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Native Americans and Type 2 Diabetes: The Discourse of Predisposition and its Politics

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Native Americans and Type 2 Diabetes: The Discourse of Predisposition and its Politics

A Dissertation submitted in partial satisfaction of the requirements for the degree of

Doctor of Philosophy

in

Anthropology

Laurette Ann McGuire

December 2012

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This has been a long journey, and there is no way I can adequately thank those who have given so much of themselves to get me to this point. To those community members who gave of their time, knowledge, and friendship: Thank you. To my wonderful committee, Juliet, Tom, Diane, and Chikako: Thank you for your encouragement, support and time. You have been more than committee members and faculty mentors; you have changed my life in ways I have yet to understand. My family, you have sacrificed so much for me, there are no words for what it has meant to have your love and support. Jerry, your humor and willingness to invest in my dreams have kept me sane. Isaiah, you are the light of life; thank you for always giving me a reason to strive for excellence. Mom, thank you for always stressing the importance of education and always, always being such a cheerleader. I love you.
Dedication

This is dedicated with love and respect to my grandmother, Ignacia, who never stepped into a classroom, but whose spirit and knowledge of the important things in life I carry with me every day.
ABSTRACT OF THE DISSERTATION

Native Americans and Type 2 Diabetes: The Discourse of Predisposition and its Politics

by

Laurette Ann McGuire

Doctor of Philosophy, Graduate Program in Anthropology
University of California, Riverside, December 2012
Dr. Juliet McMullin, Chairperson

This research examines the discourse between geneticists, clinicians and their patients to elucidate the linkage of type 2 diabetes in Native American populations and larger social processes such as genetics, race, colonialism, and global capitalism. The goal of this work is to understand the mechanisms that perpetuate the hegemony of scientific knowledge as it constructs the diabetic body as belonging to a specific category of “otherness.” As a result, this work will contribute to a better understanding of how diabetes has become the newest epidemic in Native communities and constitutes contemporary racialized and
politicized domains for the exercise of power. Using historical and ethnographic methods, this research examines the construction, distribution and use of knowledge about type 2 diabetes. The main objective is to enhance understanding of the influence of racial/ethnic discrimination in health care delivery and its association with disparities in disease incidence, treatment and outcomes among Native Americans. This objective will be achieved by examining current understandings of predisposition for diabetes. When usual interpretations of causality fail to explain a disease, biomedicine often relies on such concepts of predisposition. Yet, such interpretations fail to give meaning of such an affliction to the sufferer (Finkler 1994:14). Type 2 diabetes needs to be situated within the historical context from which it arose and contextualized with current understandings of predisposition as they are used in the categorization and determination of diabetes treatment. This project follows the work of anthropologists who examine the political economy of health and argue that poverty and stress directly impact health, a factor that, while acknowledged, is often obscured in the biological emphasis in medical discourse.
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CHAPTER 1

Introduction

I was at the elementary school to speak to the principal and take a tour of the school grounds. The principal was a short white woman in her mid-fifties. After a tour of the campus, the principal took me to a classroom where we could talk. The room was large and not decorated like a typical class. Against one wall was a large stone fireplace, an overwhelming presence with a large iron kettle perched on a stand. Next to the fireplace, a butter churner and rocking chair sat, and in the corner of the room stood a loom and wheel. This was the Pioneer Room, set up to replicate for school children what an “American” home might have looked like during the eighteen hundreds. Over the course of our conversation, the principal asked what I did. I gave her my standard answer: “I work on type 2 diabetes in Native American communities.” She smiled and said, “I have diabetes. I understand that it is a real problem for Native Americans.” She went on to say, “I told my doctor I had a grandmother who was part Indian. He said, ‘That may be why you have diabetes.’” This story to me served as a touchstone for my writing, as it encapsulated much of the discourse of type 2 diabetes. In this discourse, type 2 diabetes is inherently an Indian problem, one traced to ancestors’ blood, and one in which history is negated in favor of a discourse that emphasizes genetic determinism.
I tell this story not because it was or is a rare occurrence but because of how often it actually occurs. Over the past six years, I have heard similar stories from a variety of people. In the retelling of these stories ideas/images reflect the prevalence of the discourse of type 2 diabetes as an “Indian problem” tied to bad or “thrifty” genes. Over time, this discourse has increasingly become part of a popular discourse of diabetes. This dissertation tells the story of two discourses that surround type 2 diabetes in Native communities. In one, the discourse follows that the high rate of diabetes is in large part due to a genetic predisposition and a population that is inherently risky. The other discourse is often heard in the narratives of Native people. In this discourse, the etiology of diabetes is tied to colonialism, commodity foods, poverty, land tenure and access to healthy foods.

In this work, I examine how diabetes has come to be viewed as an “Indian” disease. Diabetes in Native American communities has been viewed by biomedicine as based on race and genes in a changing environment. This discourse ignores historical and structural inequality. I argue that genetic research in Native American diabetes is permeated with cultural stereotypes. I focus on how diabetes, considered a disease of “affluence” at the turn of the twentieth century, was made invisible in Native American communities until Neel crossed “the color line.” Diabetes has been considered a product of “civilization.” “Civilization” was shorthand for middle and upper-class lifestyles and longer life spans of Anglo-Americans.
The rise of diabetes in Native Americans is often portrayed as an abrupt transition in which infectious diseases were replaced by degenerative diseases of civilization. What I contend is that diabetes didn’t happen suddenly in Native communities, but that it had been made “invisible” through constructions of race and disease etiology. If “primitive” people don’t get chronic disease, then why look for it? This paper is not looking for epidemiological truths; rather, its focus is on the evolving epidemiological and social perceptions in which diabetes became viewed as an Indian problem. In seeking to answer these questions, the story told becomes about how biomedicine creates ideologies of race and difference.

In approaching type 2 diabetes in Native communities, I focus on historical processes, which shape the discourse in the production and reproduction of diabetes knowledge. What I contend is that while much research has been done on genetics and diabetes, there has been little work focused on the rise of diabetes in Native communities and the linkages between U.S. government Indian policy and current research agendas of diabetes. The issues raised point to the intersection among three broad arenas of scholarly investigation: the production of knowledge, the social construction of racial hierarchies, and the politics of U.S. Indian policy.

My aim is to frame this discussion through Native American discourse regarding diabetes etiology and to use it as the lens through which I examine how diabetes has been constructed in Native Americans through policy, biomedical genetic reductionism, and the creation of Native Americans as an
inherently risky population. This work explores the social and cultural dynamics that surround diabetes discourse. I use the term “discourse” to refer to “a broad conglomeration of linguistic and nonlinguistic social practices and ideological assumptions that together construct power or racism” (Schiffrin et al. 2006:1). By defining discourse in this way, I can speak of the “discourse of power.” It is in this sense that I speak of a discourse that creates Native Americans as inherently risky and diseased. This discourse is exerted not only through linguistic practices of predisposition and risk but also through the ideological assumptions that are practiced through U.S. government health policy regarding Native Americans.

Through this work, I attempt to examine three seemingly divergent threads to weave together the complicated story of diabetes in Native communities. To do this, I examine historical trauma as a model for looking at diabetes in Native American communities, U.S. government Indian policy as a form of structural violence, genetic discourse regarding diabetes in Native Americans, and the construction of Native people as an inherently risky population. I situate U.S. Government Indian Health Policy and genetic discourse alongside Native American explanations of the rise of type 2 diabetes in the hopes of understanding how policy and research have impacted health outcomes for Native Americans. In doing this, I attempt to privilege Native American knowledge about the relationship between diabetes and social processes.
Native Americans and the Politics of Health

Native American Nations and the United States Government have had a unique relationship. The trust relationship established through treaty rights with Native American Nations and the United States Government have since their inception been variously interpreted and understood within the particular political climate of the time. How these rights have been interpreted and enforced or broken has too often been at the whim of different administrations. “Indians suffer severely with each new administration because, in spite of campaign promises, they are always far down the list of interest groups that need attention” (Deloria 1997:15). For Native nations seeking a political voice, the problem has often been finding the political will in a congress and senate where there are fifteen states without any federally recognized tribes.

For anthropologists, much of what we do has historically been centered on modernity, core/periphery, and how marginalized groups resist the state. While Native Americans as individuals today (this wasn’t always the case) are U.S. citizens, many of them are also citizens of another nation. Members of federally recognized tribes have a unique status as citizens of the United States and as citizens of Native nations in that they have a trust relationship with the federal government. Anthropologists have long ignored the ways in which this relationship impacts the lived experience for Native people. To address this relationship, I use the term “remediation”, which I take here as a conceptional extension of the ethnographic tool kit. The goal of anthropology “is not
destruction or deconstruction but a reevaluation; its goal is not reform or revolution but rather a type of remediation” (Rabinow 2008:3). The term “remediation” implies a remedy to something, for example, the remedying of a privileged top down approach that historically has been a typical approach of anthropologists. Through remediation, one can critically integrate earlier narratives and hypotheses written by anthropologists from the field, just as we need to take on existing narratives. As an object of anthropological study, Paul Rabinow has argued that there is a narrowing of scope in anthropology to “an actual object domain in the present whose recent past, near future, and emergent forms can be observed” (2008:5). Rabinow goes on to suggest that the object of anthropology, while it is dynamic, is partial. The focus of anthropological research of the contemporary becomes, as Rabinow stated,

Connections between figures of anthropos and the diverse, and at times inconsistent, branches of knowledge available during a period of time; that claim authority about the truth of the matter; and whose legitimacy to make such claims is accepted as plausible by other such claimants; as well as the power relations within which and through which those claims are produced, established, contested, defeated, affirmed, and disseminated (2008:4).

In this sense, the object of study here is knowledge production about diabetes in Native Americans. It is through new modes of collaboration where problem-spaces are emergent, and problems and their significance can no longer be taken for granted.

I situate my work among critical medical anthropologists who have sought to understand power relations affecting biomedicine. They question how power
is expressed in social relations of various groups and how dominant ideological
and social patterns in medical care are intimately related to hegemonic
ideologies and patterns outside of biomedicine. Critical medical anthropology
attempts to understand the context of class, race and imperialist relations
inherent in the capitalist world system (Baer, Singer, and Susser 2003: 31-54).
My interest lies at the intersection of biomedicine, genetics and race and how
these imperial social relations are reproduced through genetics in the
conceptualization of diabetes in Native Americans.

As an anthropologist, I am interested in how these historical processes
work to shape experience in day-to-day living, and in showing how discourse,
policy and history are embodied in a system of inequality that directly impacts
health equity for Native American people today (Nguyen and Peschard 2003;
Navarro and Shi 2001). While there is a mountain of written material on Native
American Health, there is surprisingly little on Native American Health Policy and
its history. Using a critical medical anthropology (CMA) approach that focuses
on the analysis of how economic and power structures shape people's health
status and their access to health, CMA examines how economic and political
systems create and perpetuate social inequality in health status. Critical medical
anthropology argues that illness is more often a product of one’s culturally
defined position than of something “natural.” CMA allows me to look first at how
larger structural forces such as health policy determine the distribution of illness
and people’s response to it, while simultaneously being concerned with how an
individual may, through personal agency, resist such forces. This approach is specifically designed to question the hidden assumptions behind the ahistoric, scientific, epidemiological, “natural” history approach to understanding disease and international health problems. The scientific method is built upon open and constant critique developed within CMA of scientific medicine and medical anthropology, the sources of health problems in contemporary society, and a range of other issues pertinent to the field of medical anthropology. In focusing on type 2 diabetes, I endeavor to identify the political and social structural processes that contribute to the etiology of diabetes. During the eighteen hundreds, both Friedrich Engels and Rudolf Virchow viewed disease as having a social as well as biological origin (Engels 1845:190-193, Virchow 1879:11-122).

Building on the work of Lock, Comaroff and others, the body, rather than being purely “natural,” is a construct of culture and therefore always implicated in relations of dominance and subordination (Lock 2007, 2010; Comaroff, 1992, 1993). Difference has been tracked, represented, and made visible through the body. This difference has been marked and dispersed through modern knowledge regimes (e.g., science). Scientists have not merely observed and reported on bodies but have in effect produced them (Foucault 1973, 1978; Marks 1995; Rabinow 1992; Rose 2006). The result is the construction, imaging, and experience of the body in light of these modern regimes of power and knowledge. Foucault’s description of the body as a site of power describes and articulates its involvement with discourse while denying that any one discourse
can define and map it fully (Punday 2000:509). The body as a site of discourse and power relations that are contested and resisted can be exemplified in genetic researchers, Native Americans and diabetes.

Knowledge, Health and Type 2 Diabetes

Drawing on ancestral knowledge systems regarding health, food production, and land use, Native Americans contest the bio-medical view of the body. This construction of a pathological body, one predisposed to disease, is juxtaposed against the “native” body as one that embodies history, knowledge and health. The “native body,” similar to Juliet McMullin’s “healthy ancestor,” is constructed historically and is tied to land access, food systems, health and wellbeing (McMullin 2005, 2010). While both researchers and Native community members see a changing environment as the etiology of type 2 diabetes, each has its own understanding and discourse about that environment. For Native Americans, the focus is not on the diseased body, but rather transformations in food and lifeways. It is the recognition that diabetes is an outcome of unequal social processes; it rejects the notion that they have inherited a diseased body but simultaneously provides a guide for a Native body that is integrated into the social, physical, and spiritual world.

Human genetics entangle society’s racial and economic biases with any genetic differences that can be detected, particularly if any of these differences are differentially distributed by race, ethnicity, or class (Krieger 1999). The “thrifty” gene theory obscures the politics necessary to create the diseased
Native body as inherited through a singular aspect of life. In their refusal to accept genetic reductionism, focusing rather on their inheritance of knowledge about how to live, Native Americans struggle to re-create the Native body, and in doing so, they struggle to define and contest modern knowledge regimes.

The association between colonialism, race and risk gives us insight into how knowledge is produced regarding diabetes and Native Americans.

According to Paul Rabinow,

The fact that the human genome has been mapped, and population differences at the molecular level identified, does not mean that older understandings of race disappear in the light of this new knowledge. But neither does it mean that all of the older understandings of what constitutes difference undergo a total transformation (2008:3).

This is evident in the narrative of “thrifty” gene and the transformation of that narrative over time. We can understand how this occurs by Michael Foucault’s concept of governmentality. Governmentality is a form of activity designed to shape, affect, or change the conduct of a person or persons (1978).

Governmentality can be understood as both the government of the self and others. Governmentality affects everyone to the extent that we are not the free individuals that the liberal framework would have us believe. The self is constituted by others, by official discourses, and by what Foucault calls "power/knowledge" (Rabinow 1984).

The proliferation of disease categories and labels in medicine has resulted in ever more restricted definitions of the normal, and has in effect created a sick majority. In the thrifty gene hypothesis, we see that regardless of narratives that
position scientific/medical research as existing outside of social relations, there are many sites in their production, interpretation, and use that transform them from conveyers of objective, authoritative knowledge into socially situated objects that construct the body in complicated ways (Young 1993:108-128). Such discourse is used to naturalize the object while at the same time depending on ideology to provide an institutional base. In this view, discourse and ideology are separate but intersecting systems of knowledge. Changes in the organization of social life in advanced industrial societies has allowed medicine to assume a hegemonic role in shaping a "diseased" body. For example, Mary Ellen Kelm (2005) has argued that colonial medicine was used to pathologize Aboriginal bodies. Kelm notes that that since the beginning of the last century, non-Native assumptions of Native bodies were naturalized, ignoring the extent to which Native bodies and what happened to them were made by history (1998:xvi). This is in effect what Foucault calls, “The phenomenon of the social body is the effect, not of social consensus, but of the materiality of power operating on the bodies of individuals” (Rabinow, 1984:180). Governmentality is obtained not by a totalizing deterministic or oppressive form of power, but by bio-power directed in a manner at whole populations and, at the same time, individuals so that they are both individualized and normalized. For Foucault, power ceased to be solely a function of formal political institutions but became something inscribed in everyday life. Whoever dominates these relations also controls the economic and ideological conditions under which knowledge and truth are defined.
Dominating classes inscribe their power in Foucault’s scenario in and through a series of tactics and strategies that instruct people to be a certain way in the world. In this light, scientific knowledge is shown to be a historical construct.

This exercise of power in the service of maximizing life carries a dark underside. When the state is invested in protecting the life of the population, anything can be justified. Groups identified as threats to the existence of the life of the nation or of humanity can be eradicated with impunity. In this light, biomedicine and genetics are implicated in the creation of a “normalized” identity for Native Americans.

**Racialized Constructions of Type 2 Diabetes**

Understanding the body as a historical and social object has enabled a cross-cultural understanding of how social relations condition disease patterns. Scheper-Hughes and Lock attempt to deconstruct concepts of the body by examining three ways in which to view and understand the body (1987). To view the body by focusing on just one aspect of the body, such as the lived experience without understanding how that lived experience is shaped by interactions between the individual, culture and society, will not yield a better understanding of the body. The biomedical framework that looks for moncausal explanations of disease and ignores the social processes that shape Native American experience does not give a better understanding of the disease but rather serves to place disease causation within a purely biological frame that ignores structural inequality.
The links between the broader social context and individual stories of diabetic Native Americans raise important questions. Social inequity underlies poorer health outcomes. For example, by what mechanisms do social forces ranging from poverty to racism become embodied as individual experience? In societies where the resources are more equitable, distributed health outcomes are better than in those wealthier societies that have large class divisions (Farmer 2003). This work demonstrates how inequality is structured and how Native American populations become labeled as “diseased.”

