated as being psychologically abnormal or unhealthy (de Leeuw, Greenwood, & Cameron, 2010; Deloria, 1969; Poudrier, 2003; Poudrier, 2007; Smith, 2012; Tuck, 2009; Walter & Andersen, 2013). For example, in describing American Indian health A.B. Holder (1892) states:

> If the Indian were lifted at once from the wildest savagery in which he can now be found, to full civilization – that is, to comfortable and hygienically constructed clothing and housing, to abundant and well prepared food, to a knowledge and practice of the rules of health governing the more intelligent individuals of the white race – his condition would at once and permanently be greatly improved as to health and longevity. (p. 177)

Contemporary health and social science researchers typically portray Indigenous people as being problematic by constructing depictions of them as deficient (Poudrier, 2007; de Leeuw, Greenwood, & Cameron, 2010; Smith, 2012; Tuck, 2009; Walter & Anderson, 2013). These portrayals create narrow, yet encompassing and essentializing ideas of what it means to be Indigenous and are similar to early colonial constructions of indigeneity. For example, Barnes, Powell-Griner, and Adams (2010) conclude, "The non-Hispanic American Indian Alaska Native (AIAN) community faces many health challenges as reflected in their higher rates of risky health behaviors, poorer health status and health conditions, and lower utilization of health services" (p. 1). Maggie Walter and Chris Andersen (2013) would refer to Holder's (1892) and Barnes et al.'s (2010) negative characterizations of American Indians as being "deficit Indigenes" that are seen as abnormal and are in need of intervention by the nation state to fix them in order to achieve parity with white people.

Prevailing nineteenth-century notions about American Indians portrayed them as savage and uncivilized, aligning with development-based discourse that justified the taking of Indigenous lands (Walter & Anderson, 2013). The prevailing notion today is that American Indians are at greater risk for social ills (Poudrier. 2003; Walter and Andersen, 2013). In both cases, American Indians are positioned against whites, with the latter being the standard or norm. As an Indigenous person, I am tired of being seen and treated as being at greater risk for social ills, and I am certain that I am not the only one.

Nation states constructed colonial narratives of Indigenous people consisting of abject disease and poverty to legitimize paternalistic policies and practices (Poudrier, 2007; de Leeuw, Greenwood, & Cameron, 2010; Smith, 2012; Walter & Anderson, 2013). Indigenous health reports and publications rarely give explanations of the historical and social factors rooted in colonialism that play a role in the lived experiences of Indigenous people today. Michelle Chino and Lemyra DeBruyn (2006) state that there is a "…common and often unconscious tendency of public health officials to use images and stereotypes of "culture" to deflect blame away from inadequate policies, institutions, and public health infrastructures and onto oppressed people themselves" (p. 599).

Eve Tuck (2009) cautions that even research that sets out to implicate those in power and hold them accountable by documenting "people's pain and brokenness" can still be detrimental. Although the intention seems good, such research characterizes communities as depleted and broken. Analysis of health disparities must not pass the blame on to those experiencing the inequities, but must look at systemic failures and policies that produce inequities (Chino & DeBruyn, 2006). Analysis of systems and

policies, which I also advocate, places culpability where it is more appropriate instead of blaming those that are the recipients of unjust and inequitable treatment.

Contemporary National American Indian Health Reporting

Jennifer Poudrier (2003) reminds us that, “Neither epidemiological nor genetic sciences are neutral in the questions they ask, the way they go about producing knowledge, and the way their findings are disseminated through public health discourse” (p. 114). Where a person comes from historically, socially, culturally, politically, economically, geographically and so on matters and makes neutrality unlikely. A person’s positionality and contextual background foregrounds how they collect, analyze, and interpret data and associate meaning with their findings (Walter & Andersen, 2013).

With my positionality as a Pueblo social justice scholar concerned about Indigenous representation at the forefront, I conducted an exploratory study that critically questioned and analyzed the results of a national health report on American Indian health to demonstrate how data is not neutral and how it is constructed to produce a particular narrative of Indigenous health. I analyzed the National Health Statistics Report, *Health Characteristics of American Indian or Alaska Native Adult Population: 2004-2008* (Barnes et al., 2010). Data contained in this report are collected by the U.S. Centers for Disease Control (CDC) and Prevention’s National Center for Health Statistics and is from the National Health Survey, which is intended to monitor the health of the U.S. population. The survey first was administered in 1957 as a representative survey of U.S. households (http://www.cdc.gov/nchs/nhis/about_nhis.htm). Survey data is collected through household interviews. Data described in the national report includes

demographic characteristics, health behaviors, health care utilization, conditions, selected immunizations, mental health status, and health status.

My analytic strategy included identification of common or standard quantitative data practices critiqued by Walter and Andersen (2013) that were present in the National Health Statistics Report (Barnes et al., 2010) to demonstrate how Americans Indians are characterized by contemporary national health data. Those practices include use of simple comparisons and limited interpretation, simple frequency counts, aggregated data reporting, dichotomous comparisons, and decontextualized representation (Walter & Andersen, 2013). The following table (Table 1) is a representation of the common data practices that were identified in the national data report describing American Indian health.

Table 1

Common Data Practices Identified in the National Health Statistics Report, Health Characteristics of American Indian or Alaska Native Adult Population: 2004-2008 (Barnes et al., 2010)

Deficit Representation of Indigenous People				
Simple comparison & limited interpretation	**Simple frequency counts**	**Use of aggregated data**	**Dichotomous comparison**	**Decontextualized representation**
✓		✓	✓	✓

Adapted from "Indigenous Statistics: A Quantitative Research Methodology," by M. Walter and C. Andersen, 2013, pg. 36-39, Copyright 2013 by the Left Coast Press.

In my systematic review of a representative national data report on American Indian health (Suina, 2014), I found a number of areas to be problematic and inaccurate. I did not have to read far into the report to identify four out of the five common data

practices that paint a deficient picture of American Indian people identified by Walter and Andersen (2013). First, beginning with the abstract, the results indicate that American Indians are more likely to be current drinkers compared to other adults. Yet, the data reported in the selected results section for health behaviors, the closing discussion section, and data tables contradict this finding and show that white men and women are actually more likely to be current moderate or heavy drinkers compared to all other groups. The abstract concludes that American Indians have higher rates of risky health behavior and poorer health status.

The introduction section indicates that chronic liver disease and cirrhosis are the sixth leading cause of death for American Indians. A common cause of chronic liver disease and cirrhosis is alcohol abuse. The authors point out that these liver conditions are not included in the top ten causes of death for the other comparison populations, and yet they fail to identify the top causes of death for American Indians or other groups masking other critical causes of mortality. Data presented on the first page alone discussed so far are instances of simple (and inaccurate) comparison with limited interpretation using aggregated data to generalize conclusions about all American Indians. These figures may not apply to any community because they are based on a representative or average U.S. household. Further, the data presented up to this point and throughout the remaining report are decontextualized, and the authors do not describe historical and social causes that underlie health inequities.

The authors provide a deficient picture of American Indian health using data practices that provide a narrow, yet encompassing representation of American Indian people. The national health report analyzed in this study presents associations between

race and health outcomes as if it is a causal argument (i.e., race causes health condition or race leads to health) ignoring that race is a social construct and ignoring the factors and context in between that contribute to health outcomes. To gain a better understanding of American Indian health one must first ask what health means to American Indian people and select indicators that construct health in way that is more meaningful. It is also critical to include the historical and social forces that shape health when analyzing the state of American Indian health in national reports.

Challenging Research Narratives

Tuck (2009) calls for a moratorium by communities on damaged centered research, in order "to reformulate the ways research is framed and conducted and to reimagine how findings might be used, by, for, and with communities" (p. 409). Graham Smith (2000) calls for Indigenous people to be careful about how we, as Indigenous people, name and label ourselves, and suggests that we run the risk of perpetuating our own subordination by using terms (i.e., minority, oppressed, exploited, subordinate) that elevate others as being dominant. I would suggest we also consider how public health "at risk" terminology also falls into harmful labeling practices of Indigenous people, especially when compared to other populations (Swadener & Lubeck, 1995).

I agree with Tuck and Smith and further question how we talk about our collective experiences of colonization so that it does not define us as a colonized people who need to be decolonized otherwise we continue to position ourselves as vanquished. This is why I am reluctant to label Pueblo people as being colonized, because I do not believe colonization has been complete since contemporary Pueblo people still maintain their connection to their ancestral life ways that include use of their heritage languages,

practice of traditional ceremonies and customs, practice of traditional governance, and connection to place where their ancestors also lived. Suina and Smolkin (1994) point out that, "Among the Indian tribes in the United States, the Pueblos of the southwest are considered the least changed by encounters with Europeans, their languages, governments, social patterns, and cultural components remain uniquely Pueblo" (p. 116).

I believe that it is imperative that we question narratives that are told about Indigenous people including the stories told about our health that are produced by research studies. We must question the reasons why these stories were and continue to be constructed while at the same time insist on telling our own stories, as Alfred and Corntassel (2005) suggest, of what and who we are and what it means to be healthy from an Indigenous standpoint.

My Reluctance Toward Research – An Autoethographic Study

Midway through my doctoral studies I decided to turn the research lens on myself and become the subject of a research study by conducting an autoethnography to examine my relationship to research. I have observed a major disconnection between researchers and the researched, during the thirteen years that I worked for a university that fed my own caution and reluctance towards research. I am well aware that in many instances my caution was perceived as me being uncooperative or difficult, because like most non-Indigenous researchers they were not aware of the role that research has played in imperialism and colonialism.

Words and phrases used by non-Indigenous researchers when talking about research triggered my discomfort, including: "we need to exploit our unique population," "let's take advantage of our state's diversity," "biospecimen collection," "evidence-

based," and "research enterprise." The symbolic violence embedded in these terms seemed to go unnoticed by non-Indigenous researchers, but served as red flags for me because of my positionality. Therefore, it made sense for me to use autoethnography to systematically examine and articulate my ambivalence toward research within a larger historical framework. I felt that I could not think about conducting research without starting with myself first to examine my own biases towards research.

Autoethnography allows for the personal experience to be examined within a larger societal context (Chang, 2008; Ellis & Bochner, 2011; Houston, 2007; Reed-Danahay, 2001; Wall, 2006) and for personal stories to emerge in research as the primary source of data. Indigenous people are calling for the recognition and honoring of stories and oral tradition as a legitimate form of knowledge and data (Brayboy, 2005; Ortiz, 1998; Smith, 2012). My journey to reclaim research for Pueblo Indian people instead of feeling used by the research enterprise---which I felt after working in academia for over a decade---- began with my conducting an autoethnography. I took on the simultaneous role of the researcher and the research subject to find balance between these typically binary oppositional roles.

Roxanne Bainbridge (2007) describes the qualitative nature of autoethnography as being a subjective and flexible research tool. Rather than calling for neutrality of the researcher, autoethnography recognizes that individual experience contributes to a greater understanding of culture and society. Ultimately, autoethnographic studies challenge the canonical nature of how research is done (Ellis et al., 2011), which makes autoethnography a promising approach for researchers that come from epistemologies and ontologies that are situated outside of western understanding and knowing.