Throughout the nineteenth and much of the twentieth century, indigenous peoples were viewed as primitive and harbingers of infectious diseases. Charles Briggs’ work demonstrated how the Venezuelan state failed to protect indigenous and poor populations from a cholera outbreak. In dealing with the outbreak, government and health officials, through media reports, demonized and racialized the indigenous populations as dirty, primitive, and carriers of cholera (2003). Until fairly recently, health research attributed racial disparities in disease, particularly those disparities that remained after adjusting for socioeconomic indicators, to biological, genetic, cultural, or lifestyle choice differences between racial groups. While most current research in racial disparities has abandoned blatant racist ideology, much of it still assumes that racial variations in disease are due to underlying differences in biology. Notions of race that are based on a typological approach to human variation continue to pervade the literature. For example, Briggs suggests that the cholera narratives...
served to portray the Venezuelan health agency as the protector of the social body. Official reports of possible effects on the poor and indigenous communities as those populations most at risk for cholera left other Venezuelans with the sense that they would not be affected by the disease. Briggs argued that it is this characterization that places the disease within a system of racialization. This racialization of cholera gave the criollo that primarily represented upper and middle-class segments of society a false sense of security that they had nothing to fear from the cholera epidemic (2003:19-58). For them, cholera was a far off disease of the poor and indigenous, or those “primitive,” less modern populations. What this served to do was further marginalize this segment of society.

**History of Diabetes**

The earliest accounts of “the diabetes” come from Egypt in 1552 BC, from the Egyptian physician Hesy-Ra who documented a mysterious disease that caused frequent urination and gauntness (Dinsmoor 1996). The Greek physician Aretaeus of Cappodacian described the disease in 100 AD. Aretaeus’s account of a tortured, emancipated body, in a vicious cycle of unquenchable thirst and need to urinate is quite striking. Fortunately, he remarks, diabetes was “not very frequent among mankind” (Tuchman 2009:1140). In the second century, Roman physician Galen remarked that, in his career, he had only seen two cases of what we now know as diabetes. (Tuchman 2009). It wasn’t until the seventeenth century that a London physician was the first to develop a diagnostic tool for
diabetes. He found that patients with diabetes had urine that had a sweet taste. This method of diagnosis went largely unchanged until the twentieth century.

By the early twentieth century, diabetes rates were rising quickly in the United States and Western Europe. Dr. Elliott Joslin believed this was due in part to better records keeping. Joslin was troubled by the nearly 80 percent increase in diabetes death rates in the United States from 1900 to 1915 (Joslin 1927). Prior to the 1920s, the treatment of diabetes would be a restrictive diet. A low calorie diet of as low as 450 calories per day was often the prescription. It wasn’t until 1921 that researchers from the University of Toronto, Canada, discovered and developed insulin. It was found that insulin was the most effective on acute cases of diabetes. It wasn’t until 1935 that researchers found that there were two types of diabetes: insulin sensitive (type I) and insulin insensitive (type 2). Understanding that there were two different types of diabetes had in part to do with the new discovery of insulin and that some patients responded better to insulin injections than others. It wasn’t until the 1950s that medications were developed that effectively treated type 2 diabetes. Prior to 1950, patients with type 2 diabetes had to make do with just taking more insulin in an effort to control blood sugar levels (Dinsmoor 1996).

**Diabetes- The Numbers**

According to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the term diabetes refers to any of several metabolic disorders that exhibit similar symptoms of frequent urination and excessive thirst. It is a
chronic disease that has no cure. A metabolic disease, diabetes disturbs the body’s ability to produce enough insulin or to properly use insulin. Cells with the help of insulin absorb glucose, and without insulin the body is unable to use the glucose. Cells need the glucose for energy and growth (NIDDK 2007). Insulin is a hormone produced in the pancreas. If the body cannot produce insulin, or cannot produce enough insulin, or the cells do not respond properly to the insulin, the result is a buildup of glucose in the bloodstream.

There are three different types of diabetes: type 1, type 2, and gestational diabetes. Type 1, formerly known as juvenile diabetes or insulin dependent diabetes, is a disease in which the body does not produce any insulin. This type occurs most often in children and young adults. Beta cells of the pancreas can no longer produce insulin because the body’s immune system has destroyed them. Unlike type I diabetes, gestational diabetes develops in women during late pregnancy. Typically, this form of diabetes goes away once the child is born, but women who have had gestational diabetes are at greater risk of developing type 2 diabetes later in life (NIDDK 2007).

Type 2 diabetes is a metabolic disorder resulting from the body’s inability to make enough insulin or properly use insulin. It is the most common form of the disease and accounts for 90 to 95 percent of all diabetes cases. Also referred to as adult-onset or non-insulin dependent diabetes mellitus, type 2 diabetes progresses from an asymptomatic stage marked by insulin resistance to

The symptoms of type 2 diabetes are subtle and are not often apparent to the patient. As a result, approximately half of the population with type 2 diabetes are unaware that they have the disease, and by the time the disease is diagnosed, secondary complications may have already occurred. Some of the secondary complications include eye problems, high blood pressure, kidney failure, coronary heart disease, and loss of sensation in both the hands and feet. Worldwide, type 2 diabetes is nearing epidemic proportions (American Diabetes Association 2002). Overall, the prevalence of type 2 diabetes in Native Americans is 14 percent, vs. 5.2 percent in the general population. According to the American Diabetes Association (ADA), in some tribes, 50 percent of the population has diabetes (2002). Rates of type 2 diabetes among other indigenous groups worldwide are on the rise. Type 2 diabetes is prevalent in groups that had rarely reported any incidence of it forty or fifty years ago. Now they are reporting high rates of the disease.

According to the World Health Organization (WHO), there are 346 million people with diabetes worldwide (2011). Furthermore, it is estimated that in 2004, 3.4 million people died from complications of diabetes. This number is expected to double by 2030 (WHO 2011). In the United States, 8.3 percent or 25.8 million people have diabetes with another 79 million people considered prediabetic (American Diabetes Association 2011). The impact of this epidemic is beginning
to be felt at a time when, in the United States, the cost of diabetes is 174 billion in both direct and indirect healthcare dollars (NIDDK 2007). If we factor in the additional costs of undiagnosed diabetes, gestational diabetes and those considered prediabetic in the United States, the cost in 2007 was closer to 218 billion (NIDDK 2007).

Diabetes also has major consequences for virtually every system in the body, resulting in often debilitating complications that greatly impact a diabetic’s quality of life. The duration of the disease is a major factor for the development of complications. This is a major concern for the increasingly younger age of onset of type 2 diabetes. Besides cardiovascular disease and stroke, diabetes is a major risk factor for end stage renal disease, gastroparesis, peripheral neuropathy, hypoglycemia, non-traumatic limb amputations, blindness, lipid abnormalities, erectile dysfunction, periodontal disease, infections, and depression (NIDDK 2007).

According to the National Institutes of Health (NIH), the risk factors for type 2 diabetes include having had gestational diabetes or giving birth to a baby weighing more than nine pounds, inactivity, high cholesterol, having a parent or sibling with diabetes, being of Alaskan Native, Native American, African American, Hispanic/Latino, Asian American, or Pacific Islander heritage, being over the age of 45, and being overweight (NIDDK 2007).

Diabetes in Indian country is a very real phenomenon. The lived experience of those with the disease, and of their caregivers, family and friends
as well, is a daily negotiation of dealing with its management. For example, Mary recalls the weekly trips to take her grandmother to the hospital for dialysis:

When I was a teenager I remember my grandmother would have to go for dialysis. Sometimes I would take her. I think she was on dialysis for three or four years, maybe. It was real hard on her, you know… she would just be really tired when we got back. She had a hard time controlling her blood sugar. Now thinking about it… just seemed liked sugar diabetes was just part of life, you know. I mean I know not everyone has it but it was always around. You have to check your sugar level; some have to take insulin… it takes control. Like what you do and don't do.

Setting

Working under the umbrella of California-Native American Research Center for Health (CA-NARCH), my field research was conducted with North San Diego County reservations of La Jolla, Los Coyotes, Mesa Grande, Pala, Pauma, Rincon, San Pasqual, and Santa Ysabel. During my field research, I collected life histories from diabetic community members. This research brings together both policy and discourse in understanding how both have impacted health care delivery for Native Americans.

In 2001, the Indian Health Service partnered with the National Institute of General Medical Sciences of the National Institutes of Health to support the Native American Research Centers for Health (NARCH). The NARCH initiative supports partnerships between AI/AN tribes or tribally based organizations and institutions that conduct biomedical and behavioral and health services research. The goal of the program is to meet the needs of AI/AN communities through research, training and development. The purpose of NARCH is to develop a
cadre of AI/AN scientists and health professionals engaged in biomedical, clinical, behavioral and health services research in Native communities (CA NARCH 2012).

In order to accomplish such goals, CA-NARCH partners with Indian Health Council (IHC). IHC is a consortium of nine tribes with facilities located in Rincon and Santa Ysabel. Indian Health Council serves about 15,000 individuals from the surrounding area. In 2011, IHC registered 8431 patients for services (IHC 2012).

I did not approach this research with the intent of doing an ethnographic study on Native Americans with type 2 diabetes and how they construct knowledge about the disease. Rather, my interest arose from discussions as an undergraduate in my medical anthropology courses at the University of California, Riverside, and my discussion with friends and family on and off the reservation. Through these conversations, I began to hear two very different discourses. In conversations with friends and family, again and again, I heard similar stories of diabetes and its connection to land and commodity food programs. While the conversations often began with tales of their diabetic experience and a sort of recounting of family members with diabetes, rarely in those conversations were genes, inheritance or predisposition mentioned. This is not to say that conversations didn’t include ideas about diabetes being seen in families or that Native Americans had a lot of diabetes. The emphasis on diabetes causation was on the social relations. Yet, as an undergraduate
student sitting in an upper division medical anthropology course, I listened to the professor speak about the high occurrence of diabetes in Native Americans. He went on to tell the story of the “thrifty” gene. This was the first time I had heard the narrative for Native American’s genetic predisposition, although I had been told by my doctor that as an Native American from the Southwest, I was at increased risk for metabolic syndrome, which includes diabetes. With this new information, I went back to my family and friends, and when diabetes came up in conversation, I began to ask, “Have you heard about a ‘thrifty’ gene?” While some hadn’t, many had, and again in those conversations I began to hear resistance to the “thrifty” discourse.

I am a Native American of Pueblo descent and grew up in southern California, and I have never lived on reservation land. As Bea Medicine once wrote, “I am a part of the people of my concern and research interests” (2001:3). While I am not from the community in which I did fieldwork, I must acknowledge that my being “Native” as well as looking “Native” gave me easier access at times, but also complicated the “field” for me. While outsiders conceptualize Native Americans as largely homogenous with similar cultural beliefs and practices, there are differences among groups, and those differences do mark individuals as not being from a particular Native community. Because of this, I would often have to tell people where I was from (meaning tribal affiliation) and how I ended up in San Diego. In addition to situating myself within “Indian Country,” I would make sure to let them know I was not an enrolled member. As
such, during my time in the field, I occupied what some may consider a liminal space between insider and outsider. That being said, I have friends from the area I worked and have spent time on and off the reservations in the southern California area, as well as attended community social events. Since 2003, I have worked on several other projects in the community related to health.

I have often been asked by other Native people, “Why anthropology?” My response has always been that I felt I could use the anthropological methods I had learned to look at how knowledge was constructed by researchers and how that process may reveal alternative ways to think about diabetes and its prevention. After working on other projects that involved clinicians, I had come to the conclusion that it wasn’t necessarily Native “understandings” of diabetes that were central to health care delivery (though these are very important), but rather how researchers and clinicians view diabetes and their cultural construction of the disease. This I believe is important because there is a need to deconstruct (decolonize) western, biomedical knowledge systems that are viewed as normative, objective knowledge systems. Clinicians had often spoken about “cultural competency” training as being important, but I soon found out that their ideas and my ideas of “cultural competency” were different. Often “cultural competency” was a proxy term used by clinicians for “I just want to know how to get them to do what I ask.” There seemed to be little interest in the idea that by being respectful and responsive to non-western knowledge systems, better health outcomes could be achieved.
An alternative discourse that I often heard from clinicians was, “I have worked with Indians for a long time and know their culture.” While this may at some level be true, what I often found was that racial stereotypes existed among many of these same clinicians. With this in mind, I began to think about how I wanted to focus my dissertation work on the ways clinicians thought about diabetes. So that while I privilege Native American causation of diabetes, I examine how those social processes are produced in western knowledge systems. It is the interplay between western knowledge systems and Native American’s focus on social relations in the causation of diabetes that is the space in which this research takes place.

**Methodology**

This was a multi-sited project in the sense that I moved back and forth from the archive to the reservation and back again. This project is rich in qualitative data collections. My data set includes governmental and clinical documents as well as peer reviewed articles and interviews with Native American diabetics. Qualitative data is a source of well-grounded, rich descriptions and explanations of processes in identifiable local contexts. The word “qualitative” implies an emphasis on the qualities of entities and on processes and meanings that are not experimentally examined or measured in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry (Denzin and Lincoln
With qualitative data, one can preserve chronological flow, see precisely which events led to which consequences, and derive fruitful explanations. The main interest in this research is to explicate the ways people in particular settings come to understand, account for, take action and otherwise manage their day-to-day lives (Miles, Huberman 1994:1-15). This research employs both archival and ethnographic methods. Archival work began in June of 2006. I began with an examination of archival data to shed light on governmental policy and public health discourse. Archival research was conducted at the National Archives Regional Archive in Laguna Nigel in southern California. There I examined public health announcements that appeared in boarding school papers, billboards, field nurse monthly reports and the like. I have systematically examined field nurse narrative reports from nurses working in the southwest region of the United States from the 1930s through the 1950s. This data also included a sample of peer-reviewed journal articles on genetic predisposition and diabetes from the 1960s through 2012. This data represents a cultural archive as told by those in power. What I mean here is that these documents came from those with the power to impact policy and health decisions of Native Americans. Documenting changes in the recognition and rise of diabetes by the creators of the records is used to correlate changes in rates and historical events, thus, allowing me to examine the intersections between structural factors including education, class and family history, and their influence on knowledge about type 2 diabetes. More importantly, the archival data
facilitates the analysis of “official” discourse regarding the cause and treatment of diabetes in Native communities.

An examination of current health data, historical records and policy in conjunction with interviews with Native American patients will articulate diabetes within its historical and social context. In December of 2007, I began conducting interviews. Diabetic narratives are used to obtain information regarding Native American perspectives about diabetes. Interviews with Native Americans suffering from diabetes have provided insight into how bio-medical discourse is interpreted and resisted. In regard to the small sample size as discussed above, the focus of the interview is to get the experiences of a life of medical encounters, thus the interviews and analysis are time intensive. In other words, the focus of this type of data collection is to understand how concepts of race emerge in knowledge about diabetes and the processes of medical practices that reflect and affect medical encounters. Thus, the emphasis is not on generalizing to Native communities as a whole, but rather on showing how such processes occur. From this position, the information generated in life histories will provide hypotheses to be tested and ultimately generalized to the larger community. The sample size was also informed by the level of saturation, which was when the stories began repeating; when there were no new concepts or processes being generated, data collection stopped (Handwerker, Hatcherson and Herbert 1997). This project has the potential of helping Native people through the documentation of scientific discourses of race and ethnicity as they apply to Native American’s
incidence of diabetes and to contextualize the relationship between discourse and diabetes care delivery. Participants for the project have been recruited through research networks. These individuals are friends of colleagues or have participated in other research projects. While there are increasingly more studies of type 2 diabetes in Native communities, few of these studies have examined the impact of medical discourse about diabetes and race on and interactions with Native American who have diabetes.

As it is well known in studies of race and inequality among Native people (Young 1994; Steeler 2001; Trafzer and Weiner 2001), the nuances of the interaction between patients, medical knowledge and the perpetuation of inequality take place in the details of daily life over time, and not only in single visits with physicians (Gramling and Carr 2004). Therefore, this study conducts life histories with Native people. These life histories are used to contextualize experience with the views of medical science. Life histories have been described as a data collection strategy that details an individual's life. It is a qualitative account of a life that gives emphasis to the experiences of an individual. The benefit of doing these life histories is twofold. First, for the individual, these narratives may construct meaning about illness and put experience into perspective (Ochs and Capps 2001). Second, such interviews can reveal themes and raise questions that can then be examined further.
Interviews were recorded with a digital recorder and transcribed into a text management program, NVivo. All field notes and demographic data were also transcribed into the text management program.

Outline of Chapters

The rise of diabetes in Native Americans is often portrayed as having been an abrupt transition in which infectious diseases were replaced by degenerative diseases of civilization. Prior to 1955, we see that there is relatively little reporting of incidence of diabetes among Native Americans if we look at field nurse, public health and commissioner reports. For about a ten-year period prior to 1955, there is a silence in documentation, U.S. policy, and health records regarding Native Americans. This could be in part due to the political push for termination policy during this time. In 1955 Indian Health is moved to Health and Human Services; it seems to be at this point that we see a proliferation of reports on the epidemic of type 2 diabetes in Native communities. From this point, researchers begin to talk about diabetes as an Indian disease.

Chapter 2 opens with a brief history of southern California Native nations. Drawing from historians, I begin with the history of these nations prior to European contact and continue through the loss and removal from the land during the mission period through the U.S. period of termination. I use the model of historical trauma to examine how intra-generational stress, loss of land and resources, and in some cases language can impact health. In framing the chapter in this way, I discuss how these events shape Native American’s ideas
and attitudes regarding diabetes and health. It is through this lens that these events can be used to contextualize current health inequalities and biomedical discourse.

Chapter 3 begins with an examination of U.S. government Indian policy. Drawing on the work of Castro and Singer on the anthropology of policy and Analise Riles’s work on documents, chapter three examines U.S. policy and praxis. This is done by focusing on policy created at the federal level and through an examination of Bureau of Indian Affairs (BIA) directors John Collier through Dillion Myer and Department of Public Health reports in the 1950s. I contextualize this at the local level with field nurse reports to understand how structural factors such as lack of funding, political voice, and poor policy and management, coupled with racial and stereotypical ideas of disease etiology, in fact hid the rise of diabetes in Native American communities.