Indigenous Autoethnography

Bainbridge (2007) and Jennifer Houston (2007) identify autoethnography as a promising method for Indigenous researchers and Indigenous research. Bainbridge advocates for the use of autoethnography, because it grounds research in Indigenous epistemology and ontology. Houston argues that "indigenous autoethnography in practice is a form of scholarly resistance; a challenge to the way in which Aboriginal people, particularly Aboriginal women, have been represented and depicted by others" (p. 45). Autoethnography allows Indigenous voice and self-representation to emerge that typically are absent in ethnographical studies on Indigenous people and other forms of research that are generally conducted from an outside perspective.

Leslie Marmon Silko (1998) describes the importance of the oral narrative and story for Pueblo people in her essay, *Through The Stories We Hear Where We Are From*.

> …the ancient Pueblo people depended on collective memory through successive generations to maintain and transmit an entire culture, a worldview complete with proven strategies for survival. The oral narrative, or story, became the medium through which the complex of Pueblo knowledge and belief was maintained (Ortiz, 1998, p. 8)

She further goes on to say that it was the collective responsibility of the community to maintain stories. Brayboy's (2005) Tribal Critical Race Theory also "honors stories and oral tradition as real and legitimate forms of data and ways of being" (p. 439). Brayboy further states that "Stories are not separate from theory; they make up theory" (p. 439). If proven strategies for survival are embedded in stories, then autoethnography is a promising method for documenting and analyzing those stories to pass on to future generations so that they can maintain their connection to ancestral knowledge and wisdom.

Autoethnography Methods

By utilizing an autoethnographic approach, the researcher becomes the object of study to glean insight on phenomena that is occurring. In my case, I intended to understand the disconnect that occurs between researchers and the researched, a dynamic that situated me in the middle. Heewon Chang (2008) points out that the usual ethnographic research process of field data collection, data triangulation, and analysis occurs when conducting an autoethnographic study. My data sources include my journal self-observations, my scholarly writings, and my personal professional documents, items that all identify critical issues in academia and the research enterprise that contribute to my reluctance towards research.

Although the nature of autoethnography is flexible and subjective (Bainbridge, 2007), it does not mean a systematic approach and rigor is absent from this type of study. I managed data by using a web-based qualitative data analysis package, Dedoose, Version 4.5.95. I first coded data into in vivo codes and then clustered these in vivo codes according to thematic content. I analyzed the thematic clusters for general themes and used them to develop my auotethnography.

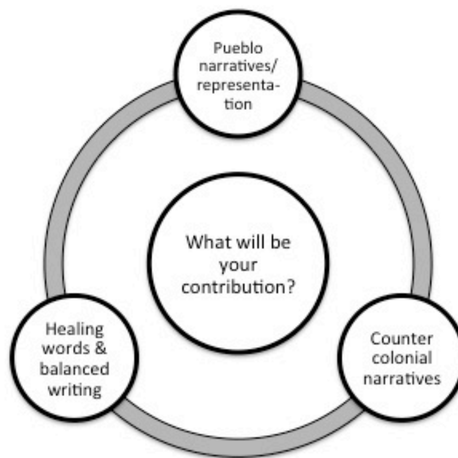
Autoethnography Findings

In conducting my autoethnography, I learned more about where my scholarly efforts must focus and the work that I need to continue. I could truly begin to answer the seminal question asked by the Leadership Institute at the Santa Fe Indian School of Pueblo people: “What will be your contribution?” The work and writing that I do must contribute to the collective healing and well-being of Pueblo people and accomplish the following:

- Repatriate our own knowledge by telling our own stories especially stories of our resilience to counter negative accounts and characterizations of Indigenous people often disguised as scientific data.
- Capture things that go unquestioned and document stories of injustice to help us remember our history so that we don't forget the impositions that have disrupted our communities and resulted in health and social conditions we face today.
- Teach non-Pueblo people about considerations for more appropriate research methodologies from a Pueblo Indian standpoint.

I will individually discuss the three themes (or my contributions to Pueblo people) that emerged from my autoethnography and that are depicted in Figure 1, including: Pueblo narratives/representation; healing words and balanced writing; and counter-colonial narratives.

Figure 1 – Autoethnography Key Themes: My Relationship to Research



Pueblo Narratives and Representation. Having more Pueblo scholars is important so that more Pueblo perspectives and stories can emerge and effective solutions to the challenges we face can surface. Therefore, it is critical that Pueblo people tell our own stories and define who we are on our own terms. The Pueblo PhD cohort to which I belong constantly reflects on Pueblo ontology, epistemology, and axiology by talking about our lived experiences as Pueblo people. The stories we tell reveal our sense of knowing----what we know, how we know, who taught us, and the way we are supposed to be. Our stories reveal how we view others and how we view ourselves in the world and our orientation to life. In our stories is our connection to the past, present, and future. In our stories are our strengths and resiliencies as Pueblo people. In our stories are our own solutions to the challenges we face. This is why it is important that we have Pueblo people to do research and solve problems from a Pueblo context to ensure our vitality and continuity. We have a vested interest!

I have often asked myself if I am even able to write about Pueblo knowing because I cannot speak the language of my ancestors. Somewhere along my path, I began to discount what I *do* know, because I cannot speak Keres. This began for me as a child because I have always been painfully aware that I cannot fully understand the meaning/s of what is happening around me when I participate in traditional activities or when elders talk to me in Keres. On many occasions throughout my life, I have not felt "Pueblo enough," which speaks to the lingering effects of colonialism at the individual level. American policies were intended to supplant my Pueblo sense of wholeness with a fractured sense of self to augment the assimilation of Pueblo people into American society. However, I do know what it is like to be a Pueblo person in this lifetime, an

experience, which may be relatable to others. As such, my intention is to a) add to the story of Pueblo continuance with my life; b) present a snapshot in time of another Pueblo experience for future generations to learn from; and c) present an opportunity to bring other Pueblo experiences to the forefront in my scholarly work to legitimize our own ways of knowing and solutions to the challenges we face.

Healing Words & Balanced Writing. It is my belief that healing from the historical traumas inflicted by colonialism must occur on a personal and community level in order to realize the Pueblo health ideals of maintaining a healthy, mind, body, spirit, and heart discussed at the 2012 Pueblo Convocation convened by the Leadership Institute at the Santa Fe Indian School. Therefore, my scholarly work must contribute to Pueblo healing from the historical assaults we have experienced. I will accomplish this by being cognizant of the words I choose to describe Pueblo people and the challenges that we face so not to replicate negative colonial narratives of our people that are often disguised as factual and unbiased through the use of data and theory. Words have the power to heal or to further perpetuate violence towards others. We can write to heal and bring people together or we can tear down others and create more conflict. I am committed to finding a balanced and historically informed approach to writing about Pueblo health in my scholarly work.

The Leadership Institute has played a critical role in my personal healing journey, helping me unload the colonial baggage that has impacted my life and contributed to my own personal struggles. Through the Leadership Institute I began to better understand the critical role I play in Pueblo vitality and cultural continuity and the necessity to live life grounded in Pueblo core values such as love, respect, compassion, faith, understanding,

spirituality, and balance. Our core values provide us with direction in our lives and how we should treat one another. The scholarly work that I do must be grounded in Pueblo core values and must contribute to the collective wellness of Pueblo people.

Counter Colonial Narratives. I have grave concerns about how Indigenous people are depicted by health researchers and research data in journal publications and reports that often characterize Indigenous people in negative and deficit based terms. I am even more concerned when Indigenous people themselves embrace western ways of describing problems through the use of data without critically reflecting on what it means to problematize their own communities to secure funding. Controlling the discourse about Indigenous people by producing dehumanizing narratives and terms (i.e. barbaric, uncivilized, savage, etc.) played a key role in colonialism informing policy used to justify mistreatment and appropriation of land and resources (Smith, 2012). To this day, health professionals continue to classify and negatively compare American Indians to other races and ethnicities through the use of data, typically without discussing the role that colonial history, social inequity, and injustice plays in health disparities.

The disproportionate rates of morbidity (i.e. sickness) and mortality (i.e. death) experienced by Indigenous people are deeply rooted in colonization (Roubideaux, 2002; SFIS Leadership Institute, 2008; Smith, 2012). In my experience within academia, medical scientists often try to explain diseases as being the result of individual behaviors and underlying racially based genetic predispositions not quite yet understood. The role that colonial history, fraught with ongoing dispossession and loss, plays in Indigenous health is generally not acknowledged or even considered by medical researchers. I see this as a form of erasure. Yet, for many Indigenous people the impacts of historical

traumas resulting from colonialism, such as an unequal burden of certain illnesses, are felt in day-to-day living.

Understanding history is an important part of health education and provides an understanding of why social and health conditions exist as they to do today (SFIS Leadership Institute, 2008). To counter negative colonial narratives of Indigenous health, I will name the historical roots of the health inequities we experience to place culpability where it is more appropriate instead of blaming our people for the conditions created by systematic attempts to eliminate us as a people and appropriate our land and resources. I commit myself to further understanding colonial narratives of health and the role research has played in the creation and maintenance of these narratives to reinforce notions of American Indian inferiority that continue today through the use of epidemiological data void of the discussion of colonial history.

Common Research Practices and My Reluctance Toward Research. Further analysis of qualitative data from my autoethnography helped me to document why I am reluctant to become involved in certain research projects. My reluctance is based on common research practices that I witnessed during my time working for an academic institution. Some of the reasons for my reluctance included:

- Lack of community involvement in the development of projects.
- Benefit of research to communities was unclear.
- Context of community not reflected in project (i.e., knowledge systems, values, beliefs, infrastructure, timelines, etc.).

- Reliance on American Indian staff to be responsible for building relationships and to gain entry into communities (i.e., lack of relationality on part of researcher). I felt like I was being used.
- Proposed projects did not add to or enhance my work in health education for American Indians.
- Internal university support and capacity for projects was not always clear.
- Pilot projects are often a means to collect data that will not benefit local people.
- Timeframe of projects often are unrealistic.

My reluctance to become involved with research has helped me to think about how I need to be in relationship with research so that the spirit I put into my scholarly work is grounded in Pueblo core values of love, respect, compassion, faith, understanding, spirituality, and balance that the Leadership Institute reminds Pueblo people to stay true to.

Factors Impacting Research With Pueblo People

Limited Research Benefits

Issues with research that I identified through my autoethnography are also issues discussed by other Pueblo scholars and validated my concerns with research that resulted in my reluctance towards research. Research and scientific discovery brings recognition, prestige, and monetary gain for the research institution and researchers. Yet, for Pueblo people research has not brought the same benefits and direct benefits are not always clear. Instead research has brought skepticism as stated by Cochiti Pueblo scholar Mary Eunice Romero (1994), "Pueblo people have become very skeptical of research in

general as a result of innumerable experiences with outside research which have had a consistent pattern of little or no direct benefit to the Pueblo communities" (para. 9). Dozier Enos (1999) talks about the need for research to benefit tribes and the importance of Pueblos in identifying research needs rather than an outside researchers identifying the needs for Pueblos. Dozier Enos (2002) asserts, "…research is worse than useless if it cannot uncover concrete ways to serve the community being researched" (p.8). If Pueblos play a role in identifying their own research needs, then beneficial and useful research for Pueblos seems like a more attainable reality. In my experience within academia the typical approach was for researchers to conceptualize their studies based on their own areas of interest without community involvement or understanding true community research needs, context, or history with research.