In chapter 4, the work of James V. Neel becomes the focus. Neel’s “thrifty gene” hypothesis for the high rates of diabetes in Native Americans has been considered an important heuristic tool for researchers working on diabetes. In this chapter, I lay out the framework of genetic knowledge as it relates to diabetes in Native communities. I follow the development of the “thrifty” gene hypothesis from its inception to its use as a common narrative in biomedical understandings of diabetes in Native Americans. I argue that it is with the rise of this hypothesis that diabetes in Natives becomes “visible” to biomedical practitioners and researchers. It is once “thrifty” genes are viewed as a
maladaptation to modernity that diabetes is no longer seen as a disease of civilization and affluence but can now be recognized in populations that Western knowledge systems viewed as “primitive.” This highlights the ways in which biomedical praxis and cultural constructions of disease etiology come together to create a body that is inherently diseased while ignoring the social and cultural determinants that impact health.

Chapter 5 examines how Native Americans viewed as genetically predisposed become an at risk population. This chapter examines how alleged cultural traits, behaviors, or beliefs, have implicitly or explicitly been associated with Native Americans, and are often seen as constant, unchanging, and independent of social and historical processes. Analyses that construct culture or lifestyle in this manner simply substitute an essentialized notion of culture for race, with little attention to the structure of constraints within which people make lifestyle choices.

In the conclusion, I attempt to draw all the threads together to show how discourse, history and policies are linked in the embodiment of the Native American diabetic.
Chapter 2

The essence of the Native attitude toward peoples, lands, and other life forms is one of kinship in which no element of life can go unattached from human society. Thus, lands are given special status because they form a motherhood relationship with the peoples who live on them. It shapes and teaches our species and produces certain basic forms of personality and social identity which could not be produced in any other way. As with all living things the land must be taken care of, as a reciprocal agreement (Deloria 1999:131).

Now, you know we have lived in this area forever. Our ancestors lived all over this area. My family moved to the reservation here when I was little but we had always lived in the area. Our people have been through some really disturbing, you know, I mean horrible times first with the missions and after when the Americans came but we stayed together and people remembered. They kept the stories and knew the places. Ummm, you know my children and grandchildren are learning Kumeyaay and their culture and history from the elders. That’s different than when I was young so I am glad of the changes (Jenny 2008).

Introduction

Any discussion of the health of Native people must begin with a consideration of their “fourth world” context. The fourth world refers to situations in which an indigenous population exists in a nation wherein institutionalized power and privilege are held by a colonizing, subordinating majority. In every instance, these fourth world nations are actively engaged in a struggle to maintain or gain some degree of sovereignty. It is within this context that I turn to the history Native Americans in California.

In my research, I use an “indigenist” perspective that is a progressive, Native viewpoint that acknowledges the colonized or fourth world position of
Natives. Indigenization or decolonization of dominant research approaches attempts to critique western research approaches, and to bring indigenous knowledge systems to inform research methodologies that are inclusive of all knowledge systems (Chilisa 2012:24). Decolonization is not passive; rather, it requires praxis. As Waziytawin & Yellow Bird state,

> In accepting the premise of colonization and working towards decolonization, we are not relegating ourselves to a status as victims. On the contrary, we are actively working toward our own freedom to transform our lives and the world around us (2005:2).

Indigenous approaches are not meant to replace a western research paradigm, but to challenge them and contribute to the body of knowledge regarding Native peoples. Indigenous methodological frames also recognize all knowledge as socially situated, partial and grounded in subjectivities and experiences of everyday life (Moreton-Robinson 2007).

> With that in mind, this chapter examines the legacy of colonialism, genocide, loss of land and resources as a historical trauma that has exacerbated the persistence of underlying bio-psychosocial stress that contributes to the continued poor health of Native peoples. In examining type 2 diabetes in Native communities, I argue that current biomedical understandings and public health models have largely ignored the role of health policy, biomedical reductionism, and the creation of risky populations in the discourse of diabetes. The point here is to show that there are many variables that contribute to the high rates of diabetes. I challenge the idea that diabetes in Native American communities can be reduced to genes in a changing environment, and I argue that the “thrifty”
gene hypothesis and the racialized discourse of diabetes need to be situated within in their historical and cultural contexts. By examining history, health policy, biomedical reductionism and the creation of risky populations, I attempt to weave together seemingly disparate threads to tell a more complete story of diabetes in Native American communities.

The following focuses on the history of those communities in which I interviewed people to situate their particular history within the experience of Native Americans and diabetes. Despite the array of tribal cultural practices, many Native communities share historical and contemporary experiences, intertribal organizations, and often have congruent worldviews and values.

**History of Southern California Tribes**

Issues of culture, well-being and health care must be understood within the context of Native American historical experiences. Practices and perceptions pertaining to health and illness cannot be separated from a group’s culture and history. This chapter begins with an overview of southern California Native nations’ history to better situate and contextualize history with the lived experience of historical trauma. Interviews were done with both Luiseño and Kumeyaay individuals.
Clearly, both groups’ social and political structures have changed over the past several hundred years; nevertheless, many individuals within both communities and in other Native communities rely upon the particular framework of indigenous belief systems in order to negotiate the world in general and health in particular. Prior to contact with Europeans, the geographic area known as California was home to more than 500 Native nations that were culturally and linguistically diverse. The history of California Native nations and colonialism, while unique in its specifics and, it could be argued, particularly brutal, shares some commonalities to colonization throughout the Americas that commenced with the Spanish—for example, loss of land, resources, and practice of religion.
What follows is by no means an exhaustive history of Native nations in California; it is an overview of the historical trauma endured by some. The following is a brief history of California Native nations that focuses on the colonial history of the area rather than on the rich individual tribal histories in California. The focus primarily on California is due to the fact that the people I interviewed were from southern California Native nations, but the historical trauma that they and their ancestors have survived, while specific to the area, may be applied more broadly to Native nations across the United States.

It should be noted here that I do not include a detailed map of tribal territories in the area; rather, I intentionally use a map that does not delineate boundaries. I do this because it has been noted to me by tribal authorities that maps of territories that anthropologists have included in their work historically have been used by state and federal government officials to define traditional boundaries, and that these maps differ by each anthropologist, but the result can have a negative impact on Native nations today.

The following is a brief history of the original peoples of southern California. I give a history of the area in order to develop the idea that Native people have an ancient history in the area and that Native people’s worldview of the relationship between land, humans, plants, and animals is an important aspect in understanding the rise of diabetes in Native communities.

A philosophical view held in common by many Native American groups is the belief that the Creator taught the people the proper relationship between
humans and the world around them (Cajete 1999; Cordova 2007). “Native tradition looks to the primacy of direct experience, interconnectedness, relationship and reciprocity in the natural world” (Madrigal 2008:24). The implication is that when one’s relationship with the world around them is out of balance, individuals suffer. Anthony Madrigal suggests

> The Native view of the world considers the inter-relationships of all beings at all levels of existence and here differs from Western tradition where understandings of the natural world are often separated from the spiritual realm and are considered in a secular, compartmentalized manner (2008:24).

Such philosophical understandings of the world are seen in traditional land management practices but also encompass a view of health as relating to a whole living system that is interconnected.

In exploring these epistemologies, I look to the work of Kimberly Tallbear. Tallbear suggests that knowledge resulting from relations among humans and non-human subjects, in this world and in the spiritual realm, involves creating the spaces and faithfully tending to the relationships that cause us to be in the right place at the right time to receive knowledge as a gift (Tallbear 2005:38). In this view, knowledge is a gift rather than an entitlement, and an individual is not entitled to all knowledge. According to Diane Weiner, the Luiseño view certain types of sacred power as existing in the form of “knowledge”. Knowledge therefore occurs differentially in individuals since we are all unique (48). Not all individuals have the ability to obtain or share all forms of “knowledge power” (White 1957).
Pre-European Contact

Prior to European contact, what is today the state of California was the most linguistically diverse area in the Americas (Kroeber 1925). Native nations in what is today southern California included the Cahuilla, Luiseño, and Kumeyaay people. The Kumeyaay occupied an area from northern San Diego County to northern Baja Mexico. Kumeyaay are part of the Yuman language family and the largest group in the area. They are divided into to the Ipai (northern) and Tipai (southern).

The Cahuilla and Luiseño are part of the Takic language family. The Luiseño live in the northern part of San Diego County and in Riverside County. The Cahuilla occupy primarily the desert areas of Riverside County (Bugbee, 2011). While the Kumeyaay are a distinct language family from the Luiseño and Cahuilla with a very different origin story, they are connected through ceremony, marriage, kinship, and trade.

These groups were known for their horticultural activities. The Cahuilla used conventional irrigation by means of ditches from wells, springs and streams. David Barrows wrote of the Cahuilla, “They were famed well diggers. Their wells were usually great pits with terraced sides leading down to the narrow hold at the bottom where water was found” (1900:26). The mountain Cahuilla planted corn, melons, pumpkins and wheat. In the desert, they planted beans and squash.

In southern California, Native groups lived in groups loosely related according to ancestral and linguistic affinities (Costo 1995). Most tribes in this
area identified themselves as “the people” in their own language. Considering that each tribe, clan, and family was identifiable to all its members, it was not necessary to adopt a name in order to distinguish them as people occupying a certain area. They did however, name other tribes. According to Costo, “To the so-called Gabrielinos, the Cahuilla were “easterners,” but the Luiseños called those people northerners” (1995:118). A variety of environmental resources were utilized by bands living in the area. Trade and exchange enriched the tribal economy while simultaneously building relationships among groups. Bands in southern California were noted for their travel and trading activities. Contact between coastal and interior southern California was extensive as well as trade between southern California tribes and tribes in the Southwest (Ruby 1970).

Traditionally, the Luiseño people occupied approximately 50 miles of the southern California coastline, north of present-day San Diego, extending inland for about 30 miles. For the Luiseño, nuclear families would often have household gardens where oak trees and vegetables were grown with milling stones where they could be processed (White 1959). Seeds, roots, berries, tubers, native varieties of grapes and cherries where also harvested. Evidence suggests that upland Luiseño were irrigating and cultivating grass-grain and corn crops by the late seventeen hundreds (Shipek 1987). Other food items supplemented Luiseño diets, including wild greens, cactus leaves, cactus fruit and yucca (Shipek 1988). Wild game included rabbits, deer, and wood-rats. Food from fresh and salt-water resources was also available.
The Kumeyaay Nation, located in what is today eastern San Diego County, occupied the land from the coast of San Diego east some 100 miles into the interior and south into what is today Baja-California. They are a Yuman-speaking people. The Kumeyaay had access to a variety of resources and their diet reflected this variety. Kumeyaay people relied on oak and some pine trees, native grain, and a variety of annuals, as well as rabbit, shellfish, fish, deer, antelope, birds, duck and other water fowl. The Kumeyaay managed the environment through controlled burns and erosion control (Jordon 2003). The Kumeyaay, while historically portrayed as seasonally nomadic, lived in villages, and evidence suggests that irrigation of crops by ditches from springs was practiced as well as the construction of wells (Treganza 1947). They did travel to the ocean to fish and obtain salt. Wild species and cultigens were harvested and irrigated whenever needed.

The Mission Period

California Indians had heard of and perhaps even seen Euro-Americans prior to the influx of the Spanish during the mission period. By 1769, Europeans including French, English, Portuguese, Russian, Spanish, and the newly formed United States of America had been dividing the “New World” and fighting for territory for nearly 300 years. Spain had laid claim to Alta California by right of discovery in 1542 when Captain Juan Rodriquez Cabrillo sailed into what is today known as the San Diego Bay and went ashore near Point Loma. Cabrillo named the area San Miguel. For California Indians, the mission period could well
be argued the most devastating period in California Indian history. Spain sent other expeditions into Alta California, such as the 1602 visit by Vizcaino when he called the region San Diego, but it was not until 1769 that Gaspar de Portolá of the Spanish Army landed with an expedition and moved into what was to become San Diego. By the mid-eighteenth century, California was inundated by foreign invaders and the missionaries that accompanied them. Spain had worried about access to Alta California for more than 200 years before actually beginning the invasion and missionization of California. By 1770 other European powers were becoming active in the Pacific, and the Spanish found it necessary to settle the area if they hoped to confirm their claim to the land. By 1769 the Spanish Empire had begun to decline; Spain’s interest in Alta California appears to have largely been due to incursions into Alta California from Russians to the north, and the view of an encroaching western move by other western powers and white settlers (Phillips 1974).

In 1770, engineer and cosmographer Miguel Costanso spoke of the importance of settling California.

The peopling of the discovered part of California with useful inhabitants, capable of cultivating its lands and profiting by the rich products which it offers in minerals, grain or other fruits, and likewise taking up of arms in defense of their homes whenever the occasion should arise (Brandes 1970:79).

Along with Portolá was Father Junípero Serra, President of the Franciscan Mission in Alta California. Serra would be the founder of 10 of the 21 missions
constructed in Alta California. As Costo notes regarding the mission system in California,

[They] have been perceived as a romantic, nostalgic part of the state’s history. Spanish activities were not so romantically viewed in the southern continent. By the time they had arrived in California they had accumulated more than two hundred years of genocide, destroying ancient civilizations of the Aztecs, the Mayas, Incas and most of Central and South America (Costo 1995:156).

The lives of California Indians were greatly disrupted during the mission period. The forced resettlement into missions and conversion to Christianity greatly disrupted and the lives of Native people in California. California missions were essentially religious labor camps. The Spanish introduced domestic stock animals that ate native foods. The health consequences of contact with Europeans were particularly devastating, with no natural immunity to the new diseases introduced by the Spanish. Smallpox, diphtheria, chickenpox, syphilis, influenza, and measles caused death among Indians in and near the missions.

In 1806, thousands of Native children and adults from San Francisco to Santa Barbara died of measles (Jackson 1987; Cook 1976). Demographer Sherburne F. Cook concluded that perhaps as much as 60 percent of the population decline of mission Indians was due to introduced diseases (Cook and Borah 1979).

The health of California Indians was not only negatively impacted by infectious disease but also through diet. Under the mission system, the diverse diet of native foods that was part of California Indians’ food system was now replaced by wheat, corn, and beans. Although California Indians were able to continue their traditional subsistence activities to some extent, the effects of loss
of land and of grazing domestic animals limited access to traditional foods (Jackson 1987; Walker et al. 1989). Skeletal evidence suggests that Indians held at the missions were significantly smaller than those of California Indians before European contact. The difference could be due to nutritional deficiencies of the mission diet or the combined effects of under-nutrition and infectious disease (Walker et al. 1989:354-355).

The military and priests that moved into California with the missions needed a labor force to build the presidios and missions. In order for the Spanish mission to succeed, it was imperative to the mission system that there be a steady supply of new converts to provide the new missions with protection and self-sufficiency. This meant forced conversion for some native people; priests would organize military sorties into the inland areas to capture and return neophytes that had escaped missions and to obtain new converts. With the establishment of missions in Alta California, native people were often used as forced labor. The missions would trade surplus food supplies with the presidios and ships that came in. While the goal of the Spanish was establishment of a military and religious basis for an empire, the Native Americans served to create wealth for the missions and for Spain (Costo and Costo 1987; Monroy 1993).

The Mexican Period in California

With the end of the mission period and the increasing encroachment of Russian settlers to the north and Anglo-Americans from the east, Mexico was incentivized to settle California. With a relatively small Mexican population, the
new nation worried that the settlement of Russians at Bodega in northern California was an indication of Russia’s desire to claim Alta California.

Mexico’s Colonization act of 1824 sought to stimulate immigration to the Mexican frontiers by liberalizing land policy. In 1823, Mexico’s Lucas Alamán, head of Interior and Exterior Relations stated,

> The government believes, therefore, that the distribution of land to the converted Indians, lending them from the mission fund the means for cultivation… would give a great impulse to that important province (As quoted in Bancroft 1886:488).

With the Mexican era, titles to plots of land were granted to individuals; however, these grants were provisional. Grantees could not rent or subdivide the land. It was required that a home be built within a year and that the land be cultivated. If these requirements were not met, the grant could be revoked and another party could claim the land (Monroy 1993).

With the secularization of the missions, the number of land grants greatly increased. While the original intent with secularization was to divide land among Indians that had lived on mission land, most grants were given to influential Mexicans. Mexican law established rules for land grants in California and served to break the monopoly of the missions while making it easier for settlers to obtain land grants.

By the end of the mission period, Native Americans were drawn to ranchos as laborers. Unlike the missions that had preceded them, ranchos did not require Christian religious practice. Native Americans were at once the key
to the emerging need for rancho labor demands and the technical holders of the vast mission lands which stood as a barrier to the expansion of the ranchos.

The governors granted approximately seven hundred ranchos in California, with neither the territorial nor the Mexican government receiving any form of payment. Grantees were required only to build a house, settle on the land and stock it with cattle. The Spanish had brought with them a classification system derived from Spanish concepts of race and ethnicity and modified on the basis of their experience in the “New World.” The basic distinction was between “Spaniards” and “Indians.” The category of “Spaniard” was then divided into two principal subcategories: the Peninsulares (those born in Spain), and Criollos (those born in the New World). Native Americans were also subdivided and classified by tribal identities and as being “civilized” or “barbaric” (Martínez 2010). For example, the Pueblo people of what is today New Mexico were viewed as “civilized” because they practiced agriculture and lived in permanent settlements. Those Indians that had converted to Christianity were called Cristianos, Bautizados or Conversos, and were distinguished from those who had not converted (Gentiles).

Christianized Indians were further categorized according to their acceptance of colonial conditions. Those who rebelled against their oppressors were characterized as apostates, fugitives or cimarrones. Joining the categories “Spaniards” and “Indians” came a third division that labeled individuals of mixed European, Indian, and African heritage. The general term was castas (castes).
The people that fell under this classification were also collectively categorized as *gente de razón* (people of reason). Many Spaniards carefully distinguished themselves from the mixed *gente de razón*, whom they considered as inferior (Merill 1993:129-163).

For the *gente de razón*, a class in search of social standing, the idea of the Native Americans as their opposite played a central role in the formation of a social person. Whereas the mission system priests concerned themselves with Native peoples’ heathenism and for the most part were uninterested in their physical features, by the rancho period, race now came to be an operative force in the marking of peoples of California. According to Douglas Monroy:

> To be de razon meant not to be like Indians, who drank to excess, had sex, worked at a pace bound to nature, had a demonic religion, and were generally wild. But in fact the gente de razon were mestizos who also drank, had sex, were not known for dedication to hard work. Indians served not only as a work force but also as a contrast to us (1993:103).

With the Secularization Act of 1833, the Mexican government took possession of mission lands that had been held by the Spanish. Mission priests were allowed to keep the church and their housing. The Mexican government set up commissioners to be overseers of mission land. They were tasked with the oversight of the crops and herds and assuring that land was divided into a communal pasture. While secularization marked the end of an era, it did not suddenly change the lives of California Indians.
Commissioners also oversaw the development of a town plot and individual plots for Indian families that had resided at the missions. However, instead of dividing the land and holdings among the mission Indians, authorities kept it for themselves and their families. Rather than land being returned to Native nations, Native land taken for missions was now used as ranchos that produced hides for shoe factories and tallow for candle shops in the eastern United States. At the end of the mission system, California Indians that had been under mission influence moved to the civilian pueblo areas to seek work, became laborers on private ranchos, or returned to their homeland. Those that went to the pueblos or ranchos found little improvement from mission life. Poverty and the peonage system on the rancheros ranged from economic persuasion to outright slavery (Castillo 1978).

After 1828 with liberalized Mexican trade policies and immigration laws, Anglo-Americans moved to settle in California. The Naturalization Law of 1828 only required that one reside continuously in the area for two years, be useful and moral, and be Catholic. The new inhabitants of California pushed California into a global market economy while accumulating wealth and power for themselves on the labor of Native Californians (Monroy 1993). During the Mexican period, warfare and violence against Indian people continued with the Mexican assembly resolution of 1846 that devoted revenue to “active efforts” against Indians. Disease was still a major factor in the health of California Indians. Measles, pneumonia, smallpox, scarlet fever, cholera, and tuberculosis
ravaged missionized tribes. It is estimated that military casualties accounted for 6 percent of the population decline of Native People in central and northern California (Costillo 1978:106).

The American Period

On May 13, 1846, the United States declared war against Mexico, and on July 7, 1846, U.S. forces took Monterey, the capital of California, and terminated the authority of Mexico. With the Treaty of Guadalupe Hidalgo in 1847, California became a territory of the United States and a state in 1850 (Castillo 1978).

Article 11 of the Treaty of Guadalupe Hidalgo concerned California Indians, who were granted no land rights. The article declares that the United States is responsible for policing of tribes, preventing their raids into Mexico and their warring against citizens within the United States. The article also asserts the process of removal of the Indians, and settlement of the land by U.S. citizens (Hass 1995). Article 11 served to deny civil and property rights to tribes. Over the next decade, the California Indian population would decline by eighty percent, more rapidly than any other time in history (Hass 1995; Rawls 1986).

The Treaty of Guadalupe Hidalgo included a provision honoring Mexican land grants. When congress passed the Act to Ascertain and Settle the Private Land Claims in the State of California in 1851, a federal land commission was appointed to hear evidence regarding Mexican land titles and to determine lands held by Indians. Land grant holders were required to present their titles to the Board of California Land Commissioners, which placed the burden of proof of title
on landholders. Over its tenure, the Land Commission confirmed 604 of the 813 claims it reviewed. Many claims ended up in the courts and on average took as many as 17 years to resolve. The act also required the Land Commission to determine Indian lands. Lands not confirmed by the commission, which were almost all Indian lands, were declared to be public and therefore open for homesteading. Indian people under the U.S. government were required to carry a passport or permission from an employer when they moved about, and were prohibited from gathering in crowds (Hass 1995).

In 1850, the legislature passed a law declaring that any Indian on the word of a white man could be declared a vagrant, thrown in jail, and have his labor sold at auction for up to four months with no pay (Costillo 1978:108). The law went further, stating that “any Indian adult or child with the consent of his parents could be legally bound over to a White citizen for a period of years laboring for subsistence only” (Costillo1978:108). The result was that Indians were rounded up, made to work, and left to starve when there was no more work.

California Indians had suffered greatly under the Spanish and Mexicans, but fared no better under the United States government. In 1851, California’s Governor Peter Burnett, when speaking of California Indians, stated, "That the war of extermination will continue to be waged until the race becomes extinct must be expected.” To back this up, the California Legislature authorized payment of claims to pay militia for bounties on dead Indians. The first state bond issued in 1854 was to pay for bodily proof of executed Indians (Madley 2008).
United States sent a special commission to deal with the "Indian problem" in California. Treaties were presented to leaders in southern California to be signed. In total, some 18 treaties were signed. These treaties covered nearly nine million acres of land, allowing for most bands to remain on their traditional lands. When the treaties were brought back to Washington for congressional approval, congress refused. Congress had received a report opposing the treaties. There was also resistance from wealthy Mexican landowners and Anglo-American settlers, as well as the California Legislature that recommended the removal of all California Indians to Indian Territory (Forbes 1993).

Throughout this time, conditions for Native people living in San Diego continued to deteriorate. By the 1890s most reservation land had been established. The reservations of San Pasqual and Pala were created with much of the land being too rocky and without a good source of water to support the population (Shipek 1978; Hass 1995). Not interested in leaving their ancestral homes, many Kumeyaay felt that they were being removed to an area that was unsuitable for farming and they would be unable to provide for themselves (Pico 2011). Land historically granted to Native nations under Spanish and later Mexican law was again ignored.

The State of California

By the late eighteen hundreds open violence against Native American people had largely ceased but the United States government continued to enact laws that marginalized and traumatized the lives of Indian people. Policies such
as off-reservation boarding schools that were implemented to erase Indian culture, and the General Allotment act of 1887, served to further erode the land base of Native Americans. The period from 1880 to 1920 was a time when Native Americans came increasingly under bureaucratic control (Forbes 1993). These years were characterized by increasing interference of the Indian Service in all aspects of Indian life. For example, in 1902 the BIA advised agents that Indian men applying paint or choosing not to cut their hair would result in the withholding of rations and supplies (Castillo1978:121). Often ignoring the immediate needs of Native nations, the Bureau of Indian Affairs controlled all funds and all decisions for how funds would be used on reservation land.

Throughout the twentieth century, California Indians continued to struggle to survive. In 1929, California Indians filed suit against the government for land lost by the U.S. Senate’s 1851 tabling of treaties. The Attorney General of California appointed the attorney to represent the tribes, over their protest. The result was the court’s awarding $17.5 million, or $1.25 per acre, for treaty land lost. The award was to be “subject to appropriation by Congress for educational, health, industrial, and other purposes for the benefit of said Indians” (Forbes 1993).

While these issues impacted tribes throughout California, it was the issue of water rights that could be said to have had the largest impact. While the loss of arable land devastated California Indians ability to provide for themselves, the demand for water by the newcomers to California proved just as devastating. In
an area where water is a precious resource, water rights issues have in the past and will continue to be litigated into the future (Pico 2007).

**The Impact of Termination Policy**

Native Americans, in August 1953, watched as the United States Congress passed Public Law 280, transferring legal authority from the federal government to states (Daly 2009:427). Six states—Alaska, Minnesota, Nebraska, Wisconsin, Oregon and California—were given criminal jurisdiction over tribal members and other people on reservation land. Consent of tribes was not required and tribes were not consulted. Prior to PL 280, criminal jurisdiction was shared between federal and tribal government with little state involvement. The impact of the federal government’s termination policy (PL 280) left California Indian nations dependent on the state. In 1953 PL 280,

> [PL 280] extended concurrent state jurisdiction over criminal matters and led to state and local intrusion into tribal affairs and sovereignty. Public Law 280 also served as the excuse for federal withdrawal of services and support for California tribes, contravening the federal trust responsibility (Goldberg 2002:44).

PL 280 terminated all federal services, except those relating to the land trusteeship. Native nations now had to rely on the same state government that had long sought their demise for aid and assistance with problems on reservation land.

In 1944, Commissioner of Indian Affairs William Zimmerman submitted a list of tribes to congress. The amount of mixed blood, acceptance of white institutions, levels of acculturation, and willingness of state to assume
responsibility were the criteria used to determine which groups appeared on the list. Native nations picked for termination “were given a choice to divide communal lands into individual allotments or forming a private management corporation to administer tribal property” (Daly 209:429).

The passage of PL 280 signaled a change in U.S. government philosophy regarding federal Indian policy. No longer would the federal government profess responsibility for the welfare of tribes and tribal members. States would assume that responsibility. The Bureau of Indian Affairs used PL 280 as an excuse to redirect federal support away from tribes in PL 280 states. This is seen in California, where Congress singled out 41 reservations for termination (Fixco 1990). PL 280 and termination ate away at the funds authorized for Indian welfare, health and education in California.

In southern California, the Mission Indian Federation viewed termination as an opportunity to rid Native nations of the BIA and its officers who were seen as not serving the needs of reservation communities. The Mission Indian Federation saw the BIA as being an impediment to Indian sovereignty. Individuals who did not belong to the Mission Indian Federation held a different view. The Spokesmen and Committee Group were one such group. The Spokesmen and Committee Group actively worked to resist termination. They viewed termination as endangering land, water and mineral rights (Daly 2009). The effect was that, for many families, there was much disagreement regarding termination. Dee recalls, “We don’t really talk about it about much but I know that
my family had mixed emotions; you know, with some thinking it would be a good thing and some of ‘um thinking no. It caused lots of tension, I think.”

For many San Diego Indians, Public Law 280 meant new constraints on social and economic means. County officials used the law to enforce county health and construction codes, and the policing of reservations was now controlled by the county sheriffs. Law enforcement often interrupted cultural activities and rarely responded to emergencies (Weiner 1993). This, coupled with the county of San Diego’s refusal to provide welfare benefits and pensions to California Indians who refused to sell their land (Costillo 1978), led to increasing Indian voices calling for an end to termination.

By the late 1960s, it was apparent that the policy of termination was a failure. The 1968 Indian Civil Rights Act imposed the basic requirements of the Bill of Rights that had not previously been applicable to Native Americans. President Richard Nixon declared an era of self-determination with federal assistance and protection. The U.S. enacted and implemented programs under the Economic Opportunity Act, the Indian Education Act, and the establishment of the Senate Select Committee on Indian Affairs. During this time, Native Americans started to win court victories to rectify broken treaties and started to organize. Events, such as the Washington State tribes’ clash with state officials over fishing rights and the occupation of Alcatraz, brought attention to the plight of Native Americans. This meant that many tribes began to assume control over programs and education previously administered by the federal government.
The courts began to recognize Indian tribal sovereignty and legislation began to recognize religious freedom.

Reinterpretation of Public Law 280 by the circuit court has enabled reservation organizations to obtain needed social services. In 1980, the Rincon Band of Mission Indians challenged how health services were delivered in California since the enforcement of PL 280. IHS benefits had been eliminated in California from 1953 to 1969, resulting in increasingly poor health outcomes for California Indians. State health services in California had never materialized and by 1970, IHS services were formally restored, but funding was limited (U.S. General Accounting Office 1993). The outcome of the Rincon suit was a court order directing IHS to take steps to reduce disparities that existed in area funding.

The term “self-determination” seems to have first entered the vocabulary of Indian affairs in 1966, when the National Congress of American Indians (NCAI) convened to develop an agenda to counter the threat of termination policy. The concept of self-determination is more in line with legal concepts with Native nations viewed as domestically dependent nations subject to the superior sovereignty of the U.S. (Deloria 1985, Cooper 1990, Pevar 1992).

Under the Reagan administration, cutbacks in government programs resulted in increased unemployment and hardships for tribes. By the 1980s, tribes undertook new economic development strategies to bring in badly needed
revenue, including gaming. During the Clinton administration, there was a renewed interest in strengthening tribal sovereignty.

**Historical Trauma**

The history of Native American and Anglo-American relations could be characterized by the long and extended exposure to violence and trauma experienced by Native people. Dr. Maria Yellow Horse Brave Heart defined historical trauma as “a constellation of characteristics associated with cumulative group trauma across generations” (1998:290). Work on historical trauma examines the relationship of health and disease outcomes to the individual, community and intergenerational effects of the events of colonization, environmental degradation, genocide, forced assimilation, and relocation. In this sense, trauma is the intense feelings of stress, grief, and fear in response to intentional harmful mental, emotional and physical situations and events. It includes the cumulative impact historically traumatic events have had and are still having on Native American communities (Duran, Firehammer, Gonzalez 2008). Historical trauma can be linked to the physical, mental, emotional, and spiritual health of Native Americans (Evans-Campbell 2008; Ferreira and Lang 2006; Gone 2009; Nebelkopf et al. 2011). Different from other types of trauma in that it is shared by a collective group of people who experience the consequences of the human created event, the trauma is held personally and can be transmitted over generations (Brave Heart 2003, 2011). An example of a historical trauma is that of the boarding school experience of Native Americans. In the last quarter of
the nineteenth century, young Indian children were taken to off-reservation schools where their hair was cut and they were no longer allowed to speak their language or practice their religion. The point of the boarding school was to “civilize” the Indian. R.H. Pratt said, “We make our greatest mistake in feeding our civilization to the Indians instead of feeding the Indians to our civilization” (1892). Some 500,000 Native American children were taken to boarding schools from the 1870s through the 1960s. The boarding school served as a form of cultural genocide that often meant cultural and psychological isolation for students. The result of the trauma was forced separation from tribal communities, leading to loss of parenting skills and tribal knowledge of gender and family relationships. The trauma of boarding school survivors was inadvertently passed on to their descendants.

There is ample evidence that trauma and stress place indigenous people worldwide at high risk for type 2 diabetes. A growing body of literature focuses on the relationship between stress/trauma and diabetes (Surwit, Schneider and Feinglos 1992; Canguilhem 1991; Scheder 2006, Ferreira 2006). Studies have shown that chronic stress can have a profound effect on heart disease, diabetes and stroke (McEwen 2008; McEwen and Gianaros 2010). Evidence can be found among trauma victims suffering from PTSD who were found to have higher rates of conditions such as asthma, ulcers, and diabetes. Furthermore, depression is associated with poorer health outcomes for people with diabetes (Ciechanowski et al. 2003). Researchers at the University of Washington
revealed that diabetic patients with depression had decreased physical function and were less inclined to adhere to lifestyle changes. Long-term stress can result in hormonal changes, including elevated cortisol levels, leading to insulin resistance a precursor to diabetes (Weisberg et al. 2002).

An understanding of health inequalities is paramount for the development of effective health policy. In interviews conducted with Native Indian diabetics, a common narrative emerged to the question, “What do you think causes diabetes?” In these narratives, the etiology of diabetes has in part been created through the historically untenable transformations in Native American’s daily lives. As Mae states:

Well, it just seems like… that we get it ‘cause, look, we have lived off government food; all that food is bad. There is lots of things we have gone through. I don’t think that kind of a….stress is good; it has something to do with it.

To the same question Julie stated:

We used to live different. Move around more, you know. We ate food that was … ummm… good like rabbit and cactus leaves, you know, all that stuff you can find around here. We don’t do that now, you know.

While these narratives are not explicit, they do reveal a relationship between health, the land, history, policy, cultural knowledge, and diet, while simultaneously resisting biomedical reductionism. As such, they link diabetes to social inequality stress and trauma.

The stress of living with diabetes can be seen in a conversation I had with Anna. I was at Anna’s house in on a beautiful clear day in May. Anna doesn’t
live on reservation land but maintains close ties to family on the reservation and participates in social events there. Anna says she would like to move back to the “rez” but her job and her husband’s job keep her in the city. Her home sits in an old neighborhood in the city of San Diego. I asked Anna about the ways in which diabetes has changed her life.

So far, I have been able to keep my diabetes under control. Sometimes it seems to be worse than others but …you know… for the most part, I’m good. At first when I found out, I was good about what I ate for a while then I just …well, you know, I stopped doing what I was I supposed to. I would eat whatever I wanted. Umm… it’s really hard to eat right. I never had eaten good. Anyway, I started to get sicker and my husband just told me, he said, “We need to do something different.” Well, I eat better now; I’m not like totally good but you know I started my own garden in the backyard.

Anna has had to think of new ways to incorporate healthy eating into her life. She has chosen to plant and maintain a garden that incorporates both traditional and non-traditional foods. Diabetes discourse is complicated; there are common discourses, but that is not to say that there is consensus about the etiology of the disease.

Discussion

The historical experience of Native Americans in general and California Indians in particular have influenced and impacted political, social and economic outcomes. Throughout this time, continued cultural continuity and knowledge systems and the ability to incorporate outsider knowledge has prevailed.

The health problems of Native people are not simply an artifact of genetics, culture or lifestyle. Through this examination of the vulnerabilities and
fourth world context suggests that geography, racism, poverty, and discrimination undermine physical health. Precisely how historical and current traumas of unresolved grief and mourning are related to loss of land and place effect the health of Native People has yet to be empirically documented. Within Native communities however, these stressors are viewed as key factors related to poor health.
Chapter 3

Introduction

Native people have long recognized the impact of policy on their lives, and yet there has been little attention paid by anthropologists to the linkages between health policy and poor health outcomes for Native Americans. In this chapter I examine health policy through the lens of structural violence. Structural violence as it is used here is the almost invisible way that structural inequality is embedded in social structures and normalized by institutions and regular experience. In this way, structural violence occurs whenever people are disadvantaged through legal, political or economic forces. Structural inequities almost always seem ordinary, the way things have always been done.

Similar to Paul Farmer, Margaret Lock, Merrill Singer, and others’ work on structural violence, this chapter’s focus is on how health policy may reproduce large scale social forces, such as racism, poverty and other social inequalities rather than advance the goal of improving health outcomes. Native American health policy is examined to show the implementation of structural violence through governmental policy. The goal here is to situate U.S. Indian health policy within the narrative of Native American diabetics. In doing this, I am attempting to show how health policy during the first half of the twentieth century was impacted by racial and cultural constructions of what types of disease Native American people suffered from.
This chapter is a critical examination of the United States government's development of Indian health policy prior to the period of self-determination. In looking at the relationship of policy to lived experience this chapter attempts draw the links between U.S. Indian health policy and poor health outcomes. How is the lived experience of Native American diabetics today linked to United States Indian health policy?