Broken Trust and Pueblo Secrecy

Research has brought broken trust due to exploitation of entrusted knowledge and has contributed to Pueblo secrecy as stated by Suina (1992),

> Perhaps the most frequent and irritating infractions are committed by professional photographers, writers, and scholars. Time and time again, they have managed to gain the trust of Pueblo people who, in turn, share bits of information in good faith, only to see this knowledge made accessible to the general population. (p. 63)

Romero (1994) identified the seclusive nature of Pueblos as having an impact on research. Suina refers to this protectionism among Pueblo communities as "secrecy," a response with deep historical roots dating back to first European contact with the Spanish and further reinforced by U.S. federal Indian policy. Suina (1992) states that "Secrecy has become synonymous with cultural and religious preservation" (p. 62) and has resulted in

the purposeful concealment of information from outsiders even into the present. Dozier Enos (2002) describes the impact Pueblo secrecy has had on her as a Pueblo researcher,

> …as a Pueblo person doing research in Pueblo communities, I find I must sacrifice some of the ethnographic "thick description" (Geertz, 1977) that is so valued in qualitative research in order to honor the limits of information that may be shared outside the Pueblo world. (p. 5)

Pueblo secrecy is something that I am mindful of as well and has contributed to my own hyper vigilance in making sure I am careful of what cannot be shared outside of the Pueblo world. Divulging information not meant to be shared outside of my Pueblo can result in being ostracized from my Pueblo (Pecos, 2007). When researchers too curious about certain things approach me, I automatically pull away and let them know that certain things are not open for discussion and provide them with my father's article about Pueblo secrecy.

The thought of being barred from my community is frightening, but the thought of being associated with the exploitation of community knowledge or harm caused by insensitive research, is absolutely terrifying to me. I would rather be blacklisted within academia for being uncooperative than by my own community for breaking a sacred trust. I have to go back to my community, but a researcher with no connection to my community does not have to worry about this or their standing like I do. For researchers who do not understand how history impacts interactions with Indigenous communities, it is important for them to gain a better understanding of local history and recognize that history matters when attempting to engage Pueblos in research. I have encountered non-Indigenous researchers that have discounted the power that history has on research conducted today.

Whose Knowledge Counts as Valid? Who is Generating Knowledge?

The challenge with health research that produces research validated health education programs and curricula that are implemented in Pueblo communities with the intention of improving health, is that these programs are typically based on western notions of health and are not validated in Pueblo communities; they rarely, if ever, include Pueblo health concepts. Whose health knowledge gets privileged in health research is a social justice issue because it is based on who has power and what is deemed "valid" health knowledge. Pueblo health research should include Pueblo conceptualizations of health that are more complex than biomedical notions of health which tend to focus primarily on the body and physical health. Today, many Pueblo people often equate health with health care and disease probably because of the biomedical emphasis, but it is so much more. Pueblo health is about having a healthy body, mind, spirit and heart and balance between these multi-dimensions (SFIS Leadership Institute Pueblo Convocation, 2012).

At a recent university meeting where tribal leaders were asked to share a health priority that could be addressed by the university, one leader identified land as a health priority and challenged university health researchers to help tribes get their land back. How can research be used to assist tribes in getting their land back or in preventing the loss of traditional languages, two elements that are also critical for health? How can research be used to inform policy to protect Pueblo land and cultural resources? Cochiti Pueblo tribal leader Regis Pecos (2007) recalls how legal research played a key role in finding documentation that provided evidence for a Pueblo's claim regarding the wrongful taking of 24,000 acres of their land base. The return of land to that Pueblo is an

example of a beneficial research outcome that is important for Pueblo health because land is intimately connected to health.

Romero's (1994) study on Pueblo giftedness highlights the importance of grounding research in Indigenous knowledge in determining what giftedness means to Keresan Pueblo people. Romero situated her study, involving several Keres speaking Pueblos, in their own Pueblo knowledge, values, and learning. Similarly, grounding health research in Pueblo knowledge systems is critical for developing approaches and opportunities that may be overlooked by focusing solely on western health concepts. I feel that it is important to clarify that when I refer to Pueblo knowledge, I am referring to our own ontological (i.e., related to what we know), epistemological (i.e., related to how we know), and axiological (i.e., related to our values) orientation to the world gained from our lived experiences as Pueblo people. It does not refer to sacred knowledge that is only meant for Pueblo people. This knowledge must be kept sacred.

Santa Clara Pueblo scholar Greg Cajete (2008) also addresses the issue of grounding research in Indigenous knowledge. He identifies the need for endogenous research that comes from within and the need to have our own Indigenous scholars so that research is guided by the needs of Indigenous people and controlled by Indigenous people. Merely having a Native person on a research team is not enough to be culturally sensitive in research and can result in tokenism of the individual (Dozier Enos, 1999). I often felt tokenized when I worked for an academic institution.

If research is ultimately about learning to better understand a particular phenomenon to produce new knowledge, then research that involves Pueblo people should be about Pueblo knowledge production that has meaning and benefit within a

Pueblo context and compliments Pueblo learning processes. Acoma Pueblo scholar Simon Ortiz (Justice Studies – Indigenous Literature, Art, and Humanities lecture, November 22, 2013) discussed the differences between Pueblo and Euro-American knowledge. According to Ortiz, social, emotional, and spiritual contexts are present in a Pueblo knowledge base whereas knowledge is not personal and is removed from humanness in the Euro-American scientific approach. Cajete (1999) also describes Indigenous learning as a holistic process that occurs in "highly context social situations" (p. 53) and having as one of its critical elements, appropriate timing for what is taught and when it is taught. Suina and Smolkin (1994) reflect on the idea of individual readiness for acquiring knowledge within the Pueblo world versus when one is curious within the Euro-American world.

> In the Euro-American world, when one wishes to know about an event a simple visit to the library and copying machine makes the knowledge portable and accessible to any who wish it. In the Pueblo world, many forms of knowledge are restricted; they are imparted only to those who are deemed ready, only to those who will have need for the information. (p. 119)

Knowledge is readily accessible through the Internet and social media, and makes protection of Pueblo knowledge more challenging. Responsibility is another attribute necessary for a learner to acquire certain knowledge (Suina, 1992), and becomes more necessary in current times with knowledge being available instantaneously.

How can research processes compliment Pueblo knowledge acquisition so that cultural based learning processes are respected? If the researchers are viewed as being learners rather than an experts or authorities, and research participants as being teachers because of their knowledge sharing, then there is an opening for a paradigmatic shift to occur in how research is carried out. And accountability of the researcher based on

Pueblo ways is built into process before research even begins. Researchers, Pueblo and non-Pueblo alike, would have to demonstrate their readiness and their ability to be responsible recipients of Pueblo knowledge. Researchers that are interested in conducting research with Pueblo people would have to provide prerequisites to tribal leadership before they are allowed to conduct research with Pueblo communities. Pueblo people would determine what prerequisites would best provide evidence that best demonstrate the researcher's readiness and responsibility to carry out research with Pueblo people. For example, tribal leaders are often asked by researchers they have not met to provide letters of support for research; perhaps tribes should begin requiring letters of recommendation from researchers describing the researchers' ability to work with tribal communities that are offered by other tribal communities in which they worked to provide support for them.

Romero's study on Pueblo giftedness (1994) discusses other factors that impact research and how they were addressed in her study. Sensitivity and respect toward Pueblo people are critical ingredients when conducting research in Pueblo communities. Romero operationalized this in her study by taking the time to build trust and adhere to tribal protocol to obtain local tribal approval to conduct research. She involved Pueblo community members throughout all phases of her study as members of an advisory committee and as members of the research team. Her study was grounded in Pueblo values, traditions, language, and lifestyles. Research findings were given back to the community in a symposium. Although these strategies may seem like they are just a given for working respectfully with any community, I have seen them overlooked and are

worth mentioning again as other Pueblo scholars (Cajete, 2008; Dozier Enos, 1999; Suina, 2004) have also previously pointed out.

Conclusion

Listening to what Pueblo scholars have to say about research is important in eliminating problematic mainstream research approaches so that it no longer alienates Pueblo people and exploits Pueblo knowledge. Moving from considerations for research from a Pueblo Indian standpoint to the development of Pueblo specific research methodologies based on each Pueblo's unique context is also of critical importance so that relevant research and health education approaches grounded in Pueblo thinking can emerge. This, in my view, is a more proactive approach that allows for creation of methodologies and supporting methods to drive Pueblo research rather than responding to western research methodologies to protect Pueblo people from harm. For this to happen, more discussion needs to happen among Pueblo people.

CHAPTER 2

BOOK CHAPTER - REFLECTIONS OF A PUEBLO INDIAN HEALTH EDUCATOR

Introduction

Working with Pueblo students as a health educator is where I really learned to be mindful in how I present health information so that I honor and respect students' life experiences and the knowledge that they bring from their communities. Not only is the way in which health information is taught, such as through pedagogical approaches, but also, the broad topic of health raises multiple issues. For example, as a Pueblo person connected with my own Pueblo community, I have several concerns about writing about Pueblo health. First, it is important for me to clarify that certain Pueblo knowledge that is only meant for Pueblo people should not be discussed in certain contexts. This is particularly relevant here as some areas that address cultural practices in the Pueblos will not be discussed in this book chapter. I will be honest and admit that as I wrote this chapter I felt some reluctance toward expressing my ideas that resulted in my procrastination with getting my chapter completed, because I worried that I may receive criticism from some Pueblo people for writing about Pueblo health. My fear is that I may be perceived as someone who is claiming expertise in Pueblo health, which I am not claiming, or that I am making assertions about Pueblo health that are not how they perceive Pueblo health to be. It is far easier for me to write about and critique typical western research practices since calling out oppressive forces is easier to rally Pueblo support in fighting against. If anything, I may receive criticism from non-Indigenous academicians and researchers, but I am okay with that.

Furthermore, it is not my intention to essentialize, objectify, or devalue the lived experiences of Pueblo health by writing about how Pueblo people view health. I also realize that once something is written it becomes accessible to the world. Since Pueblo people have been the objects of study by outside scholars that have misrepresented Pueblo people (Dozier Enos, 2002) it is important for Pueblo people to tell who we are to provide multiple perspectives of Pueblo life experiences. I offer only one Pueblo perspective about health, which includes reflecting on Pueblo health theories and wisdom (SFIS Leadership Institute, 2008; SFIS Leadership Institute; 2012). Second, there is a built-in challenge to writing about such a critical topic such as health that is connected to place, language, and culture. I am not a fluent Cochiti Keres language speaker, the heritage language of my Pueblo, even though I grew up in the place of my ancestors. At the same time, despite the fact that my first language is English, my thinking about life and my place in this world reflects my upbringing in my Pueblo and is grounded in the core values, culture, and worldview of my Pueblo.