**Anthropologists and Policy**

How have medical anthropologists engaged in larger discussions regarding health policy debates? While medical anthropologists have focused on health disparities, there has been a need for medical anthropologists to be more central and to present ourselves as public intellectuals in policy debates. As applied medical anthropologists, our work may often effect policy development and implementation at the institutional level. Yet, as anthropologists, we have often neglected a thorough examination of health policy in our endeavors. If medical anthropologists are to understand why some health initiatives succeed in terms of improving health outcomes while others fail or even worsen health problems, medical anthropologists must also examine these constraints and the core principles that guide efforts to eradicate or control disease (Saillant and Genest 2007).

Castro and Singer have called for anthropologists to critically review the intended or unintended negative impact of policy on the lives of people targeted by social policies. They have urged researchers to examine how inappropriate
health care policy can exacerbate inequalities that pose significant threats to the health of the poor and disempowered (Castro and Singer 2004; Horton and Lamphere 2006; Rylko-Bauer and Farmer 2002). Horton has suggested that there are multiple levels of analysis at which anthropologists can add to debates of health policy: “at the levels of individual behavior, institutional policy and public discourse” (Horton and Lamphere 2006:1). The following work addresses this concern with a focus on health policies that have affected the lives of Native Americans. Through a close examination of U.S. Indian health policy, I argue that racialized discourses of disease made invisible the rise of diabetes in Native American communities in the first half of the twentieth century.

Based on Castro and Singer’s definition, the term “policy” is used here to refer to the official guidelines implemented by a social institution intended to set direction for action. It includes both codified guidelines relative to health or policy with another purpose but, nonetheless, having a direct impact on health or health-related programmatic actions that reflect either codified guidelines or what are sometimes referred to as “unstated” policies (Castro and Singer 2004:xi). The formulation of health policy and its implementation is a complex social process that extends beyond legislative and bureaucratic spheres. Through an examination of U.S. Indian health policy from the late eighteen hundreds through the 1960s, I focus on the United States government’s response to complex health issues facing Native American communities, illustrating the link between history, health policy, and current health policy challenges. In an examination of
health policy and the rise of diabetes and the contestation of those discourses by Native Americans, I examine the process by which bodily-truths are produced such that they are used to justify and contest formations of power.

**Affluence and Civilization**

Traditionally, biomedical practitioners have categorized diseases into two broad categories: infectious diseases and chronic diseases, also termed diseases of poverty and diseases of affluence or civilization. Diseases of poverty are infectious diseases that first appeared with the advent of agriculture sedentism, and increased population. Diseases of poverty include influenza, respiratory infections, and tuberculosis, to name a few. Diseases of civilization or affluence are those diseases that were considered to have come with modernity, and an extended life expectancy. They include cancers, heart disease, arthritis, and diabetes. In the early 1970s this was termed as the epidemiological transition (Magee, Blumber, Narayan 2010; UN Development Program 2007; Ezzati et al. 2005). The transition was thought to be a unidirectional process, beginning when infectious diseases where predominant and ending when chronic, non-communicable disease become the leading cause of death in a country. While it is true that causes in morbidity rates change, it is much more complicated than the model suggests.

**The Etiology of Diabetes in Western Society**

A historical model for speaking about “Jewish diseases” can be found in the story of diabetes. For hundreds of years, diabetes was understood as being
transmitted within specific races. Rather than being seen as a disease of individuals, diabetes was racialized as a disease of the Jews. Diabetes as the “Jewish disease” became a curse on all Jews and part of the anxiety about being Jewish or having Jewish ancestry (Tuchman 2011).

The view of diabetes in the United States and Europe at the turn of the twentieth century was largely one of a disease of race and affluence (WHO 2005, Magee, Blumberg and Narayan 2010). The myth of chronic diseases as being tied with affluence and civilization is just now being understood. Around the turn of the twentieth century, studies started appearing alleging that Jews died of diabetes at a rate between two to six times higher than the rest of the population (Wilson 1912). J.G. Wilson, a physician with the U.S. Public Health Service, looked to race to explain why Jews experienced such a high rate of diabetes, claiming “some hereditary defect made the Jews more prone to develop the disease” (1912:6662). While, this view might have been the predominate view, it was by no means the only one. In contrast, Physician Elliott Joslin wrote, “The Jew is not prone to diabetes because he is a Jew, but because he is fat” (1924:727).

Since the 1960s, diabetes again has a racial profile, but Jews have been replaced by Native Americans. This image is reinforced by the United States government’s policy of collecting racial/ethnic information but not other confounding factors. Attention to race on websites like that of the National Institute of Diabetes and Digestion and Kidney Diseases (NIDDK) draws
attention to incidence of diabetes among certain racial/ethnic groups but excludes socio-economic-status as a risk. What is being produced in the literature is indicative of the kind of data that is collected.

At the turn of the twentieth century, the view of Anglo-Americans regarding Native Americans was that Native people were uncivilized, primitive people in need of the “civilizing” of western society.

The Indians must conform to "the white man's ways," peaceably if they will, forcibly if they must. They must adjust themselves to their environment, and conform their mode of living substantially to our civilization. This civilization may not be the best possible, but it is the best the Indians can get. They cannot escape it, and must either conform to it or be crushed by it (Thomas J Morgan, Commissioner Indian Affairs 1889).

This view served as a suffocating paternalism towards Native people. Like many other Anglo-Americans, the Commissioner of Indian Affairs Thomas Jefferson Morgan viewed Native Americans as "yet in a stage of childhood; … living in the twilight of civilization, weak, ignorant, superstitious, and as little prepared to take care of themselves as so many infants" (1891:6). Anglo-American views of Native Americans as inherently weak and primitive transferred into ideas about health and disease. From this perspective, diabetes was viewed as a disease of affluence or a disease of civilization, which did not fit into Anglo-American imagery of a disease Native Americans were likely to suffer from.

The term civilization, as Thomas Patterson points out, becomes “a theory of history, describing the change from a primitive condition to a more advanced one by means of moral intellectual and social progress” (1997:23). As Patterson
goes on to point out, civilization is about “hierarchical relations through which contempt for and fear of the ‘other’ are expressed” (1197:21). In ways too often ignored by historians and anthropologists, the divergent approaches to medicine and the treatment of illness may be the ultimate distinguishing colonial symbol (Pfefferbaum et al. 1995: 368).

The Role of Documents and Policy

Michel Foucault in “The Archaeology of Knowledge & the Discourse on Language” regarded documents as having “always been treated as the language of a voice since reduced to silence, its fragile, but possibly decipherable trace” (1972:6). For Foucault, the scholar was not to merely interpret documents but to “work on it from within and to develop it,” to transform it into “monuments” deserving of “intrinsic description” (1972:6). In this view, historical documents are not just factual histories but also “instances of discourse that produce their objects as real, existing outside of discourse” (Riles 2006:11). Bureaucratic creation of documents that represent a certain political discourse is evident in United States Indian health policy.

Clearly, these forms give us what Anne Riles suggests is a “point of entry” into understandings of modern knowledge practices (Riles 2006:2). For Riles, the document “becomes at once an ethnographic object, an analytical category, and a methodological orientation” (Riles 2006:6). The following historical documents represent policy endeavors, policy changes and how U.S. government Indian health policy was interpreted and implemented by physicians
and field nurses. Regarding how she examines documents, Ann Stoler stated, “as a corpus of writing and as a force field that animates political energies and expertise, that pulls on some ‘social facts’ and converts them into qualified knowledge, that attends to some ways of knowing while repelling and refusing others” (2009, 22). Policy takes time to move from inception to practice, and needs change over time.

**Native American Health Policy in the United States**

In order to understand how diabetes arose as an epidemic in Native American communities, the policies of the United States government need to be critically examined. While there is much written on the history of U.S. Indian health policy, few studies have linked policy to health outcomes. In this context the linkages of policy and the rise of diabetes has not been adequately understood. The focus of this chapter is to better understand the link of health policy and health outcomes to the epidemic of type 2 diabetes in Native communities across North America. In order to do this, the following looks at how U.S. Indian health policy has developed.

The role of the United States government in Indian health really begins in article 1, section 8 of the United States Constitution. It states, “Congress shall have power… to regulate commerce with foreign nations, and among the several states, and with the Indian Tribes” (US Constitution). This passage has often been cited as the basis of tribal sovereignty and federal Indian health policy. Today, this policy is the basis for the U.S. and Native nations' (federally
recognized) government-to-government relationship that is unique among ethnic/racial groups in the United States.

From the beginning, funding for Indian health care has been problematic. Prior to 1819, there seems to be no mention or interest by the United States Congress in the health of Native Americans. In 1819, the United States Congress appropriated $10,000 to several missionary groups to “civilize” Indians. While the emphasis was on “civilizing,” which typically meant Christianization, agriculture and assimilation of the Indian, some of those funds were used by these groups to provide basic health services (Pfefferbaum et al. 1995). During this time, Indian health, while under the administration of Indian affairs, fell under the jurisdiction of the United States War Department. This often meant that health care for Indians near forts was at best, unorganized and limited. Care came from military physicians stationed at forts who were commissioned to provide service to military personal.

In order to understand how the health of Native Americans became a concern of the United States government, we can look to treaties that were ratified during the Removal Period in Native American and U.S. government relations. Access to health care was often written into treaty rights signed by tribes and the U.S. government. For example, in Article 5 of the 1837 Sioux treaty, the United States government agreed to pay $8,250 a year for 20 years to provide medicine and a physician for the Sioux (1837, 494). Like the 1837 Sioux treaty, the 1854 treaty with the Oto and Missouri, the United States government
set aside funds for “medical purposes” (Article 4 1854:609). In the 1868 Treaty with the Sioux-Brule, Oglala, Miniconjou, Yanktonai, Hunkpapa, Blackfeet, Cuthead, Two Kettle, Sans Arcs, Santee, and Arapaho, article 13 states:

The United States hereby agrees to furnish annually to the Indians the physician, teacher, carpenter, miller, engineer, farmer, and blacksmiths as herein contemplated, and that such appropriations shall be made from time to time, on the estimates of the Secretary of the Interior, as will be sufficient to employ such person (1868 Treaty).

Such examples indicate that early on the United States government understood the importance of sound health policy while it simultaneously was unwilling to invest in effective health policy in regards to Native peoples.

The administration of Indian affairs moved from the War Department to the Department of the Interior (DOI) in March of 1849. With the move, Congress authorized the expenditure of $12,000 for public health. Yet it wasn't until 1873 that the United States government developed a Division of Education and Medicine in the hopes of centralizing administrative duties and coordinating medical services. Within only four years, in 1877, the medical section of the division was closed due to a lack of funding (Pfefferbaum 1995). Underfunding of health services for Native Americans by the United States government has always been problematic and is a predictor of future health services programs that are often left to the whim of current political debates.

By 1880, the DOI employed seventy-seven physicians to work in Indian country (Taylor 1983). From 1880 until the Synder Act of 1921 the U.S. policy on Indian health moved increasingly to approaches based on public health models
of disease prevention and health promotion. The Public Health Model is one that seeks to target populations rather than individuals. Public Health is one of the efforts organized by society to protect, promote, and restore the peoples’ health (Last 2001). Public Health’s functions are to monitor health status to identify community health problems; diagnose and investigate health problems and health hazards in the community; and inform, educate, and empower people about health issues. This is seen in the many sanitation education programs found on various reservations during this time. Robert Valentine, Commissioner of Indian Affairs in 1910, emphasized three goals for Indian health: 1) aggressive attack on trachoma and tuberculosis, 2) health education with an emphasis on sanitation and, 3) attention to the physical welfare of children in schools (Taylor 1983). Emphasis on the spread of infectious diseases such as tuberculosis was the main goal of public health policy during the early part of the nineteen hundreds. Such goals, while laudable, often fall short due in part to a lack of funding and the workforce to carry it out.

Anglo-Americans concerned with the possibility of tuberculosis moving into white populations living near reservations, pressed for an aggressive public health approach. Yet physicians of the time debated whether Indians were “susceptible” to such health training (Chesley 1924). The question of susceptibility centered on whether Native Americans were civilized enough to embrace health education. During this time, Anglo-Americans believed that the solution to the “Indian problem” was to teach them the ways of civilization. To
this end, in a 1932 article J.G. McCaskell argued that it is only through the implementation of a social hygiene program that Native Americans will move into modern U.S. society (1932:438-446). Bureaucrats linked hygiene and civilization or lack thereof to Native Americans as an essentialized aspect of a primitive lifestyle while ignoring the living conditions of most Indians on reservations.

From the beginning, funding for Indian Health Services was discretionary rather than an entitlement program. In 1921 the Congress, with the Synder Act, gave authorization for Indian Health Services. Funding for IHS was at the discretion of congress and, as a result, IHS policy was largely dependent on funding levels. The Synder Act is considered the beginning of modern United States Indian health policy. With the act, the United States government gave formal authorization for Indian Health Services. The act authorized the regular appropriations for the “relief of distress and conservation of health” (Public Law 67-85).

The Bureau of Indian Affairs shall expend such moneys as the congress from time to time appropriate… for the benefit, care and assistance of Indians throughout the United States.

As discretionary, funding for Indian Health Services has from the onset been subject to budget negotiations. As such, developing policy has always been subject to the political climate of the time. From the beginning, there was a lack of clarity regarding who qualified to receive these funds. The ambiguity of who qualified as "Indian" served to limit services to certain Indians on reservation land and those residing off reservation land (Taylor 1983). From the late 1880s
through the 1930s, Native American health was greatly impacted not only by the conditions found on reservations but also by the lack of funding and the paternalistic view held by Anglo-Americans.

In 1940 Dr. Elliott Joslin, in a paper titled “The Universality of Diabetes: A Survey of the Diabetic Morbidity in Arizona,” examined morbidity and mortality rates in Arizona during 1937. At the time, it was believed that Arizona had one of the country’s lowest reported rates of diabetes as a result of the state’s large Native American population. After an examination of death certificates and a survey of reported cases of diabetes, Joslin suggested that Native American death certificates were often inaccurate, and that, in fact, Native Americans had rates similar to the general population. He concluded:

A diabetic survey in Arizona supports the thesis that diabetes is universal and conforms to the rule that the incidence of diabetes is highest where: 1) the average age is the greatest, 2) women predominate, 3) obesity is most frequent, 4) the proportion of Jews is greatest, 5) medical supervision is closest and 6) deaths are most accurately reported (Joslin 1940:2038).

Like Joslin, Robert Lincoln Smith in 1957 called attention to the low rates of cancer and diabetes deaths in the Navajo. He believed that poor recordkeeping of cause of death on death certificates was not enough to explain the low rates. Smith concluded that, based on the mortality records, cancer and diabetes were less common in the Navajo than in other populations (1957).

Yet, from the Annual Report of the Commissioner of Indian Affairs to the Secretary of the Interior, through early reports from Indian Health to the U.S. Department of Health, Education, and Welfare from 1940 through the early
1960s, there is no indication given that Native Americans suffered from diabetes, let alone that there was a rapid increase in cases of the disease.

**The Meriam Report and its Influence on the Future of Indian Health Policy**

By the 1920s the deplorable living conditions on many reservations had caused concern from the general public. Concern for Native Americans created the political will and in 1926 Lewis Meriam was asked by the Institute of Government Research (today known as the Brookings Institution) to lead a survey team to investigate the Indian Administration. In 1928, their findings were released in a report titled “The Problem with Indian Administration,” more commonly known as, “The Meriam Report.” The Meriam Report used both narrative and statistical analysis to critically examine the Department of Interior’s implementation of the Dawes Act and, more broadly, the conditions on reservations and in boarding schools.

The Dawes Act, also known as the General Allotment Act, served to break up reservations by granting land allotments to individual Native Americans. Proponents of the policy viewed Indian life and the collective use of land to be backwards and antithetical to the capitalist idea of individual ownership and private property as an essential element of civilization. They believed breaking up tribal lands would foster such desires in Native Americans. Furthermore, there was the idea that Native Americans had too much land, and proponents were eager to see Indian lands opened up for settlement, as well as for railroads, mining and other industries. The act provided 160 acres of farmland or 320
acres of grazing land to each head of household. Remaining lands were declared “surplus” and opened up to Anglo-Americans. Prior to the General Allotment Act, nearly 150 million acres remained in tribal hands, but within twenty years, two-thirds of that land was gone; nearly 90 million acres were lost. No other document has influenced U.S. Indian health policy more. In regard to health care on reservations, the report pointed to the near lack of public health service, the shortage of personnel, poor salaries, and poor recordkeeping, as well as a lack of funding and policy for the poor health of Native Americans. The report provided a guideline for future health promotion on reservation land.

Field matrons had been working on reservations since 1892. Under the direction of Thomas Morgan, Commissioner of Indian Affairs, field matrons were commissioned “in order that Indian women may be influenced in their home life and duties, and may have done for them in their sphere what farmers and mechanics are supposed to do for Indian men in their sphere” (Morgan 1900, 101). Matrons’ duties were primarily to teach Native American women Anglo-American ideals of the “domestic arts” and religious education. As the report noted, “their duties, as outlined from time to time have been broad and all-inclusive” (1928, 250). Clearly the aim of all policy prior to the Meriam Report by the United States government was assimilation for Native Americans, with concern for health taking a backseat.
The report also noted that it was not the fault of the matrons but that health training was not required of them by the U.S. government (50). The report states,

In view of the instances observed, it is believed that if a similar service could have been substituted years ago in place of the field matron service, the health situation among Indians would be far different today (1928, 248).

While the Meriam report laid out many suggestions for changes within the Indian Service Administration, there are a few that are of importance to this discussion. Recommendations included the hiring of more qualified physicians and public health nurses with a salary increase that could compete with salaries of those in private practice. Importantly, the author noted that there had been a grave lack of preventive programs and that the health service had been merely palliative in practice (with the exception of the smallpox vaccination campaign). Palliative care is treatment intended to reduce the severity of symptoms or improve the quality of a patient's life, but it does not serve to halt or cure a disease. Along with an increase in physicians and public health nurses, the report stressed the need for epidemiologists, and an increased need for accurate vital statistics in the hopes of effectively planning or directing future health programs (260). The importance of keeping accurate vital statistics and records was stressed at several points in the report.
Wide variations are found between morbidity and mortality statistics obtained at the reservation and those at the Indian Office in Washington. According to the report,

\[
\text{The Office has depended too much upon the initiative and interest of its field personnel, not recognizing that such personnel were not selected for fitness in the technical field of statistics, and has not itself demanded and used accurate original basic records (266).}
\]

The authors believed that this problem could be alleviated by developing better forms, with precise instructions, and better checking of records (1928, 267). According to the author, such forms would allow for better analysis of existing facts of disease incidence in Native Americans. For the author, the lack of “good” forms and the lack of good recordkeeping by physicians were seen as an important factor in the high rates of disease among Native Americans. As an example of poor recordkeeping the author noted,

\[
\text{At one agency, a list of thirty-six deaths was examined regarding which the physician admitted that he knew one-third were incorrect. He had made no effort to rectify the errors. The annual report on disease at this agency was admittedly compiled at the close of the year by paging through Osler’s Practice of Medicine, and tabulating largely from memory the number of cases of this or that illness seen. Colds and influenza were expected (Meriam 1928, 269).}
\]

Diseases that were expected to be found were the ones that were recorded. Beliefs of disease causation could lead to expected diseases listed. This is not to say that those diseases not listed were not in fact present; rather, one can expect that new disease would be invisible in those populations.

While healthcare was still underfunded and lacked adequate staff, the Meriam Report served as a road map for future work in Indian Country.
Consequently, preventive medicine and public health service is adopted with an emphasis on the prevention of three diseases: tuberculosis, trachoma, and diseases of infancy. The Public Health Model is one that seeks to target populations rather than individuals. Public Health is one of the efforts organized by society to protect, promote, and restore the peoples’ health (Last 2001). An important outcome that resulted from the Meriam Report is the monthly report that field nurses filed changed. An examination of the form indicates that changes were made in accordance with the recommendations of the report.

With the implementation of the Meriam report, interpretation and implementation of U.S. government Indian health policy lands squarely on the backs of physicians and nurses. None felt the burden as much as field nurses who often worked alone and were responsible for implementing health policy and health education on reservation land. For example, in southern California, the agency physician was stationed in San Bernardino nearly forty-five miles away from tribal communities in San Diego County. With the closest physician so far away, it was up the local field nurse to address health issues in San Diego County.

In response to the Meriam report, new documents were institutionalized in the hopes of better recordkeeping, and were designed to address the concerns made within the report. Field nurses were now required to fill out a monthly report that included a form of how their time was spent over the month and a short narrative. These documents were made in triplicate and sent to the
superintendent, and a copy was then sent on to the Commissioner of Indian Affairs.

In this sense, the “document was an idea committed to material form such that it could be used—it could become a technology of its own” (Riles 2006, 28). While these forms were routine and important, such trained practices and the documentary forms they demanded were moments of participation in the complex institutional processes that examined epidemiological evidence. If you look at the form area marked “analysis of visits,” the only diseases listed are tuberculosis, trachoma, and diseases of infancy. These forms in fact tracked particular types of disease. They suffered from the same fundamental critique mentioned in the Meriam Report in the fact that they lacked an epidemiological component. There is no real evidence that the forms provided any better statistical information. In essence, they served to track the infectious disease that was expected but not to track new disease or rising disease rates. These were at the time the most common diseases reported on reservations.

**Field Nurse Reports**

Below are two examples of field nurse monthly reports to Indian Health Service. The two I have chosen to use as examples are taken from the same Pima agency of Arizona. The Meriam report suggested that forms were important in tracking morbidity and useful in future analysis of disease rates among Native Americans. These forms are interesting because they give an indication of what was considered important enough to track. What kinds of
information were bureaucrats interested in and believed important? Several things are striking about the forms. The forms give the reader a glimpse into the daily life of field nurses. As you can see, the forms have space for description of communicable diseases seen, and the nurses created lists of types of infectious diseases treated. From tuberculosis to impetigo, each report is detailed with a list the nurse created of infectious diseases. In the 1934 report filed by Nurse Sturges, the form is broken into several boxes that include: Analysis of Visits, Immunization work; Analysis of time, Census of cases, Analysis of New Cases; Analysis of Dismissed Cases; Callers at Office; Clinics, Doctor in attendance; Group Health Education; Administrative Work; Social Work Cases; School Visits; Analysis work in Schools; Number of Defects and Corrections Found. In addition to this, it served as a time card for how the nurse’s days were spent, i.e., in the clinic, school, administrative duties, giving immunizations. Several things are striking about the forms. From the reports, we see that field nurses were responsible for not only health prevention, education and travel, but also their job included social work.

Once the form was filled out and the narrative written, copies were sent to the Washington Office, the Superintendent, and the District Medical Director. The forms used here cover a nearly 20-year period. While the forms changed over time, the overall content remained the same. The information recorded is the same in the 1934 form as it is in the 1950 form with its emphasis on infectious disease. Of interest is the morbidity section; while communicable
diseases are broken into types, there is not the same specificity with non-communicable diseases. This form was used from 1928 through 1950, just about the time when Indian Health was moved from the Department of the Interior to the Department of Health and Human Services and the Department of Public Health.
# Field Nurse Report 1934

**A. ANALYSIS OF VISITS**

<table>
<thead>
<tr>
<th>Type</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acute</td>
<td></td>
</tr>
<tr>
<td>a. Medical</td>
<td>142</td>
</tr>
<tr>
<td>b. Surgical</td>
<td>15</td>
</tr>
<tr>
<td>c. Communicable</td>
<td>4</td>
</tr>
<tr>
<td>2. Chronic</td>
<td></td>
</tr>
<tr>
<td>3. Maternity</td>
<td></td>
</tr>
<tr>
<td>a. Prenatal</td>
<td>12</td>
</tr>
<tr>
<td>b. Delivery</td>
<td>1</td>
</tr>
<tr>
<td>c. Postpartum</td>
<td>9</td>
</tr>
<tr>
<td>d. Newborn</td>
<td>1</td>
</tr>
<tr>
<td>4. Welfare</td>
<td></td>
</tr>
<tr>
<td>a. Infant (under 1 yr.)</td>
<td>5</td>
</tr>
<tr>
<td>b. Preschool (1 to 6 yrs)</td>
<td>9</td>
</tr>
<tr>
<td>c. School child (6 to 16)</td>
<td>8</td>
</tr>
<tr>
<td>5. Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>a. School age latent active</td>
<td>27</td>
</tr>
<tr>
<td>b. Adults latent active</td>
<td>7</td>
</tr>
<tr>
<td>6. Eye diseases</td>
<td></td>
</tr>
<tr>
<td>a. Conjunctivitis</td>
<td>4</td>
</tr>
<tr>
<td>b. Ulcers</td>
<td>9</td>
</tr>
<tr>
<td>c. Trachoma</td>
<td>3</td>
</tr>
</tbody>
</table>

**B. VISITS OF INVESTIGATION**

<table>
<thead>
<tr>
<th>Type</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acute</td>
<td></td>
</tr>
<tr>
<td>a. Prenatal</td>
<td>5</td>
</tr>
<tr>
<td>b. Delivery</td>
<td>9</td>
</tr>
<tr>
<td>c. Postpartum</td>
<td></td>
</tr>
<tr>
<td>d. Newborn</td>
<td>8</td>
</tr>
<tr>
<td>4. Welfare</td>
<td></td>
</tr>
<tr>
<td>a. Infant (under 1 yr.)</td>
<td>5</td>
</tr>
<tr>
<td>b. Preschool</td>
<td>9</td>
</tr>
<tr>
<td>c. School child</td>
<td>3</td>
</tr>
<tr>
<td>5. Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>a. School age latent active</td>
<td>27</td>
</tr>
<tr>
<td>b. Adults latent active</td>
<td>7</td>
</tr>
<tr>
<td>6. Eye diseases</td>
<td></td>
</tr>
<tr>
<td>a. Conjunctivitis</td>
<td>4</td>
</tr>
<tr>
<td>b. Ulcers</td>
<td>9</td>
</tr>
<tr>
<td>c. Trachoma</td>
<td>3</td>
</tr>
</tbody>
</table>

**C. IMMUNIZATION WORK**

<table>
<thead>
<tr>
<th>Type</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acute</td>
<td></td>
</tr>
<tr>
<td>a. Smallpox vac's nurse asstng.</td>
<td>102</td>
</tr>
<tr>
<td>b. No. Schick tests nurse asstng</td>
<td></td>
</tr>
<tr>
<td>3. No. toxin antitoxin given</td>
<td></td>
</tr>
<tr>
<td>4. No. typhoid vaccine given</td>
<td></td>
</tr>
</tbody>
</table>

**D. CENSUS OF CASES**

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Brought forward</td>
<td></td>
</tr>
<tr>
<td>2. New cases</td>
<td></td>
</tr>
<tr>
<td>3. Readmitted cases</td>
<td></td>
</tr>
<tr>
<td>4. Total</td>
<td></td>
</tr>
<tr>
<td>5. Dismissed</td>
<td></td>
</tr>
<tr>
<td>6. Cases carried over (act)</td>
<td></td>
</tr>
</tbody>
</table>

**E. ANALYSIS OF NEW CASES**

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acute</td>
<td></td>
</tr>
<tr>
<td>a. Medical</td>
<td>4</td>
</tr>
<tr>
<td>b. Surgical</td>
<td>9</td>
</tr>
<tr>
<td>c. Communicable</td>
<td></td>
</tr>
<tr>
<td>2. Chronic</td>
<td></td>
</tr>
<tr>
<td>3. Maternity</td>
<td></td>
</tr>
<tr>
<td>a. Prenatal</td>
<td>15</td>
</tr>
<tr>
<td>b. Delivery</td>
<td>9</td>
</tr>
<tr>
<td>c. Postpartum</td>
<td>8</td>
</tr>
<tr>
<td>d. Newborn</td>
<td>7</td>
</tr>
<tr>
<td>4. Welfare</td>
<td></td>
</tr>
<tr>
<td>a. Infant (under 1 yr.)</td>
<td>102</td>
</tr>
<tr>
<td>b. Preschool</td>
<td>12</td>
</tr>
<tr>
<td>c. School child</td>
<td>1</td>
</tr>
<tr>
<td>5. Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>a. School age latent active</td>
<td>27</td>
</tr>
<tr>
<td>b. Adults latent active</td>
<td>7</td>
</tr>
<tr>
<td>6. Eye diseases</td>
<td></td>
</tr>
<tr>
<td>a. Conjunctivitis</td>
<td>4</td>
</tr>
<tr>
<td>b. Ulcers</td>
<td>9</td>
</tr>
<tr>
<td>c. Trachoma</td>
<td>3</td>
</tr>
</tbody>
</table>

**F. ANALYSIS OF DISMISSED CASES**

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Condition on discharge</td>
<td></td>
</tr>
<tr>
<td>a. Recovered</td>
<td>102</td>
</tr>
<tr>
<td>b. Improved</td>
<td>12</td>
</tr>
<tr>
<td>c. Unimproved</td>
<td>8</td>
</tr>
<tr>
<td>4. Dead</td>
<td>7</td>
</tr>
</tbody>
</table>

(over)
### G. Callers at Office
1. Individuals advised 8
2. Individuals treated 4
3. Medicines dispensed to individuals in field and office **Approx** 100

### H. Clinics, Doctor in attendance

<table>
<thead>
<tr>
<th>Sessions</th>
<th>Total Attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Child Hygiene <strong>Posture</strong></td>
<td>4</td>
</tr>
<tr>
<td>2. Trachoma</td>
<td>12</td>
</tr>
</tbody>
</table>

### I. Group Health Education

<table>
<thead>
<tr>
<th>Sessions</th>
<th>Total Attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Home Nursing Class</td>
<td>1</td>
</tr>
<tr>
<td>2. Nutrition Class</td>
<td></td>
</tr>
<tr>
<td>3. Health Talks to Adults</td>
<td></td>
</tr>
</tbody>
</table>

### J. Administrative Work

<table>
<thead>
<tr>
<th></th>
<th>Now</th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Conferences with doctor, superintendent, teachers</td>
<td>24</td>
<td>1</td>
</tr>
<tr>
<td>2. Meetings attended</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Visits on behalf of general activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Hours office work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Mileage (approx.)</td>
<td><strong>1000</strong></td>
<td>0</td>
</tr>
<tr>
<td>6. Cases for pay doctors</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### K. Social Work Cases

<table>
<thead>
<tr>
<th></th>
<th>Now</th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Emergency relief</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2. Supervision of aged</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Marital difficulties</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>4. Unmarried mothers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Placement of orphans</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>6. Incorrigible girls</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### L. School Visits

<table>
<thead>
<tr>
<th></th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. First visits to classrooms</td>
<td></td>
</tr>
<tr>
<td>2. Re-visits to classrooms</td>
<td></td>
</tr>
<tr>
<td>3. Other visits to schools</td>
<td></td>
</tr>
</tbody>
</table>

### M. Analysis Work in Schools

<table>
<thead>
<tr>
<th></th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No. Classroom inspections</td>
<td></td>
</tr>
<tr>
<td>2. No. Children examined by doctor, nurse assisting</td>
<td></td>
</tr>
<tr>
<td>3. No. Children given full inspection by nurse</td>
<td></td>
</tr>
<tr>
<td>4. No. Children partially inspected by nurse</td>
<td></td>
</tr>
<tr>
<td>5. No. Children with defects</td>
<td></td>
</tr>
<tr>
<td>6. No. Children who have had defects corrected</td>
<td></td>
</tr>
<tr>
<td>7. No. Children excluded</td>
<td></td>
</tr>
<tr>
<td>a. Symptoms of communicable diseases</td>
<td></td>
</tr>
<tr>
<td>b. Other reasons</td>
<td></td>
</tr>
<tr>
<td>8. No. Children given treatment</td>
<td></td>
</tr>
<tr>
<td>9. No. Sanitary inspections</td>
<td></td>
</tr>
<tr>
<td>10. No. Classroom talks</td>
<td></td>
</tr>
</tbody>
</table>

### N. Defects and Corrections Found

<table>
<thead>
<tr>
<th></th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Vision</td>
<td></td>
</tr>
<tr>
<td>2. Eyes</td>
<td><strong>2 op. 4 exams</strong></td>
</tr>
<tr>
<td>3. Ears</td>
<td></td>
</tr>
<tr>
<td>4. Hearing</td>
<td></td>
</tr>
<tr>
<td>5. Teeth</td>
<td></td>
</tr>
<tr>
<td>6. Nasal passages</td>
<td></td>
</tr>
<tr>
<td>7. Throat</td>
<td></td>
</tr>
<tr>
<td>8. Skin</td>
<td></td>
</tr>
<tr>
<td>9. Lymph nodes</td>
<td></td>
</tr>
<tr>
<td>10. Deformities</td>
<td></td>
</tr>
<tr>
<td>11. Posture</td>
<td></td>
</tr>
<tr>
<td>12. Nervous symptoms</td>
<td></td>
</tr>
<tr>
<td>13. % of children with defects</td>
<td></td>
</tr>
<tr>
<td>14. % overweight</td>
<td></td>
</tr>
</tbody>
</table>

This report is to be made in triplicate at the close of each month. One copy to be retained by the nurse, others to be sent to the superintendent, who will forward the original to the Commissioner of Indian Affairs.

Write also a short narrative report of progress of work to be sent to the Commissioner of Indian Affairs with statistical sheet. Describe new projects undertaken, new contacts made, trips, conferences with other health workers, steps taken to promote activities and development of work.

**Date** July 15, 1934

---

*Image 2b: Field Nurse Report 1934*
NARRATIVE REPORT FOR MONTH OF JUNE 1934

Twelve tonsillectomies were performed by Dr. Eilers on my school children. Four eye cases were seen by Dr. Eilers and put under treatment.

A year ago I tried to persuade a primula to come to the hospital for delivery. She would not consent. She had a difficult delivery and a dead baby. In less than three months later she again became pregnant. It took no persuasion to bring her to the clinic for pre-natal visits, or to the hospital for delivery. After a long labor she delivered and both she and the baby are alright.

Another multipara who I brought in about fourteen months ago threatened with uremic convulsions and who delivered safely with a healthy baby came in the other night with heart complications due to a sudden uremic onset. After a week under a rigid diet and medication she again delivered safely with an apparently normal baby.

For the month of June I have started a posture class with the school children of Blackwater. No children from families known to have tuberculosis were eligible. Corrective exercises were given for individual posture defects. The children were not only interested but several mothers and one father attended class to see what it was all about. The parents were interested and thought the exercises were alright.

A seven year old child died of tuberculosis in Upper Santan last week. It was necessary to give him two hypodermics of Morph Sulph gr 1/8 daily to relieve pain. Dr. Parlett saw him and ordered for him. We kept him outside to safeguard as much as possible the three remaining children.

We have asked the school children to report bi-monthly to our clinics for weight and temperature check-ups. Those under routine treatment in school for trachoma are asked to report weekly for eye inspection and new medication.

I am retyping and revising all my records this and next month.