Given these elements and along with my experiences as a health educator, I offer that the purpose of this chapter is to reflect on what I have learned in order to add to the discussion about notions of "Pueblo health." Moreover, I argue that there must be an emphasis on grounding Pueblo health education in local Pueblo knowledge systems, which is a call for Pueblo community members and Pueblo, other Indigenous, and non-Indigenous health educators and stakeholders to challenge the limitations of solely delivering health education grounded in a disease focused biomedical model. In this chapter, I also ultimately explore what I call *healing educational models* that are not

labeled simplistically as health education programs but that support Pueblo health and already exist within some Pueblos.

Background of the Problem and *Pueblo Knowing*

My journey as a health educator began in the classroom with Pueblo Indian elementary and middle school students delivering a research-validated life skills curriculum to prevent substance abuse. The evidence-based life skills curriculum was developed at Cornell University and tested on suburban youth located in New York and has been shown effective in reducing substance youth in White, African American, and Hispanic youth. The curriculum was not tested on American Indian youth. The curriculum consisted of weekly lessons designed to a) increase student knowledge about the harmful effects of substance use, b) teach skills such as decision-making and communication skills, and c) increase self-esteem. Implementation of the curriculum was supposed to strictly follow the teacher's guide and student workbook to maintain the fidelity of the curriculum and to ensure that it was being properly taught. This standardized process left little room for any type of cultural tailoring, meaning that the inclusion of Pueblo cultural values and social norms important for being healthy was limited in favor of Western values and norms.

I have a photograph of myself from my first day with these students, standing in front of the class, and with Pueblo children sitting at their desks with their hands in the air ready to answer my questions. I look back and wonder what my students really gained from that experience beyond a break from their usual teacher and class schedule. In retrospect, I believe that I probably gained more from my first day of teaching than my students. For example, I learned that it is critical to make lessons relevant to students in

order to stimulate student responsiveness and engagement: I immediately understood that I would have to stray from the teacher's guide and incorporate more experiential *group* activities into the lesson plans to counterbalance the *individual* student worksheets to better align with the collective orientation of Pueblo people. I would also have to contextualize the curriculum and use local values, norms, and examples to explain concepts embedded within the curriculum. For example, when I taught assertiveness skills I reminded my students that being assertive, according to conventional Western definitions, is not always appropriate in Pueblos. Assertiveness within the life skills curriculum was associated with refusal skills and saying no to peers in response to peer pressure. A young person might be perceived as being disrespectful if they assert themselves to an adult or elder when assertiveness is not called for and they are being asked to cooperate in order to contribute to the greater good of the community. For example, if an adolescent is asked to help in the kitchen or chop wood and he or she refuses to help. Although assertiveness is not inherently bad, it is important for youth to be able to discern when being assertive is appropriate within a Pueblo context and how to apply assertiveness to situations that challenge Pueblo people beyond the individual. Learning how to question unjust policies that impact Pueblo people is one example that comes to mind.

My career as a health educator has been spent working with Native American people. I have been fortunate to work with people from my own Pueblo and from tribes throughout New Mexico and the United States. I became a health educator to contribute to the health and wellness of Pueblo people and to play a role in our healing from the outside colonial impositions that disrupted the healthful way of life known by my Pueblo

ancestors. One central question in my role has been—How am I thinking about health education differently as a Pueblo Indian health educator? First, I am calling for Pueblo conceptualizations of health to be foundational for health education for Pueblo people. I argue that western health behavior theories, adapted from social and behavioral sciences, used to develop health interventions provide limited benefit because outcomes are based on biomedical notions of health that focus on disease and the physical body. Pueblo theories of holistic health, grounded in localized Pueblo social and behavioral theories, are important for framing health education for Pueblo people to achieve their health goals. It is my belief that Pueblo theories can produce desired outcomes for Pueblo people based on their desired health outcomes.

Scholars have argued that Indigenous epistemologies are distinct, not only from each other, but also from mainstream, popular, and Western-idealized and dominated epistemologies that frame much of our contemporary existence today as human beings (Brayboy, Fann, Castagno, & Solyom, 2012a; Brayboy, Gough, Leonard, Roehl, & Solyom, 2012b; Cajete, 2005; Wilson, 2008). In this vein, it is much easier to say that Pueblo people have a different epistemology or worldview when trying to make a case for different educational or health approaches for Pueblo people without providing any explanation. I have claimed this in professional meetings on many occasions, but what did I really mean? How does Pueblo worldview differ within an educational context for a Pueblo person with English as their first language? And why is that worldview significant? What does our Pueblo worldview offer and to whom? As a high school senior I wrote an essay about Ernest Hemingway's novel *The Old Man and the Sea*. I still have the original copy that I painstakingly typed on my parent's electric typewriter. I

interpreted the old man's pride as being self-destructive. I wrote, "On the return home the old man can't even bring himself to look at the half gone fish…His precious pride has been destroyed. He did this to himself by holding his dignity as if it were sacred." Although my paper received an "A", the comments my non-Native teacher marked on my paper did not make sense to me at the time. My teacher wrote, "Although I disagree with your thematic interpretation, you provide interesting ideas and try to back them up with data from the book. Ernest H. believed that pride was the best part of the man." My teacher even called my thematic analysis, "A different and interesting interpretation."

I now understand that my interpretation and my teacher's comments resulted from different worldviews. Embedded in my interpretation of *The Old Man and The Sea* is my Pueblo worldview. I believed the old man, Santiago, was being self-centered. Being self-centered and having too much pride were discouraged in my Pueblo upbringing. Being group oriented and having humility were encouraged and modeled instead. As a teenager, my father, a well-regarded Pueblo scholar, would tell me, "You are not an island upon yourself," when he thought I was being too self-involved. What I understand now is that tend to I take my Pueblo worldview for granted and do not see it as being something different until it is pointed out to me. However, this is an important undertaking for my identity as both a Pueblo person and an emerging researcher and scholar. As such, I believe that it is important to answer the following questions, within appropriate parameters that do not reveal sacred knowledge, if Pueblo people are to advocate for approaches and solutions to the challenges that Pueblo people face that are grounded in Pueblo knowledge systems:

1) *What do Pueblo people know and believe to be true?* (Ontology)

2) *How do Pueblo people know what we know and believe to be true?* (Epistemology)

3) *What values guide Pueblo people?* (Axiology)

My high school experience revealed that as a Pueblo person I knew that pride can be destructive. I learned this notion from my community starting with my parents, and I knew that I should be humble.

In collectivistic societies, like the Pueblos, the emphasis is on the group is and not on the individual, although the individual plays an important role in contributing to the collective. Cooperation and interdependence are highly valued. Pride singles a person out and pride is not necessarily a good thing. I watched my parents and others around me in my Pueblo being humble and I just knew this is how I should carry myself. As a Pueblo health educator I am guided by my Pueblo worldview when I teach or bring people together to facilitate dialogue in planning initiatives. My Pueblo knowing informs how I am supposed to be in relation to others, how I should communicate, how I should listen, and how I should carry myself. My Pueblo knowing informs me that health is more than the physical body, is multi-dimensional, and connected to whom I am supposed to be as Pueblo person.

Pueblo Health

A team of Pueblo health advocates, including me, were asked by the Leadership Institute at the Santa Fe Indian School[1] to develop a presentation in order to address the state of Pueblo health for the 2012 Pueblo Convocation. This historical Convocation, the

[1] The Leadership Institute at the Santa Fe Indian School is an Indigenous/Pueblo/NM tribal community development organization based in Santa Fe, New Mexico. For more information, see www.lisfis.org

first of its kind, brought together nearly 650 Pueblo people to discuss issues impacting Pueblo communities today. Part of the Leadership Institute's signature framework is to provide an overview of the past 100 years of U.S. Federal Indian Policy and the impact these polices have had on Pueblo people. While we identified specific health related policies that have had an impact on Pueblo people, such as the 1921 Snyder Act and the 1976 Indian Health Care Improvement Act of 1976, one of our main goals was to encourage Pueblo people to think about health beyond physical health and seeking health care at a local Indian Health Service facility in response to being sick.

The Pueblo Convocation health team wanted to trigger thinking and discussion about Pueblo determinants of health and to remind our Pueblo relatives that we have health solutions already within our communities if we look not so far back to how our ancestors lived. Zia and Cochiti Pueblo scholar Ken Lucero (SFIS Leadership Institute, 2012) best articulates why we encouraged Pueblo Convocation participants to remember what health means from a Pueblo worldview:

> We have lost control of our health. It has been taken away from us and turned upside down. Instead of approaching health like we have in the past we now approach medicine from a disease burden model. Instead of looking at ourselves holistically we are divided into agencies and departments. Our health is directed by regulations and legislation.

The Pueblo Convocation session entitled, *Pueblo Health: Healthy Minds, Bodies, Spirits, and Heart* (SFIS Leadership Institute, 2012), showcased photos from the early 1900s of Pueblo communities to elicit dialogue about Pueblo health. These photos included Pueblo corn dancers gathered outside of a sacred gathering place for Pueblo peopled called a *kiva*, a pristine village with a *kiva* in the foreground and a church in the background, a Pueblo man in his cornfield (See Image 1), a Pueblo family and their corn

and green chile harvest, a Pueblo woman grinding corn using grinding stones, a group of Pueblo women plastering an adobe home, and a Pueblo mother breastfeeding her baby. Convocation participants were asked, *"What is healthy? What do you see that is healthy in this picture?"* Responses contributed by participants included the following comments:

- *All together*
- *Healthy bodies*
- *Multigenerational*
- *Unity*
- *Ceremony*
- *Family*
- *Healthy community*
- *Kiva*
- *Clean community*
- *Religion, ceremony, prayer*
- *Corn*
- *Nurturing*
- *Slim*
- *Family*
- *Children*
- *Chile*
- *Hard work.*

- *Women, working hard, sharing*
- *Breastfeeding is a way to help protect the child from illnesses*

Photograph 1. My Grandfather: Celestino Quintana

A complex and more nuanced picture of Pueblo health, beyond physical health or disease, emerged from this simple reflexive exercise. Pueblo health is about having a healthy mind, body, spirit, and heart and being in balance (SFIS Leadership Institute, 2012). Pueblo health is connected to place, language, and culture. Pueblo health is connected to who we are supposed to be as Pueblo people. As Pueblo people we are reminded that our stories of emergence into this world provide us with the instructions for how we belong in this world as Pueblo people, how to behave, and how to treat one another (SFIS Leadership Institute, 2012). These concepts are Pueblo theories for health. Therefore, I argue for naming our Pueblo health and ways of knowing as Pueblo theories of health and learning instead of marginalizing our theories by saying they are Pueblo

perspectives of health and education: Although theories represent particular perspectives that try to rationally explain things it is my belief that we water down our theories when we relegate them to perspectives. Theories provide a systematic way to understand, explain, or predict certain situations (Glanz & Rimer, 2005) and Pueblo theories are not any different.