Respectfully submitted,

Gertrude Sturges
Field Nurse
Pima Agency
Sahaton, Arizona.
# Field Nurse Monthly Report 1950

**Agency:** Pima Indian  
**District:** Casa Blanca-Saguaro  
**Month:** May  
**Year:** 1950

## Analysis of Visits and Admissions

<table>
<thead>
<tr>
<th>Code</th>
<th>Line No.</th>
<th>A. Field Visits</th>
<th>B. Visits to Nurse’s Office</th>
<th>C. Admissions, Field and Office</th>
</tr>
</thead>
</table>

### (a) Morbidity:
1. Noncommunicable
2. Crippled children
3. Communicable
4. Tuberculosis
5. Trachoma
6. Other communicable eye conditions
7. V. D. Lesus
8. V. D. G. C.
9. V. D. Other
10. Other communicable diseases

<table>
<thead>
<tr>
<th>Code</th>
<th>Line No.</th>
<th>A. Field Visits</th>
<th>B. Visits to Nurse’s Office</th>
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### (b) Maternity:
12. Antepartum
13. Delivery
14. Postpartum

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### (c) Health supervision:
15. Infants
16. Preschool
17. School
18. Adults

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### (d) Investigation, promotion:
19. Special projects: **Flying Incidence** (12)
20. Informative
21. Unresultant
22. Sanitation

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### Totals: Nursing Service

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### Social work cases:
24. Patients medically treated by nurse

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### Relief dispensed:
25. Patients medically treated by nurse

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### Miscellaneous:
26. Patients medically treated by nurse

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### Notes:

* (a) Agency doctor;
* General;
* School;
* Other:
* Flying Incidence;
* Eye;
* Dental;
* Tuberculosis;

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*Image 4: Field Nurse Report 1950*
Image4b: Field Nurse Report 1950
The fly poster contest finished on the last day of school. Two first prizes were awarded to the two third and fourth grades of the Pima Central and Casa Blanca schools, second prize went to the Hayes boy of the St. Peter's Mission school and two third prizes were awarded to two children at the Santez school. One of these was a first grader whose poster was excellent considering his age and experience. The posters were put up in the hospital for Hospital Day and then moved to the school dining room for Fiesta Day where all the parents and children as well as employees could view them. There were some excellent posters. The most interesting and enthusiastic age group seemed to be the 3rd, 4th and 5th grades. One 5th grade group requested the nurse talk with them about the placing of the home privy and the water supply. They were surprisingly interested and alert to the problems around the home. Talks were given in each room that had participated in the poster contest and to the group in which the prize winners were.

Each school held a day for parents and children who enter school next Fall. The PHN was asked to meet with these parents and talk with them about the children, immunizations and because most of these parents have small babies and preschoolers at home, fly eradication and diarrea control was stressed.

The Tribal Council Health Committee is aware of the work of the PHN and interested although not too articulate. Individually these people come to the PHN and discuss problems, but no further meetings have been called. Strongly enough, they report cases to the Welfare worker rather than to the PHN directly, perhaps because they have functioned as a Welfare Committee for a longer time.

The Catholic Priest in the community came to the PHN and asked if she could get a child into the Shriner's hospital or clinic for spastic cases. He had heard there was a special spastic clinic being held in Phoenix and he wanted to get a child under speech training. This is a known spastic case who has been under care of the orthopedic clinic in Phoenix. After considerable searching, it was learned that there is a new clinic for these spastic children being held in Phoenix but it is under the supervision of the regular Crippled Children's Hospital. Appointments were given for this case and a new child and both are now under the care of Dr. Hartzman at the clinic.

The facilities for speech training are very limited and the boy would have to live in Phoenix and be transported to the speech clinic 3 or 4 a week which at this time is not possible. Instructions for physio-therapy were given to the parents of these children and the PHN will supervise the home treatments with the children returning for medical supervision to the clinic. This same procedure has been followed for the orthopedic cases but with surgery being done at the Phoenix Indian Hospital by the Contract Physician or rather orthopedic surgeon.

With school out and fewer interruptions, it is hoped the time can be found to get the records in order and other office work caught up in anticipation of a new program of MGH clinics with the hoped for arrival of the new physician. So many requests have come from mothers for MGH clinics that it will be most gratifying to be able to again offer this service to them.

Glady's D. McFadden
Public Health Nurse
Even the simplest of forms speaks to multiple audiences and is produced by multiple hands, often with quite different interests and concerns at play. This is important if we remember the recommendations of the Merriam Report and its call for better records keeping. “No systematic effort was made at this time to report morbidity. In a few instances the acute infectious diseases have been reported to the state health officers. Such reports, however, are rare. No epidemiological case record has generally been kept of infectious and contagious diseases, although possibly this may be done in some school or hospital” (Meriam 1928, 270). The forms were meant to address the Meriam critique regarding a lack of rigorous statistical records keeping.

Over time the form changed in style but not in basic information gathered. The forms include space for diseases commonly found on reservations at that time; nowhere is there space for emerging health issues. The form could only be useful to measure expected disease morbidity.

The narratives shown are indicative of themes that emerged most often from those narratives examined. These narratives included short discussions of health education classes held; these classes usually centered on sanitation, home nursing classes, and classes for new mothers. Themes also included discussions on new tuberculosis cases, vaccination clinics, and Trachoma clinics. The following example also exemplifies a common concern found in other narratives. In January 1943, Nurse Larson found that clinics were not well attended and that due to the vacancy of a physician there had been no
vaccinations given before the school year had started. In none of the narratives examined is there information on disease incidence of heart disease, cancer or diabetes.
Annual Reports

The Office of Indian Affairs Commissioner was required to write yearly reports to the Secretary of the Interior reviewing the past year and documenting proposed expenditures for the following year. I examined the years from 1940 to 1961, from Commissioner John Collier through Commissioner Philleo Nash, some 8 commissioners in two decades. In these documents, the Commissioners painted a picture of reservation life from the bureaucratic standpoint. Their writing reveals the political struggle for scarce resources while simultaneously supporting U.S. Indian policy. In all accounts the Commissioners spoke of how far they made their limited resources stretch. In his 1944 report, John Collier wrote,

The growing determination of Indians to do something about their own health problems is especially desirable in view of the critical shortage of health personnel. On January 1 of this year, there were 72 vacancies for full-time physicians, 27 for part-time physicians and 188 for nurses (249).

With such limited resources it is not hard to imagine that physicians and nurses could only address the most dire health concerns.

In 1948, Commissioner William Zimmerman discussed the change in health focus from a curative to preventative model. Describing the role of field health services, Zimmerman said, “Field health services consisting mainly of communicable disease control, school health activities, trachoma control and public health nursing were continued in approximately 60 locations in the States and 20 in Alaska” (1948:386). A year later with a new commissioner, the political
Commissioner Nichols in writing about the cost of the Indian “problem” stated,

Problems of human adjustment do not solve themselves, not when the people seeking to make the adjustment are hampered by lack of education, poor health, and deficient resources. The expenditures which have been made over the years in behalf of our Indian people were not based on any long-term plan for the orderly solving of the problems they faced. Rather, the record indicates that these expenditures and the physical effort released by them have been sporadic, discontinuous and generally insufficient. This record explains why today many Indian children of school age have no schoolrooms and no teachers to provide for their education; why many Indians are still without any kind of health care; why thousands of Indians are without any means of livelihood, either in the form of productive resources or marketable skills; why irrigable lands owned by Indians lie undeveloped in the arid West; why countless Indian communities are without roads on which to take to school, to hospital, or to market (1949:340).

Commissioner Nichols recognized the band-aid approach that had been used to address the Indian “problem” up to that point, but the political tide had become interested in getting out of the Indian business.

**A Change of Heart**

By the end of the 1930s, political sentiment for Native Americans had shifted from previous administrations. After World War II, termination became the focus of the United States government. The thrust of termination was to eliminate reservations and to turn Indian affairs over to the states. Indians would become subject to state control without any federal support or restrictions. While termination didn’t become law until 1953, there had always been those who pushed for an end to the federal government’s relationship with Native nations (Wilkinson and Briggs 1977).
In 1946, the Legislative Reorganization Act abolished both the House and Senate Committees on Indian Affairs. Indian oversight and jurisdiction was then moved to subcommittees of the Interior and Insular Affairs committees of the House of Representatives and the Senate where they remained for the next twenty years. This coincides with the U.S. government’s move towards termination.

**Termination and Governmentality**

In 1950 Dillon Myer, the former director in charge of Japanese-American detention camps during World War II, became the new Commissioner of the Bureau of Indian Affairs. Under his leadership, the BIA aggressively pursued the government’s termination policy, and in 1953 Public Law 280 was passed.

Termination policy effectively terminated federal trust protection of Native American Reservation lands. Termination policies brought contention to many Native communities with some members seeing termination as a path to self-determination while others saw it as the elimination of tribal governments and cultures (Daly 2009). PL 280 authorized the transfer of legal authority from the federal government to state governments. Native Americans would become subject to state control without federal support or restrictions. Special federal health, education and general assistance programs for Native Americans would end (Wilkinson and Biggs 1977, 153). From 1953 to 1964, 109 tribes were terminated.
While termination policy didn’t become law until 1953, Native Americans began to feel its effects long before. Prior to World War II, the government had built and staffed six Indian hospitals in California with a total capacity of 164 beds (Costillo 1978). As the government began to withdraw, Native communities often suffered; for example, in 1949 the Soboba Indian Hospital in southern California was closed, leaving only one such Indian hospital in the state (Ryan 2005). The State of California has one of the largest Native American populations in the United States with 104 federally recognized tribes—not including the many tribes that were terminated or are currently seeking federal recognition. The closure of Soboba Indian Hospital meant that southern California Indians had to seek health services from the state. Many California Indians reported being turned away from county hospitals (Costillo 1978).

The termination era brought a comprehensive program of interweaving individual termination of tribes with many new congressional acts and BIA policies. One such congressional act came in 1954 by the Transfer Act which moved responsibility for the provision of health services from the Department of the Interior (DOI) to the Public Health Service through the Bureau of Indian Affairs. The Transfer Act represented a major change in U.S. Indian health policy. PHS under the Surgeon General found itself overseeing all health facilities, programs, and responsibilities previously maintained by the Commissioner of Indian Affairs (Thierry et al. 2009). The transfer was opposed by the DOI and the Department of Health, Education and Welfare.
As a result of the Transfer Act, there was an increase in appropriations dedicated to Indian health and an additional one hundred doctors in Indian country (Zimmerman 1957). Yet arguments continued regarding health care for Native Americans. In January of 1957, the office of Public Health commented in a letter, “No Indian, either on the reservation or off, has a legal entitlement to medical service under the Indian Health Program” (Zimmerman 1957:37). Zimmerman suggested that if health care for Native Americans were given as an act of “grace,” there surely would be problems in the future (38). In the same year, 10,000 Native Americans were relocated off reservation homelands to cities. Health care that had been negotiated in treaty rights and substantiated in court cases and by executive order was now being questioned. Termination policy and the withdrawal of health services for California Indians served to further exacerbate deteriorate poor health conditions. For California Indians the result was a devastating lack of health care facilities and access to care. It was responsible for a life expectancy in 1965 of 42 years, in comparison to the 62 years for the general population (California State Advisory Commission On Indian Affairs 1966).

During the period of termination, one act impacted how Indian health would look in the future. The Indian Sanitation Facilities Construction Act of 1959 provided for safe water and sewage disposal. This act is important to understanding Native American health policy in that it was the first act to require the consultation and participation of tribes, states and other interested parties in
carrying out the provisions of the act (Thierry et al. 2009). This had important implications for future health policy in that Indian Health Service would not begin local programs until it had received a request from the tribe. As a result, tribes now had a place at the table and began to build partnerships with Indian Health Services.

In developing its program for improving the health outcomes of Indian people, the Public Health Service felt a need to develop a publication that gave basic health information on the health status of each regional area under its jurisdiction. In 1960, James R. Shaw, M.D. Assistant Surgeon General Chief, Division of Indian Health, wrote,

The Division of Indian Health has had a constantly recurring need for general summary information on the various Indian reservation groups which come under its jurisdiction. Moreover, other governmental as well as non-governmental agencies have had an increasing need for similar information. Unfortunately, no one source has been able to provide, briefly and simply, the variety of facts required (iii).

The hope was that it would provide basic health information for program development to meet health needs and could be used in recruiting workers for the IHS program. The Digest was not intended as a comprehensive study but as fact sheets for easy reference. In 1961, the Indian Health Digest, as it came to be called, focused on the Phoenix Region, which included groups in Arizona, California, Nevada and Utah. The Digest served not only as an educational resource for those working in Indian Country, but also as a source to educate public health personal on changing health policy. As the publication states,
In developing its program for improving the health of the Indian people, and in planning for the most effective use of available resources (Federal, State, and local), the Public Health Service has a need for basic facts concerning the reservation groups which, for health purposes, are under its jurisdiction. This series of “Digests” of information from a wide variety of sources has been prepared in an effort to meet this need. Separate “Digests” cover the reservation areas in each of the Public Health Service Indian Health jurisdictions (PHS 1961, ix).

In this region, health services were available in varying degrees for 53,000 Indian people at the Public Health Service Indian Health Area Office in Phoenix, Arizona.

In the State of California nearly 9000 Indians scattered in small numbers in Rancherias and on a few reservations, have varying relationships with the federal government. According to the information, California Native nations’ relationship with the federal government was in the process of conversion. Many were receiving services through local programs and local resources, while others remained beneficiaries of federal Indian programs. The variation in the status of federal trusteeship relations and the litigation of termination affected a number of these groups (PHS 1961, ix).

The actual number of enrolled California Indians in 1959 was 36,000, much greater than the 9000 sited in the report. According to the Digest, contracts to provide health care for Indian people in California from state and local health departments were limited, leaving “Indian citizens” to be served in larger and larger numbers through local programs available to all citizens of the state (PHS 1961, xv). In 1951, Attorney General of California Jerry Brown held
that “a county has the same right, duty and jurisdiction to provide indigent relief to Indians, even if residency is on reservation, as to provide such relief for other citizens resident in the county under Welfare and Institutions Code, Section 200 and Section 25000” (cited in California’s Health 1962, 73). A survey of counties in California conducted by the California State Department of Public Health in the summer of 1960 examined the extent of use by Native Americans of public health and medical resources in the ten California counties then contracting with the State Department of Public Health for services. It found that Native Americans used these services at the same rate as non-Indians (CDPH 1962, 73-76).

During this time, Indian Health Services operated two facilities in California: a small hospital of 16 beds in Winterhaven in Imperial County, and a larger hospital at Hoopa in Humboldt County.

The Digest while stating the health status of groups in these regions, gave no indication that diabetes was on the rise. Basing its information on the data collected from field nurse records, the publication listed influenza, pneumonia, accidents, and diseases of the heart as the most common health problems on reservations during this time. An examination of each of the Digests produced by the Public Health Service indicates that pneumonia and influenza were considered the overwhelming health problems in all areas of Indian country except Alaska and New Mexico. There is no mention of diabetes rates nor is there a recorded occurrence of diabetes in any of the reports. Yet, in 1962 James Neel’s article linking genes to diabetes was published. Evidence would
suggest that bio-medical researchers were aware of the increasing rates of diabetes since at least 1940 in Native American communities, yet policy makers and the public health department were not.

There were many factors that contributed to poor health outcomes for Native Americans such as underfunding, shortages of clinicians, poor records management and an uninformed health policy. Such benign neglect impacted the health outcomes of Native Americans. Public health nurses working as field nurses for Indian Health Service more than any other group were charged with putting U.S. Indian health policy into practice. To this end, field nurses followed policy and when they tried to move into areas that were not part of that policy they were often admonished by administrators. For example, Cliff Trafzer wrote of field nurse Florence McClintock who, while stationed at Morongo during the depression, asked the Office of Indian Affairs for funds for “a small amount of clothing to use in emergencies.” The response from Indian Affairs was “the purpose of the nurses is not to give aid but medical advising. It seems [at this] time to be inadvisable to confuse that purpose” (as cited in Trafzer 2009:127).

While it has been argued that the era of termination was actually beneficial and led to an increase in participation of Indians in future health policy decisions, I would argue that the era of termination created an atmosphere in which diabetes rates rose and early prevention strategies were not implemented. The anthropologist’s role is not just to expose these inequalities but to take the next step, to inform policy, as Castro, Singer and Horton have called for
Chapter 4

I first heard of a gene probably... oh, I don’t know about 12 to 15 years ago. I don’t remember all of it but I know I had been sick and seeing a doctor. When I talked to my doctor, he asked questions. He asked if I was Native American and I said, “Yes.” He asked from what area because some in the southwest have a high rate of gallstones and diabetes. I don’t know if it was when he told me I had diabetes or later but umm... I remember he said something about a gene that helped people when there was little food but was not helpful now that there is lots of food umm... it was something like that. I remember later kinda laughing to myself thinking about how I would tease my mom for giving me all the bad genes; you know... a thrifty gene,... sounds funny (Linda,2008).

Introduction

In the previous chapter, I argued that through benign neglect and the construction of Native American people as “primitive” in need of the civilizing project of Anglo-Americans, the rise of diabetes in Native communities was in fact made in invisible. In this chapter, I focus on how diabetes, once thought of as a disease of civilization and affluence, became a Native American disease. I argue that the narrative of the “thrifty” gene with its emphasis on a “primitive” maladaptation to modern conditions of living in effect creates a space wherein diabetes, once viewed as a disease of affluent, civilized society, could now be viewed as disease from which “primitive,” “uncivilized” populations suffered.

In this chapter, I trace the racialized discourse of diabetes through Neel’s narrative of the “thrifty” gene. By examining peer-reviewed articles from the early twentieth century, and through the use of a citation map, I argue that Neel’s narrative becomes a common narrative to explain diabetes (and other chronic
diseases) in terms of genes and race over the last 50 years. In focusing on race in genetics and medicine, Troy Duster argued, “It is not genetic evidence that drives the engine of scientific inquiry, but the social concerns that drives the engine of the scientific attempt to portray and explain these social concerns genetically” (1996:123). By viewing the “thrifty” gene hypothesis as a historical and cultural construct of genetic epidemiology, race becomes a biological entity and independent risk factor that becomes reified through repetitive studies and repeated telling. Within this narrative we see frequent studies of a disease that do not take into account history, culture or socio-economic status (Poudrier 2007).