Pueblo Health Education

In 2008, I collaborated with the Leadership Institute to convene a Community Institute to discuss what health education for Native Americans in New Mexico must include. The Leadership Institute best describes a Community Institute as a Native American policy think tank. Participants of this institute stressed that Native American health education must be taught within a cultural context that is consistent with Native American core values and teachings about health. The core values important for sustaining health and wellbeing that were identified included the importance of family and community, service to community, nurturing relationships, spirituality and prayer, and traditional wisdom/practices. The Community Institute participants further advised that Native American health education must incorporate holistic Native American health models and not be in response to a health crisis or specific disease, but instead should be part of a long term plan for community wellness. Incorporating history and dialogue about the impact of federal policies on Native American communities into health education is also critical for providing a framework for understanding the health issues Native Americans face today. Finally, teaching Native American youth about what Native Americans believe about health was an identified as important to help to prepare them for challenges they will face in life.

There is a strong desire to create health education programs that align with and support Pueblo core values and health theories (SFIS Leadership Institute, 2008). Cochiti tribal leader and Co-Director of the Leadership Institute, Regis Pecos (SFIS Leadership Institute, 2008; SFIS Leadership Institute, 2012) reminds us that if education is not defined for Pueblo purposes then we run the risk of replicating federal programs that were intended to assimilate Pueblo people into mainstream American society to supplant Pueblo core values with foreign values. One must remember that the goal of settler colonialism was to eliminate the Natives, by whatever means necessary such as assimilation, to appropriate their land base and resources to benefit the colonial settlers (Wolfe, 2006). Sandy Grande (2008) explains how education was a means to appropriate Indigenous resources,

> The miseducation of American Indians precedes the "birth" of this nation. Indeed long before the first shots of the Revolutionary War were fired, American education was being conceived as a foundational weapon in the arsenal of American imperialism…the colonialist project was never simply about the desire to "civilize" or even deculturalize indigenous peoples. Rather, it was deliberately designed to colonize Indian minds as a means of gaining access to Indigenous resources. (p. 235)

Since the time of colonial Spanish occupation Pueblo people had to fight to protect their way of life, which is deeply connected to place and their ancestral homelands, from colonial settlers. Pueblo people banded together in response to the inhumane and suppressive treatment by the Spanish in what is known today as the Pueblo Revolt of 1680 (Sando, 1992). Therefore, it is not surprising that contemporary Pueblo scholars write that the purpose of Pueblo education is to protect and sustain a Pueblo way of life (Dozier Enos, 2002; Cajete, 2008). Therefore, a cornerstone for rethinking Pueblo health education is how it will contribute to the protection and sustainability of a Pueblo

way of life. Pueblo learning theories also provide guidance in rethinking Pueblo health education approaches.

Pueblo learning theories remind us that teaching and learning take place within an appropriate and timely context (Cajete, 2005; Suina & Smolkin, 1994). Pueblo pedagogy incorporates approaches that are based on a collective Pueblo way of life and orientation to the world. Traditional Pueblo teaching methods include group and cooperative learning experiences, group decision-making and consensus, role modeling, and oral transmission of information in which elders are the teachers (Romero, 1994; Suina & Smolkin, 1994). Focused listening, observation, trial and error, and private practice are ways in which Pueblo students traditionally learned (Romero, 1994; Suina, & Smolkin, 1994). Creating opportunities for Pueblo teaching and learning styles to sustain a Pueblo collective way of life is important because embedded in knowledge transmission are the values of Pueblo society that are important for a healthy community.

Thinking about health education as a way to protect and sustain a Pueblo way of life takes on a heightened level of responsibility and mindfulness to not introduce ways that are in conflict with this way of life and that completely assimilate Pueblo people into mainstream society so that we no longer recognize who we are as Pueblo people. There are Pueblo-driven programs, such as language revitalization programs and the Leadership Institute at the Santa Fe Indian School, which support and reinforce Pueblo health that can be learned from and contribute to a Pueblo way of life. I will briefly describe them, but acknowledge that they will require their own extensive study to further explore their promise as health education approaches or what I call healing educational models.

Pueblo Language Programs

I think of the language program in my Pueblo as a healing education model because it teaches information necessary for participating in the Pueblo world that revolves around the cyclical traditional calendar. The Pueblo traditional calendar of ceremonial activities that engage the entire community throughout the year is about sustaining a healthy spirit, mind, and body (SFIS Leadership Institute, 2008). I attended my Pueblo's language class for adult women for a period of time. In these classes language lessons were tied to the traditional calendar and provided women with highly contextualized knowledge for participating in cultural activities. We learned about traditional cooking and how to care for ourselves as women. The most important thing that I learned was how to pray in my traditional language. Since I carried shame and embarrassment for not knowing my traditional language, I did not learn how to pray in my heritage language until I attended language classes as an adult. The language class began a healing process to restore balance in my life and reconnect me with knowledge I need to participate in my community. Lessons taught in the language classes I attended support and are consistent with holistic Pueblo health theories.

Leadership Institute at the Santa Fe Indian School

Another healing educational model that actually played a critical role in helping me to step into a language class is the Leadership Institute at the Santa Fe Indian School. The Leadership Institute convenes Community Institutes that bring together Pueblo men and women, elders and youth, professionals and students, policy makers and tribal leaders to talk about critical issues impacting Pueblo people today and to come up with solutions that are grounded in our own Pueblo knowledge systems. The Leadership

Institute model reinforces Pueblo core values, teaches the impacts of federal and state policy, and reminds Pueblo people that each person plays a fundamental role in sustaining a Pueblo way of life. The Leadership Institute model, grounded in Pueblo thinking, is consistent with Grande's (2008) idea of Red Pedagogy and Paolo Freire's (1970) concept of critical consciousness that both critically question historical and social forces that create injustice and inequity.

Responsibility to community and future generations is a distinct feature of Indigenous Knowledge Systems (Battiste, 2002; Brayboy et al., 2012a) that must be incorporated into health education for Pueblo people. I propose that Pueblo language revitalization programs and the Leadership Institute are critical mechanisms to teach what Pueblo people believe and to reconnect tribal members with our own knowledge systems critical for health and wellbeing to transmit to future generations.

Education Not Designed By Us

Education is a vehicle for teaching the values of a society (Okakok, 2008). Whose values were embedded in the life skills curriculum that I first taught as a health educator working with Pueblo youth? Did these values support Pueblo ideology and worldview? Western education can still be a form of displacement (SFIS Leadership Institute, 2008; Ball, 2004) and has played a key role in the assimilation and indoctrination of Native Americans into U.S. society. This is best described by Vine Deloria, Jr. (2001) when he states:

> Education in the English-American context resembles indoctrination more than it does other forms of teaching because it insists on implanting a particular body of knowledge and a specific view of the world, which often does not correspond to the life experiences that people have or might be expected to encounter. (p. 42)

Research validated health education programs and curricula intended to improve health, like the life skills I implemented as a new health educator, are based on western notions of health and are not validated in Pueblo communities. Programs that are not validated in Pueblo communities do not consider how Pueblo people define health or the role that history plays in health issues experienced today by Pueblo people. Similarly with mainstream education programs, Euro-centric knowledge is privileged and Native students are often left confused and conflicted by well-intentioned non-Native educators (Suina, 2003). My father and Cochiti scholar Joseph Suina further states,

> Perhaps even worse, they render them incapable of finding their own solutions to problems...Students must come to learn that some solutions will evolve out of their native worldview. After all, their native world provided answers for their forefathers for hundreds of years before the white man came on the scene. Learned helplessness is a problem many tribal leaders worry about: Indian youth have come to have little faith in their native abilities and their community's viability. (p. 8)

Battiste (2002) describes the underlying tension between western and Indigenous knowledge when she states, "For as long as Europeans have sought to colonize Indigenous peoples, Indigenous knowledge has been understood as being in binary opposition to "scientific," "western," "Eurocentric," or "modern" knowledge" (p.5). Indigenous knowledge was dismissed because it was not understood and was believed to be unsystematic.

How often is western knowledge privileged and Pueblo knowledge discounted and left out of health programs implemented in Pueblos? How often are Pueblo people rendered incapable of finding their own solutions? How often are Pueblo people left out of conceptualizing and designing health programs that will impact their community? Based on my experience, these things happen far too often and result in the development

of health programs that are incongruent with Pueblo epistemology, ontology, and axiology that shape health.

Suina and Smolkin (1994) describe the discontinuities between the culture that Pueblo students are born into and the classrooms they are educated in that often takes place in elementary education. Discontinuities occur when Pueblo knowledge acquisition, cultural patterns, social norms and mores are not included in or reflected back to students in the classroom. The discontinuities that I observed with the life skills curriculum that I implemented with Pueblo youth included a disconnection between social and communication patterns. Critically thinking about what discontinuities occur in health education instruction to reduce gaps between Pueblo and western-based health knowledge has implications for how health education is approached among Pueblo people. It is also important to first start out with how Pueblo people define health and then identify gaps to root Pueblo health education in Pueblo health and learning theories.

My solution as a health educator to address the discontinuities that are embedded in western educational approaches is to create an "insurgent space" at the beginning of health education sessions that calls for the group to define health and that honors their Indigenous theoretical frameworks for health. My goal is to affirm that their health theories are critical for wellness and preventing illnesses and are just as legitimate as those that are validated by western standards. I use historic photos from Southwestern tribes from the early 1900's to trigger dialogue by asking the simple question, "What is healthy in this picture?" This approach was applied to the 2012 Pueblo Convocation health presentation described earlier.

What often occurs with this photo exercise is that people often reflect on Indigenous knowledge and core values which have been passed on to them to take care of their health and wellbeing. Discussion also typically emerges about the historical disruptions that have occurred in their communities that impacted health. I have been able to draw out Indigenous health theories and connect them with western-based health knowledge. Creating space as a part of health education to reflect on Pueblo health theories and history, especially as it relates to colonial policies that disrupted Pueblo ways of life and wellness is consistent with Grande's (2008) idea of Red Pedagogy. Red Pedagogy is grounded in Indigenous knowledge and praxis informed by critical theory that works toward building collective agency to dismantle colonial and imperial oppression.

Application of Pueblo thought is critical to find solutions to the challenges that Pueblo people face including those challenges that are related to the health and wellness. Suina (2003) reflects on the federal government's paternalistic treatment of Pueblo people, "Almost always a tribe like mine has had to follow the dictates of the dominant culture, of the "Great White Father," with no considerations for the wishes of the tribe" (p. 5). For example, to receive federal funding to improve community health Pueblo communities must select from "evidence based" strategies that are typically validated in communities vastly different than their own that do not share the same values or context. The federal government rewards those that are able to choose strategies that are aligned with federal ideas of health that are validated by scientific research. Tribes are expected to select from western evidence-based approaches and set aside their own evidence.

Pueblo health theories are typically ignored in requests for proposals. Applicants must conform to governmental ideas grounded in western thought for successfully achieving health after demonstrating a dire need to receive funding that often paints their own communities as being depleted and without any homegrown solutions. Pueblo communities are forced to part from their own cultural based ways of sustaining health if they want to receive much needed monetary resources to enhance or create opportunities for health to address the pressing health disparities that their communities experience. They must align with the strategies endorsed and encouraged by the “Great White Father” for being healthy even if the approaches do not acknowledge or align with their own ideas of health and their own unique context. Pueblos must do extra work and adapt mainstream approaches.

What this approach also ignores is the role that the U.S. federal government played in contributing to the health disparities experienced today by Pueblo people. Many of the health conditions we face today have deep roots in colonization and U.S. federal Indian policies (Jones, 2006; Roubideaux, 2002; SFIS Leadership Institute, 2008). For example, in my own Pueblo the United States government threatened to condemn our reservation and relocate my Pueblo to build one of the largest man-made dams in the world for flood control and to create recreation to benefit nearby cities in New Mexico (Pecos, 2007). Relocation did not occur and the dam was built that resulted in the loss of sacred sites and destruction of traditional farmlands. Our healthy traditional way of life was impacted by construction of the dam. Water began to seep into once fertile farmlands one year after the dam opened that destroyed our agricultural way of life for three decades. My Pueblo successfully sued the U.S. government to repair the damage brought

by the dam and is still in the process of reclaiming our agriculture. Unfortunately, the sacred sites that were destroyed by the federal government can never be reclaimed.

Scientists that try to explain the health disparities that we face as being the result of individual behaviors or of genetic predisposition are not considering the assaults our people have faced from colonization. Focusing on finding the genetic underpinnings for the health issues we face is a form of erasure (Kaomea, 2003) of this nation's colonial history that tries to forget how this country came to be, at whose expense, and the resulting social conditions that were created. The western biomedical model that is based on treating disease in an individual patient also contradicts Native American holistic health constructs that values traditional healing and traditional healers. In Making Cancer Health Disparities History (DHHS, 2004), describes the conflict between the western medicine and traditional health practices:

> The culture of medicine and the disease-based paradigm can often be incompatible with traditional or cultural beliefs about health and wellness. Without communication, respect, and understanding of these differences, patients often experience a western medical model and system that is hostile to traditional ways of dealing with health complaints and the promotion of wellness. (Appendix A-21)

Attempts to make health education programs more culturally appropriate often fall short. Kreuter, Lukwago, Bucholtz, Clark, and Sanders-Thompson (2003) describe strategies to culturally enhance health promotion programs as follows: (1) *Surface strategies* include superficial packaging (i.e., pictures, fonts, images, symbols) to appeal to a certain group of people; (2) *evidential strategies* present evidence (i.e., data) that shows impact of a health issue on a certain group of people; (3) *linguistic strategies* incorporate native language; (4) *constituent strategies* include individuals from the group of people that a program is designed for in staffing the program, planning, and decision

making; (5) *socio-cultural strategies* reinforce cultural values, beliefs, and behaviors to offer context for the program. Even these strategies start out with a tacit assumption that the foundation of health programming is based on western health knowledge and information. Otherwise there would not be a need to culturally enhance a program to make it more compatible and acceptable. I argue for flipping the paradigm and starting with Pueblo health as the foundation for health education programs and adding on western health knowledge that is deemed appropriate as necessary.

Conclusion

The tension I felt, as a new health educator, between the western life skills curriculum that I was charged with implementing and who I am as a Pueblo Indian person was clearly the result of an epistemic clash between western and Pueblo knowledge systems or worldviews. This clash was not any different than my experience as a high school student when I was confronted with my “different” and “interesting” interpretation of an American classic novel. Both of these experiences made me feel like I was on the fringe. How often are Pueblo people made to feel like they are on the fringe when their knowledge is not reflected in health education programs? This is something that must no longer happen.

I have implemented several other health education programs since I first began my career as a health educator, including a few that were developed specifically for Native Americans. These programs were based on western medical health knowledge and notions of health. Culture was superficially added on as packaging. I am not saying this approach is not valid, but I am not so sure how much impact this type of approach can show. These types of programs do not approach healing at the community level and

instead focus on developing skills at the individual level to facilitate individual behavior change. The focus on individual rather than on the community goes against the collective orientation of my Pueblo. Collective health education approaches that support the goals of Pueblo health are necessary.

Using a strength-based approach, that honors culture and recognizes community wisdom, is important for addressing health in indigenous communities (Bird, 2002; Bowekaty, 2002). Respect for both indigenous and western knowledge systems is important (Battiste, 2002). Finding a middle ground between the two knowledge systems so that they are complimentary instead of polarizing (Barnhardt & Kawagley, 2005; Brayboy & Maughan, 2009; Dozier Enos, 2002;) is also important, especially since Pueblo people today rely on a western medicine to prevent and treat diseases that has been of benefit. Therefore, evaluation of how western knowledge is currently utilized is critical to rethink how this knowledge can compliment, instead of eclipse, our Pueblo health knowledge.

CHAPTER 3

POLICY BRIEF - CHANGES TO NMDOH RACE AND ETHNICITY PRESENTATION IN HEALTH DATA STANDARD: AMERICAN INDIANS AND ALASKA NATIVES IN NM RECLASSIFIED AS HISPANIC

An Urgent Call to Action for Tribal Leaders and Tribal Health Advocates

Introduction

As part of the cohort dissertation requirements we developed policy briefs to address current issues impacting American Indian people in New Mexico. As a health professional from Cochiti Pueblo I am gravely concerned about the decision made by the New Mexico Department of Health, without Tribal Consultation, to change how they present race and ethnicity in health data that has immediately impacted American Indians in New Mexico.

I prepared a policy brief for Tribal Leaders in New Mexico in anticipation of the Tribal Consultation session regarding this issue that will take place at the end of April 2015. The policy brief that I have written identifies gaps in the evaluation process conducted by the New Mexico Race and Ethnicity Workgroup that was formed in July 2012 to evaluate their guidelines for presenting race and ethnicity in health data. I also identify recommendations for Tribal Leaders and the State of New Mexico to be considered for determining the best way to represent AI/AN health data so that it does not negatively impact AI/AN.

I first became aware of this issue from the Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC) where I currently work as a program director. AASTEC has been a champion for American Indian communities by calling into question the

State's decision to change how they present data and raising awareness of this important issue. I have written the policy brief with the support of AASTEC, the Albuquerque Area Indian Health Board, and the Leadership Institute at the Santa Fe Indian School. The content in the policy brief has gone through an extensive review process with key stakeholders.

The Problem

Healthy self-determined American Indian communities resist outside governmental decisions that undermine their sovereign status and that negatively impact their communities and future generations yet to come. The State of New Mexico must honor and uphold the State-Tribal Collaboration Act.

On July 13, 2013 the New Mexico Department of Health (NMDOH) changed its standards for how race and ethnicity is presented in all health data without tribal consultation.[2] This was a violation of New Mexico Senate Bill 196, referred to as the New Mexico State-Tribal Collaboration Act. This act indicates that, "A state agency shall make a reasonable effort to collaborate with Indian nations, tribes or pueblos in the development and implementation of policies, agreements and programs of the state agency that directly affect American Indians or Alaska Natives."[3]

This major decision, which significantly impacted American Indian/Alaska Native (AI/AN) population estimates in NM, was based on findings from just one survey that generalized conclusions for all AI/ANs in NM. How sound is a decision that affects a whole population of people (i.e., AI/AN) based on one survey that did not consider the

[2] https://ibis.health.state.nm.us/resource/RacEth2013.html
[3] http://www.iad.state.nm.us/docs/legislation/SB0196.pdf

historical and social factors that play a role in how AI/ANs are identified including self-identification?

- Changes to NMDOH reporting standards immediately resulted in the removal of 39,636 American Indian and Alaska Natives (AI/AN) from NM population estimates and reclassified them as Hispanic.
- Funding for health services and programs for AI/AN may be negatively impacted because population estimates are factored into funding allocations.

The NM Race and Ethnicity Workgroup was formed in July 2012 to evaluate existing guidelines for presenting race and ethnicity in health data.[2] A review of their evaluation process exposes several gaps, including:

- AI/ANs were not represented on this workgroup.
- Workgroup recommendations are based on findings from only one survey, the 2011 Behavioral Risk Factor Surveillance System (BRFSS), which was administered entirely by telephone.
- BRFSS findings do not give information for why some people choose one race and another ethnicity. Quantitative survey results from one survey are insufficient to assess the balance of benefits and harms of changing race and ethnicity presentation standards.
- The State tribal epidemiologist and liaison positions were both vacant when the decision was made to change the race/ethnicity presentation standard.

Additional information is needed to assess the validity and appropriateness of changes made to the NMDOH presentation standards for NM Tribal leaders and health advocates to weigh in on.

NMDOH Race/Ethnicity Presentation Standard[4]

Persons designated as Hispanic ethnicity, regardless of race, will be categorized as 'Hispanic.' Persons not designated as Hispanic will be categorized by their single race ('Black or African American,' 'American Indian or Alaska Native,' 'Asian or Pacific Islander,' 'White,' or 'Other'). If a person is mixed race and ethnicity with their reported race being AI/AN and ethnicity being Hispanic they will be categorized and designated as Hispanic only and will not be included in AI/AN population estimates.

Why is this a problem?

- Current NMDOH presentation standards don't consider the historical and social factors that play a role in how racial and ethnic identity are formed at societal and individual levels.
- Health research and data collection about AI/AN are situated within a historical backdrop of imperialism and colonialism where Indigenous people have been misrepresented, especially as being deficient, which often seems to go unquestioned by the non-Indigenous.
- State government is replicating colonial federal policies of statistical elimination, such as blood quantum practices, that were intended to terminate and assimilate AI/AN into mainstream society to seize their land base and resources.
- Enrolled tribal members may wrongly be assigned into non-AI/AN racial/ethnic categories. Undercounts could put their tribal communities at a disadvantage for federal, state, and private resources for health services and programs.
- Formation of race and ethnic identity is complex and is not static. This identity

[4] https://ibis.health.state.nm.us/resource/RacEth.html

can change for a person during their lifetime.

- Switching presentation standards will make it difficult to impossible to examine health trends across time.

The following questions about the Behavioral Risk Factor Surveillance System (BRFSS) are critical for determining if findings from this survey provide sufficient evidence for changing presentation standards for race/ethnicity in all health data.

- Was the preferred race/ethnicity question appropriate for assigning ethnicity (i.e., "Which one of these groups would you say best describes you? Hispanic or Latino, White, Black or African American, Asian, Native Hawaiian or Other Pacific Islander, American Indian or Alaska Native or Other")?
- Are those individuals that self-identified their race as AI/AN, but their ethnicity as Hispanic enrolled tribal members?
- Do those individuals that self-identified their race as AI/AN, but their ethnicity as Hispanic know that their health services (if using IHS or other tribal based programs) could be negatively impacted?
- Was there harm done to individuals that self-identified their race as AI/AN, but their ethnicity as Hispanic because health services and programs for AI/ANs may be impacted? Was there harm done to all AI/ANs in NM?

Recommendations

- NM Tribal Leaders must call into question this recent action of the State of NM.
- NM Tribal Leaders and health advocates must participate in the process to determine the best way to measure race/ethnicity and represent this data so that it does not negatively impact AI/ANs: A tribally appointed AI/AN task force should

be convened to review additional evidence necessary to inform a decision that will impact AI/ANs in NM.

- A more detailed plan needs to be developed by the State of NM to look at ways reduction of numbers will have negative impacts for NM Tribes.
- Additional mixed methods studies (i.e., qualitative and quantitative studies) are needed that look at the long-term impacts of changing presentation standards for race/ethnicity. Those studies should include a costs/benefits analysis based on Tribal needs.
- Review of similar cases must take place to synthesize lessons learned to inform the NMDOH race and ethnicity data presentation standard. Similar cases include changes that were made in 2007 to U.S. Department of Education race and ethnicity data reporting guidelines and those cases that have occurred among other Indigenous peoples regarding their identification in data such as in Australia and Canada.[5,6,7]
- Creation of a formally sanctioned Tribal data committee, similar to the All Pueblo Council of Governor's sanctioned committees, by NM Tribal Leaders is needed to address current and future data issues that impact AI/AN.
- An educational module on data needs to be developed to brief NM Tribal Leaders about how data collection, analysis, and presentation can impact their Tribal communities.

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[5] http://www.ncai.org/policy-research-center/initiatives/data-quality

[6] http://www.ncai.org/attachments/Resolution_dJIeLxKycJqoTSsQiRsnYggoHIYMqycZshJoqIZnKNVdgeXzeVF_RAP-10-031.pdf

[7] Walter M, Andersen C. Indigenous Statistics: A Quantitative Research Methodology. California: Left Coast Press, Inc; 2013.

One of the ways Tribal leaders can take action in response and in order to intervene is to participate in the Tribal Consultation session meeting that will happen at the end of April 2015. Points to emphasize include the following. The State of New Mexico must:

- Create an AI/AN task force appointed by NM Tribal leaders to review additional evidence that must be taken into consideration in how race/ethnicity is presented/reported for AI/AN in NM.
- Conduct impact studies looking at similar contestations of governmental data practices by other Indigenous peoples such as in Australia and Canada.
- Revert 2013 NMDOH race/ethnicity presentation standards back to previous standards until further comprehensive studies are completed to determine best action.
- Honor and uphold the State-Tribal Collaboration Act, NM Senate Bill 196, where any state agency shall make a reasonable effort to collaborate with Indian nations, tribes or pueblos in the development and implementation of policies, agreements and programs of the state agency that directly affect American Indians or Alaska Natives.

REFERENCES

Alfred, T., & Corntassel, J. (2005). Being Indigenous: Resurgences against contemporary colonialism. *Government and Opposition*, *40*(4), 597-614.

Bainbridge, R. (2007). Autoethnography in Indigenous research contexts: The value of inner knowing. *Journal of Australian Indigenous Issues*, *10*, 54-64.

Ball, J. (2004). As if indigenous knowledge and communities mattered: Transformative education in First Nations communities in Canada. *American Indian Quarterly*, 28(3/4), 454-479.

Barnhardt, R. & Kawagley, O.A. (2005). Indigenous knowledge systems and Alaska Native ways of knowing. *Anthropology and Education Quarterly*, 36(1), 8-23.

Barnes, P. M., Powell-Griner, E., & Adams, P. F. (2010). *Health Characteristics of the American Indian and Alaska Native Adult Population, United States, 2004-2008*. US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics.

Battiste, M. (2002). Indigenous knowledge and pedagogy in First Nations education: A literature review with recommendations. Ottawa: Indian and Northern Affairs Canada.

Bird, M.E. (2002). Toward wisdom. In W. Kane & M. Quackenbush (Eds.), *Eliminating disparities: Conversations with American Indians and Alaska Natives* (pp. 14-27). Santa Cruz, CA: ETR Associates.

Bowekaty, M. (2002). From science to the spirit of the people. In W. Kane & M. Quackenbush (Eds.), *Eliminating disparities: Conversations with American Indians and Alaska Natives* (pp. 48-60). Santa Cruz, CA: ETR Associates.

Brayboy, B. McK. J. (2005). Toward a tribal critical race theory in education. *The Urban Review*, *37*(5), 425-446.

Brayboy, B. McK. J. & Maughan, E. (2009). Indigenous epistemologies and teacher education: The story of the bean. *Harvard Educational Review, 79*(1), 1-21.

Brayboy, B. McK. J., Fann, A.J., Castagno, A.E., & Solyom, J.A. (2012a). Framing the conversation. In *Postsecondary Education for American Indian and Alaska Natives: Higher Education for Nation Building and Self-Determination* (pp. 11-30). San Francisco, CA: Jossey-Bass.

Brayboy, B. McK. J., Gough, H., Leonard, B., Roehl, I. I. R., and Solyom, J. (2012b)'Reclaiming Scholarship: Critical Indigenous Research Methodologies'. *Qualitative Research: An Introduction to Methods and Designs. San Francisco: Wiley*, 423-450.

Cajete, G. A. (1999). *Igniting the Sparkle: An Indigenous Science Education Model*. Kivaki Press, PO Box 1053, Skyland, NC 28776.

Cajete, G. (2005). American Indian epistemologies. *New Directions for Student Services*, 109, 69-78.

Cajete, G. (2008). Sites of strength in Indigenous research. In M. Villegas, S.R. Neugebauer, & K.R. Venegas (Eds.) *Indigenous Knowledge and Education: Sites of Struggle, Strength, and Survivance* (pp 85-92). Cambridge, MA: Harvard Educational Review Reprint Series No. 44.

Chang, H. (2008). *Autoethnography as method*. Walnut Creek, CA: Left Coast Press.

Chino, M., & DeBruyn, L. (2006). Building true capacity: Indigenous models for indigenous communities. *American Journal of Public Health*, *96*(4), 596-599.

de Leeuw, S., Greenwood, M., & Cameron, E. (2010). Deviant constructions: How governments preserve colonial narratives of addictions and poor mental health to intervene into the lives of Indigenous children and families in Canada. *International journal of mental health and addiction*, *8*(2), 282-295.

Deloria, V. (1969). *Custer died for your sins: An Indian manifesto*. University of Oklahoma Press.

Deloria, V., Jr. (2001). Knowing and understanding. In Deloria, V., Jr. & Wildcat, D., *Power and Place* (pp. 41-46). Golden, CO: Fulcrum Resources.

Dozier Enos, A. (1999). Listening: Implications for Qualitative Research.

Dozier Enos, A. (2002). Deep Sovereignty: Education in Pueblo Indian Communities. In *Paper delivered at the annual meeting of the National Indian Education Association on Nov* (Vol. 4).

Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: an overview. *Historical Social Research/Historische Sozialforschung*, 273-290

Freire, P. (1970). *Pedagogy of the oppressed*. New York: Herder and Herder.

Glanz K, & Rimer, B.K., National Cancer Institute (2005). Theory at a glance: A guide for health promotion practice. Bethesda MA: National Institute for Health, US Department for Health and Human Sciences.

Grande, S. (2008). Red pedagogy: The un-methodology. In N.K. Dennzin, Y.S. Lincoln, & L.T. Smith (Eds.) *Handbook of Critical and Indigenous Methodologies* (pp. 223-253). Los Angeles: Sage. *54*(3), 211-219.

Holder, A.B. (1892). Sanitary effects of civilization. Medical Record, 42 (7), 177-182.

Houston, J. (2007). Indigenous Autoethnography: Formulating Our Knowledge, Our Way. *Australian Journal of Indigenous Education*, *36*, 45-50.

Irwin, L. (1997). Freedom, law, and prophecy: A brief history of Native American religious resistance. *American Indian Quarterly*, 35-55.

Jones, D. (2006). The persistence of American Indian health disparities. *American Journal of Public Health*, 96(12), 2122-2134.

Kaomea, J. (2003). Reading erasures and making the familiar strange: Defamiliarizing methods for research in formerly colonized and historically oppressed communities. *Educational Researcher*, 32(2), 14-25.

Kreuter, M. W., Lukwago, S. N., Bucholtz, D. C., Clark, E. M., & Sanders-Thompson, V. (2003). Achieving cultural appropriateness in health promotion programs: targeted and tailored approaches. *Health Education & Behavior*, *30*(2), 133-146.

Okakok, L. (2008). Serving the purpose of education. In M. Villegas, S.R. Neugebauer, & K.R. Venegas (Eds.). *Indigenous Knowledge and Education: Sites of Struggle, Strength, and Survivance* (pp 268-286). Cambridge, MA: Harvard Educational Review Reprint Series No. 44.

Ortiz, S. J. (Ed.). (1998). *Speaking for the generations: Native writers on writing* (Vol. 35). University of Arizona Press.

Pecos, R. (2007). History of Cochiti Lake from the Pueblo Perspective, The. *Nat. Resources J.*, *47*, 639.

Poudrier, J. (2003). Racial "categories and health risks–Epidemiological surveillance among Canadian First Nations. *Lyon, David (Hrsg.)*, 111-134.

Poudrier, J. (2007). The geneticization of aboriginal diabetes and obesity: Adding another scene to the story of the thrifty gene*. *Canadian Review of Sociology/Revue Canadienne De Sociologie, 44*(2), 237-261.

Prucha, F.P. (1984). The Great Father: The United States and the American Indians. *Vol. II (Lincoln, 1984)*, 957-63.

Prucha, F.P. (1990). *Documents of United States Indian Policy.* 2nd ed. Lincoln: University of Nebraska Press.

Reed-Danahay, D. (2001). Autobiography, intimacy and ethnography. *Handbook of ethnography*, 407-425.

Romero, M.E. (1994). Identifying giftedness among Keresan Pueblo Indians, the Keres study. Journal of American Indian Education, 34(1), 35-58.

Roubideaux, Y. (2002). Perspectives on American Indian health. *American Journal of Public Health*, 92(9). 1401-1403.

Sando, J. (1992). Pueblo Nations: Eight Centuries Of Pueblo Indian History Author: Joe Sando, Regis Pecos, Publisher: Clear Light Books Page.

SFIS Leadership Institute (2008). Summary of recommendations. Native American Cancer Education Community Institute, Tamaya, New Mexico.

SFIS Leadership Institute. (2012). Pueblo Convocation, Tamaya, New Mexico.

Smith, G. H. (2000). Protecting and respecting indigenous knowledge. *Reclaiming Indigenous voice and vision*, 209-224.

Smith, L. T. (2012). *Decolonizing methodologies: Research and indigenous peoples*. Zed books.

Spicer, E. H. (1962). *Cycles of conquest: the impact of Spain, Mexico, and the United States on the Indians of the Southwest, 1533-1960*. University of Arizona Press.

Stevenson, MC. Strange rites of the Tewa Indians. *Smithsonian Misc Coll* 1914;63(8):73-83.

Suina, J. H. (1992). Pueblo secrecy result of intrusions. *New Mexico Magazine*, *70*(1), 60-63.

Suina, J. H. (2003). The Pueblo People and the Dominant Culture: Conflict, Confusion, and Astonishment. Encounter: Education for Meaning and Social Justice, 6(1), 1-5.

Suina, J. H. (2004). Native language teachers in a struggle for language and cultural survival. *Anthropology & education quarterly*, *35*(3), 281-302.

Suina, J. H., & Smolkin, L. B. (1994). From natal culture to school culture to dominant society culture: Supporting transitions for Pueblo Indian students. In P. Greenfield & R. Cocking (Eds), Cross-cultural roots of minority child development (pp. 115-130). Hilldale, New Jersey:Erlbaum.

Suina, M. (2014). Data construction American Indian health. Unpublished paper, Arizona State University.

Swadener, B.B. & Lubeck, S. (1995). *Children and families "at promise": Deconstructing the discourse of risk*. Albany, NY: State University of New York Press.

Tuck, E. (2009). Suspending damage: A letter to communities. *Harvard Educational Review, 79*(3), 409-428.

U.S. Health and Human Services. (2004). Making cancer health disparities history. Trans-HHS Cancer Health Disparities Progress Review Group. Full Report. http://planning.cancer.gov/library/2004chdprg.pdf. Accessed: April 28, 2013.

Wall, S. (2008). An autoethnography on learning about autoethnography. *International Journal of Qualitative Methods*, *5*(2), 146-160.

Walter, M. & Andersen, C. (2013). *Indigenous Statistics: A Quantitative Research Methodology*. Walnut Creek, CA: Left Coast Press.

Weber-Pillwax, C. (2001). What Is Indigenous Research?. *Canadian Journal of Native Education*, *25*(2), 166-74.

Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Fernwood Pub.

Wolfe, P. (2006). Settler Colonialism and the Elimination of the Native. *Journal of Genocide Research*, *8*(4), 387-409.

APPENDIX A

POLICY BRIEF COVER LETTER

April 15, 2015

Dear Honorable Tribal Leaders,

I am a current PhD Candidate at the School of Social Transformation at Arizona State University as a part of the Pueblo PhD Doctoral Cohort in Justice Studies that was launched by the Leadership Institute at the Santa Fe Indian School. The inaugural cohort will graduate on May 11, 2015. The program was designed to train students to address issues related to social justice and social transformation that impact American Indians in New Mexico.

As part of the cohort dissertation requirements we developed policy briefs to address current issues impacting American Indian people in New Mexico. As a health professional from Cochiti Pueblo I am gravely concerned about the decision made by the New Mexico Department of Health, without Tribal Consultation, to change how they present race and ethnicity in health data that has immediately impacted American Indians in New Mexico.

Changes to NMDOH presentation standards immediately resulted in the removal of 39,636 American Indian and Alaska Native (AI/AN) from NM population estimates and reclassified them as Hispanic. Funding for AI/AN may be negatively impacted because population estimates are factored into funding allocations.

I have prepared a policy brief for Tribal Leaders in anticipation of the Tribal Consultation session regarding this issue that will take place at the end of April 2015. The policy brief that I have written identifies gaps in the evaluation process conducted by the New Mexico Race and Ethnicity Workgroup that was formed in July 2012 to evaluate their guidelines for presenting race and ethnicity in health data. I also identify recommendations for Tribal Leaders and the State of New Mexico to be considered for determining the best way to represent AI/AN health data so that it does not negatively impact AI/AN.

I first became aware of this issue from the Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC) where I currently work as a program director. AASTEC has been a champion for American Indian communities by calling into question the State's decision to change how they present data and raising awareness of this important issue. I have written the policy brief with the support of AASTEC, the Albuquerque Area Indian Health Board, and the Leadership Institute at the Santa Fe Indian School. The content in the policy brief has gone through an extensive review process. If you have any questions about this issue please contact me at (505) 764-0036 or msuina@aaihb.org.

Thank you for your time and leadership on behalf of all American Indians.

Respectfully,

Michele Suina, PhD Candidate

APPENDIX B

POLICY BRIEF

Changes to NMDOH Race and Ethnicity Presentation in Health Data Standard: American Indians and Alaska Natives in NM Reclassified as Hispanic

An Urgent Call to Action for Tribal Leaders and Tribal Health Advocates

Healthy self-determined American Indian communities resist outside governmental decisions that undermine their sovereign status and that negatively impact their communities and future generations yet to come. The State of New Mexico must honor and uphold the State-Tribal Collaboration Act.

Summary

On July 13, 2013 the New Mexico Department of Health (NMDOH) changed its standards for how race and ethnicity is presented in all health data without tribal consultation.[8] This was a violation of New Mexico Senate Bill 196, referred to as the New Mexico State-Tribal Collaboration Act. This act indicates that, "A state agency shall make a reasonable effort to collaborate with Indian nations, tribes or pueblos in the development and implementation of policies, agreements and programs of the state agency that directly affect American Indians or Alaska Natives."[9]

This major decision, which significantly impacted American Indian/Alaska Native (AI/AN) population estimates in NM, was based on findings from just one survey that generalized conclusions for all AI/ANs in NM.

How sound is a decision that affects a whole population of people (i.e., AI/AN) based on one survey that did not consider the historical and social factors that play a role in how AI/ANs are identified including self-identification?

- **Changes to NMDOH reporting standards immediately resulted in the removal of 39,636 American Indian and Alaska Natives (AI/AN) from NM population estimates and reclassified them as Hispanic.**
- **Funding for health services and programs for AI/AN may be negatively impacted because population estimates are factored into funding allocations.**

The NM Race and Ethnicity Workgroup was formed in July 2012 to evaluate existing guidelines for presenting race and ethnicity in health data.[2] A review of their evaluation process exposes several gaps, including:

- AI/ANs were not represented on this workgroup.
- Workgroup recommendations are based on findings from only one survey, the 2011 Behavioral

[8] https://ibis.health.state.nm.us/resource/RacEth2013.html
[9] http://www.iad.state.nm.us/docs/legislation/SB0196.pdf

Risk Factor Surveillance System (BRFSS), which was administered entirely by telephone. One pilot question included in the 2011 BRFSS used to assess race/ethnicity informed the decision to change the NMDOH race and ethnicity presentation standard.

- BRFSS findings do not give information for why some people choose one race and another ethnicity. Quantitative survey results from one survey are insufficient to assess the balance of benefits and harms of changing race and ethnicity presentation standards.

- The State tribal epidemiologist and tribal liaison positions were both vacant when the decision was made to change the race/ethnicity presentation standard.

Additional information is needed to assess the validity and appropriateness of changes made to the NMDOH race/ethnicity presentation standards for NM Tribal leaders and health advocates to weigh in on.

NMDOH Race/Ethnicity Presentation Standard Now States[10]:

Persons designated as Hispanic ethnicity, regardless of race, will be categorized as 'Hispanic.' Persons not designated as Hispanic will be categorized by their single race ('Black or African American,' 'American Indian or Alaska Native,' 'Asian or Pacific Islander,' 'White,' or 'Other').

If a person is mixed race and ethnicity with their reported race being AI/AN and ethnicity being Hispanic they will be categorized and designated as Hispanic only and will not be included in AI/AN population estimates.

Why is this a problem?

- Current NMDOH presentation standards don't consider the historical and social factors that play a role in how racial and ethnic identity are formed at societal and individual levels.

- State government is replicating colonial federal policies of statistical elimination, such as blood quantum practices, that were intended to terminate and assimilate AI/AN into mainstream society to seize their land base and resources.

- Enrolled tribal members may wrongly be assigned into non-AI/AN racial/ethnic categories. Undercounts could put their tribal communities at a disadvantage for federal, state, and private resources for health services and programs.

[10] https://ibis.health.state.nm.us/resource/RacEth.html

- Formation of race and ethnic identity is complex and is not static. This identity can change for a person during their lifetime.

- Switching presentation standards will make it difficult to impossible to examine health trends across time.

The following questions about the Behavioral Risk Factor Surveillance System (BRFSS) **are critical for determining if findings from this survey provide sufficient evidence for changing the presentation standard for race/ethnicity in all health data.**

- Was the preferred race/ethnicity question appropriate for assigning race/ethnicity (i.e., "Which one of these groups would you say best describes you? Hispanic or Latino, White, Black or African American, Asian, Native Hawaiian or Other Pacific Islander, American Indian or Alaska Native or Other")?

- Are those individuals that self-identified their race as AI/AN, but their ethnicity as Hispanic enrolled tribal members?

- Do those individuals that self-identified their race as AI/AN, but their ethnicity as Hispanic know that their health services (if using IHS or other tribal based programs) could be negatively impacted?

- Was there harm done to individuals that self-identified their race as AI/AN, but their ethnicity as Hispanic because health services and programs for AI/ANs may be impacted? Was there harm done to all AI/ANs in NM?

Recommendations

- NM Tribal Leaders must call into question this recent action of the State of NM.

- NM Tribal Leaders and health advocates must participate in the process to determine the best way to measure race/ethnicity and represent this data so that it does not negatively impact AI/ANs: A tribally appointed AI/AN task force should be convened to review additional evidence necessary to inform a decision that will impact AI/ANs in NM.

- A more detailed plan needs to be developed by the State of NM to look at ways reduction of numbers will have negative impacts for NM Tribes.

- Additional mixed methods studies (i.e., qualitative and quantitative studies) are needed that look at the long term impacts of changing presentation standards for race/ethnicity. Those studies should include a costs/benefits analysis based on Tribal needs.

- Review of similar cases must take place to synthesize lessons learned to inform the NMDOH race and ethnicity data presentation standard. Similar cases include changes that were made in 2007 to U.S. Department of Education race and ethnicity data reporting guidelines and those that have occurred among other Indigenous peoples regarding their identification in data such as in Australia and Canada.[11,12,13]

- Creation of a formally sanctioned Tribal data committee, similar to the All Pueblo Council of Governor's sanctioned committees, by NM Tribal Leaders is needed to address current and future data issues that impact AI/AN.

- An educational module on data needs to be developed to brief NM Tribal Leaders about how data collection, analysis, and presentation can impact their Tribal communities.

One of the ways Tribal leaders can take action in response and in order to intervene **is to participate in the Tribal Consultation session meeting that will happen at the end of April 2015.** Points to emphasize include the following.

The State of New Mexico must:

- Create an AI/AN task force appointed by NM Tribal leaders to review additional evidence that must be taken into consideration in how race/ethnicity is presented/reported for AI/AN in NM.

- Conduct impact studies looking at similar contestations of governmental data practices in the United States and by other Indigenous peoples such as in Australia and Canada.

- Revert 2013 NMDOH race/ethnicity presentation standards back to previous standards until further comprehensive studies are completed to determine best action.

- **Honor and uphold the State-Tribal Collaboration Act, NM Senate Bill 196,** where any state agency shall make a reasonable effort to collaborate with Indian nations, tribes or pueblos in the development and implementation of policies, agreements and programs of the state agency that directly affect American Indians or Alaska Natives.

For more information contact Michele Suina at the Albuquerque Area Southwest Tribal Epidemiology Center at (505) 764-0036 or msuina@aaihb.org.

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[11] http://www.ncai.org/policy-research-center/initiatives/data-quality
[12] http://www.ncai.org/attachments/Resolution_dJIeLxKycJqoTSsQiRsnYggoHIYMqycZshJoqIZnKNVdgeXzeVF_RAP-10-031.pdf
[13] Walter M, Andersen C. Indigenous Statistics: A Quantitative Research Methodology. California: Left Coast Press, Inc; 2013.