**Race, Populations and Disease**

The conception of race has a long history in western society. Early ideas of race viewed racial categories as biological subdivisions that linked behavioral and physical characteristics. Race in this view was thought to represent a natural category with features that defined that category. The idea of a correlation between racial categories and incidence of disease has also had a long history. Such racial categories were used in the early twentieth century as a risk factor for disease. This is not to argue that there are not certain diseases that are more common in specific populations but rather to argue that certain traits were essentailized in certain populations that made them immune from certain disease or disposed to others.
Anthropologists have argued that race is not based in biology but rather it is a social construct. Franz Boas and his students challenged popularized ideas of a biological base for race during the 1930s and 1940s. The presupposition that race was a natural structure of the human species had been viewed critically for decades. During this time, race and how it was used changed.

Into the 1920s, race was considered an essential property of the body (Marks 2012). With the rise of population genetics a reconceptualization of race “as no longer something a part of the individual but now the individual is a part of” becomes a common discourse among many scientists. Through race studies, eugenics, molecular genetics, post-colonialism and corporate genomics, physical anthropology and human population genetics have been linked and have evolved over the past century (Marks 2012). The evolutionary synthesis that occurred during the late 1930s and 1940s marked the modern synthesis regarding how evolution works at the level of populations, genes and phenotypes. While Darwin had been concerned with individuals and organisms, the modern synthesis reflected a consensus about how evolution proceeds. The role of population genetics in bringing this about was important because it showed Mendelian genetics as consistent with natural selection (Mayr and Provine 1981).

As Jenny Reardon demonstrates in, “Decoding Race and Human Difference” the ideology of race biology was replaced with population “as the category that biologists believed most usefully organized their analyses of human
diversity” (2004). These gene pools were in effect for many researchers viewed as isolated breeding populations.

A population in the genetic sense, is not just a group of individuals, but a breeding group; and the genetics of a population is concerned not only with the genetic constitution of the individuals but also with the transmission of the genes from one generation to the next. In the transmission the genotypes of the parents are broken down and a new set of genotypes is constituted in the progeny, from the genes transmitted in the gametes. The genes carried by the population thus have continuity from generation to generation, but the genotypes in which they appear do not. The genetic constitution of a population, referring to the genes it carries, is described by the array of gene frequencies, that is by specification of the alleles present at every locus and the numbers or proportions of the different alleles at each locus (Falconer 1981:8)

Geneticists had clung to the idea of “salvage anthropology,” the view that indigenous people would soon be extinct. This view coupled with discourses of isolation and purity feed into the notion of isolated gene pools (Barker 2004). As Hopi geneticist Frank Dukepoo notes,

My father (a “Hopi”) is a mixture of Hopi, Ute, Paiute, Tewa, and Navajo; my mother, on the other hand (a “Laguna”) is a mixture of Laguna, Acoma, Isleta, Zuni and Spanish. Members of other tribes share similar admixture histories as our ancestors raided, traded or kidnapped to ensure survival of their numbers (1998:242).

For population geneticists, rather than studying the inheritance of traits, the attempt is to describe the frequency of the alleles that control the trait’s change over time. In order to do this, the focus is on populations rather than individuals. While some elements of the race concept were rejected, others remain and influence how the term population is used.
Population geneticists have argued that because they do not know all the genetic variables that would predict evolutionary success, the focus is the variability of different phenotypes and genotypes in order to provide an overview of the populations. Many anthropologists and population geneticists conceived of populations as just another term for race. In this way, they conceptualized populations as isolated from other groups, not as open systems (Caspari 2003). The result is that while the term race is abandoned, population is often thought of in a similar way.

The debate over race represents not the “triumph of truth over ideology”; rather, the debate centers over the “very nature of truth and ideology and of science and society” (Reardon 2004:43). After World War II, the fields of physical anthropology and human genetics had reinvented themselves; the field of molecular anthropology now focused on classification and human evolution. Scientists coming out of the 1950s argued that biological concepts of race did not have inherent or fixed social meaning, which as Reardon points out is very different than saying that race is biological. The legitimacy of the scientific method, it was argued, was that methods over time will reveal truth. “Geneticists did not argue that all concepts of race were biologically meaningless, but only those based on visible physical traits used in society” (Reardon 2004:52). According to Caspari, the concept of race contains three characteristics: essentialism, cladistics thinking and biological determinism. While she argued that much has been written about biological determinism and conceptions of
race, little attention has been paid to essentialism. Essentialism was the view that “a race was thought to represent a natural category with unique features that defined the essence of that category” (Caspari 2003:65). Some of these elements were rejected by physical anthropologists and geneticists but others remained. By the 1970s, Richard Lewontin’s *The Apportionment of Human Diversity*, showed how the concept of race as a biological construct was a myth. His work was important in showing that there was more variation within a population than between populations (1972).

W.S. Pollitzer heralded the work of Neel for his contribution of the idea of a lineal effect. “One head-man, endowed with attributes of leadership may through polygamy contribute a disproportionate share of genes to succeeding generations—a special kind of founder effect” (Pollitzer 1981:485). The idea that genes carried not only phenotypical information but also aspects of behavior had been argued against by geneticists throughout the 1950s. For Neel and scientists of the time to suggest that to be “primitive” meant to be inherently maladaptive was to ignore the political and economic reality of indigenous people over the past 500 years and thus create an inherently diseased native body.

Jonathan Scott Friedlaender and his contemporary James Neel, like early geneticists, saw phenotype as a marker of race.

The idea that phenotype was indicative of genetic variation didn’t change until the 1980s. Much like Neel’s work with Chagnon among the Yanomami, the work of Jonathan Scott Friedlaender and his team on human population variation
of the Pacific Islanders had the stated goal “to relate culture and disease, and vice versa, in a spectrum of societies varying in respect to ethnic background and exposure to western culture (Howells 1987:3). During this time, detailed population histories and the study of the genetic structure of populations included the work of Friedlaender in his study of Bougainville Island, and Neel’s work among the Yanomami in South America. Throughout the long-term study, researchers examined the health status of groups that were more “westernized” than those in the southern region who were considered less acculturated. The belief was that isolated, “primitive” populations’ biology was different from the biology of “civilized” populations.

Friedlaender’s work in the Bougainville Islands documented the barriers to matings, both from distance and from kinship, as indicated in gene frequencies (Pollitzer 1981). The Solomon Islands represented for Friedlaender an ethnically diverse region with localized, isolated populations. Focusing on the geographic area of New Guinea and Island Melanesia, Friedlaender noted that Melanesians in a biological sense could be defined only in the context of comparisons with other Oceanic Peoples (1987). The focus of the project was to relate disease patterns to cultural practices and to see whether population distances and differences is associated with language, culture, and migration. Friedlaender found that groups most acculturated were beginning to see the highest rates of diseases of Westernization. During the 1960s, genetic studies focused on the documentation of local patterns of genetic variation with and among populations.
This was done in order to examine the effects of evolutionary mechanisms that gave rise to the patterns that geneticists were seeing.

Genetic data and what has been inferred from that data has become commonplace today. Genetics has become “big science” through projects such as the Human Genome Project and the Genographic Project, which has resulted in genes becoming part of popular culture (O’Rourke 2003). If genetic research is only interested in the identification of genes, then any environmental factors can be ignored, but if researchers are interested in the interaction of genes and the environment, it becomes much more complicated. Diabetes, like most complex diseases, is likely to have a combination of environmental and genetic factors. For many researchers in the field during the 1960s through the 1970s, the emphasis was on explaining disease rates based on genetic variation, with little focus on environmental, historical or economic factors.

Much of the current science and technology writings have emphasized the rebirth of race as based in biology, believing that, for decades, scientists had moved beyond these racial categories (Marks 1995, 2003, 2012; Koenig, Lee 2008; Reardon 2008). Such ideas persist with a significant amount of research that continues to be committed to the search for genetic variants that might explain health disparities between racial groups. Practitioners of this research believe that race is a good predictor of health outcomes and they have argued that race-specific susceptibilities will lead to increased chances of reducing health disparities.
Nearly three quarters of century before James V. Neel’s “thrifty gene” hypothesis, diabetes narratives were already focused on race and genes. Articles written at the turn of the twentieth century suggest that diabetes was a rare occurrence in African American and Native American populations (Pancoast 1898). By the early nineteen hundreds, physicians and public health officials became increasingly concerned about the rise of diabetes in middle-aged white males. While it was realized this was due in part to people living longer, this was not believed to be the primary reason. During this period, debates about the rise of diabetes centered on rising obesity rates, and the increased consumption of sugar. Increasingly, researchers of the time began to focus on the rates of diabetes among Jewish people.

Influenced by the work of anthropologists writing on cultural evolution, researchers at the turn of the twentieth century held that modern civilization had evolved from earlier primitive cultures. For Euro-Americans, Native Americans represented a snap shot of an earlier stage of cultural evolution. According to anthropologist Lewis Henry Morgan:

The latest investigations respecting the early condition of the human race are tending to the conclusion that mankind commenced their career at the bottom of the scale and worked their way up from savagery to civilization through the slow accumulation of experimental knowledge. As it is undeniable that portions of the human family have existed in a state of savagery, other portions in a state of barbarism, and still other portions in a state of civilization, it seems equally so that these three distinct conditions are connected with each other in a natural as well as necessary sequence of progress (1877:3).
As Jenny Reardon and Kim Tallbear argue that while such ideas are no longer viewed as valid anthropological theory, what has remained is the view that Native Americans and others “represent an earlier period in human evolution and thus can help modern humans understand themselves” (2012:237). Such beliefs were transferred to ideas regarding disease causation that linked disease, genes, and modernity while ignoring the social conditions from which they arose.

Ideas of race at the turn of the twentieth century influenced by the eugenics movement of the time viewed Jewish people as a separate race of people. In 1904, W.H. Thomas, a New York physician, wrote, “There is no race, which is so subject to diabetes as the Jews” (Tuchman, 2011:24). Researchers and physicians believed that increasing rates of diabetes were tied to race and genes in Jewish populations. Diabetes, largely viewed as a disease of civilization and affluence, was, according to researchers of the time, virtually non-existent in African-Americans and Native Americans. Today, African American, Latino and Native American populations have some of the highest rates of diabetes. What changed? How did a disease viewed as a Jewish disease become an Native American disease in the span of sixty years?

Arleen Tuchman traces the discourse of diabetes as a “Jewish Disease” at the turn of the twentieth century. The narrative of diabetes as a “Jewish Disease” began in Europe when a physician noted that a quarter of his diabetes patients were Jewish. Other studies of the time suggested that Jewish people died at a rate as high as six times greater than other populations (Epstein 1919). In
Germany, diabetes was so linked to Jewish people it was known by the name *Judenkrankheit* or “Jewish Disease.”

In the United States, public health officials in New York during the late nineteenth and early twentieth centuries correlated the rising rates of diabetes with the growth in the city’s Jewish population. J.G. Wilson a New York City physician claimed it was “some hereditary defect” that accounted for the rates of diabetes in Jewish populations. Other physicians were left to elaborate on the cause for the rates of diabetes in Jews. Wilson believed the high rates of diabetes as being due to cultural and biological roots (Tuchman 2011). William Osler suggested it was due to a sensitive nervous system. Osler believed it was Jews “racial tendency to corpulence” (Osler 1884).

Narratives of the disease during the early twentieth century viewed it as a “disease of great luxury.” Professor of Preventive Medicine at Columbia’s College of Physicians and Surgeons, Haven Emerson, attributed the rise of diabetes in Jewish Americans to their increased wealth and over indulgence, describing them as

bulging with the money bags of the world, fairly oozing with wealth, eating every day much more than any of our allies or opponents of the war (1924:24).

Diabetes narratives in the early twentieth century centered on racial stereotypes and cultural practices. As Tuchman suggests, the narrative of diabetes in Jews reveals how stereotypes regarding “alleged racial groups can shape the way medical communities define at-risk populations and interventions they pursue”
The idea has by no means been put to rest, and research continues to be committed to the search of genetic variants that may explain health disparities. Evidence of this comes from narratives, like that of physician Everett Lain. In a correspondence to the American Medical Association in 1913, he discussed his research findings based on his work among Native Americans in western Oklahoma. Based on his observations and examinations of skin lesions among five thousand Native Americans, Lain concludes, “The uncivilized Indian apparently is yet free from pellagra and almost immune to cancer” (170). In response to why this may be, Dr. M.L Ravitch suggests, “I think the outdoor life of the Indians keeps them comparatively free from the skin diseases which are more or less prevalent among civilized people” (171). Lain believed that degree of Indian blood gave indications to susceptibility to disease. Hence “fullbloods” were viewed as being less prone to cancers and chronic illness.

Narratives of disease causation in early twentieth century writings indicate that researchers viewed disease etiology as resulting not only from genes and the environment but also from the stresses of civilized verses primitive life. This binary seems to not be based on the environment in which one grows-up but rather in biology and cultural practice. This is reflected in the idea that “fullbloods” were viewed as more “primitive” than “halfbloods.” Isaac Levin’s study of the etiology of cancer is one such example. Levin examined data regarding 4000 patients from several hospitals in New York City. It is important
to note that the breakdown of population based on race is not given in his findings but Levin does note:

The results obtained seemed to warrant the conclusion that while cancer is occasionally met within primitive races, it occurs so seldom among the American Indians for instance, that this race may be considered practically immune against the disease. The conclusion was also reached that this immunity is not due to any purely racial characteristic but to the difference in the environment, the mode of life, the diet and mainly the fact that a primitive race does not suffer from the severe wear and tear of a civilized life (1910:776).

Those who suffered with diabetes or other chronic illnesses were seen as causalities of progress and modernity. Cancer and diabetes as other chronic conditions were considered an affliction of civilized society tied to the stress of living in a “modern” world, and one that resulted from an increase in life expectancy. While this may be so to some extent, clearly the story is much more complicated.

How are views regarding race implicated in the invisibility of diabetes in Native American populations in the early nineteen hundreds? Ideas about race, and inherent characteristics of racialized populations were abundant in research literature of the time. The repercussions of this discourse can be seen in the lack of data on diabetes in Native Americans prior to the late 1950s. Native Americans were viewed by the general public as a vanishing race of people but also as a remnant of an early evolutionary stage whose biology was such that it did not suffer from the negative effects of civilization. It is within this context that
I turn to James Neel and his “thrifty” gene hypothesis and Native American diabetes.

**Native Americans and Neel**

In the introduction to “Indigenous Peoples and Diabetes: Community Empowerment and Wellness,” editors Mariana Ferreira and Gretchen Lang ask, “Why does current research insist on the role of genetic and cultural factors and shift away from the social causes of this devastating ailment?” (2006:4). In attempting to answer this question, I have thus far examined the racialized narrative among researchers at the turn of the twentieth century. I now turn to James Neel’s work and the context within which his “thrifty” gene hypothesis arose.

The beginnings of the genetic discourse for diabetes in Native Americans can be traced to the work of James V. Neel. Neel's “thrifty” gene hypothesis has been widely viewed among researchers as a convenient narrative to explain the high rates of diabetes in Native American communities. The goal here is to describe the development of the discourse for a “thrifty” gene. In this chapter, I lay the groundwork for understanding how populations are created and racialized through scientific discourse, a key process in the historical and contemporary subjugation of Native people. The creation of a “primitive” other whose evolutionary trajectory differs from that of “civilized” populations has ended up precluding direct attention to reducing inequalities in health outcomes and encouraging the idea that healthy outcomes are best pursued through the biology
of race. Used uncritically, these racial categories become naturalized and institutionalized ways of conceptualizing populations, and serves to minimize the role of inequality in achieving health equity. Neel’s thrifty gene hypothesis is an example of how perceived racial difference reduces health to biology and ignores structural inequality that leads to differential health outcomes.

James V. Neel

With a career that spans over 50 years, population geneticist James V. Neel’s work has included examining the effects of radiation on survivors of Nagasaki and Hiroshima, as well as sickle cell anemia and African Americans. It was not until relatively late in his career that Neel turned his research interest to Native Americans. It is unclear why Neel moved from his earlier work with radiation survivors to Native Americans, but from his writings there is evidence that he viewed recently contacted groups of Native Americans in South America as the perfect population in which to study natural selection, believing that they might provide “the best approximation available to the conditions under which human variability arose” (Neel 1970:815). Funding for his work came from the Atomic Energy Commission. While there has been much controversy over the work Neel did among the Yanomami, it is not within the scope of this paper to detail the list of medical research violations brought against James V. Neel.

Jonathan Marks notes that following World War II, James Neel’s focus on medical pathologies “that focused on medical rather than social pathologies; that was oriented toward helping the family, not the race; and that exposed patients to
optional services, not coercive surgery” (2012:165) served to reinvent the fields of human genetics and physical anthropology.

By the late 1950s, Neel had developed an interest in the discipline of anthropology and had begun to read anthropological tales of the Native American (1994:119). Over time, Neel began to view native peoples as an excellent population for genetic research. In Neel’s 1957 article “The Study of Natural Selection in Primitive and Civilized Populations,” Neel lays out his ideas on a “variety of parallel studies on selective factors in advanced and primitive societies” (Neel 1957:45). Neel saw the study of selective pressures in “primitive” societies as urgently needed due to continued contact with “advanced” societies. Neel, like many of his contemporaries, viewed recently contacted Native populations as a snapshot of early man. He saw these groups as a unique opportunity to study “man” in his “natural” environment unencumbered by the accouterments of modern life. Neel’s “Prospectus for Genetic Studies on the American Indian” published in Eugenics Quarterly in the winter of 1964, suggests why Native Americans were in his view a particularly good population for genetic research.

American Indian populations offer a number of advantages for studies in human biology and evolution. Their relatively short history in the new world—perhaps some 20 to 30 thousand years—tends to define and standardize appraisals of evolutionary change. They appear more homogeneous in certain features than old world populations, as suggested by their uniformity in hair form and color (Neel 1964:244).
Neel’s suggestion was that, based on hair color and hair texture, Native American populations must be more genetically similar than other populations. For Neel, like earlier researchers, imaginary of primitive groups and civilized society would direct his research.

Best known for his work among several indigenous communities in South and Central America, Neel collected more than 9600 blood samples to study the native’s origins, evolution, and behavior (Merriwether 2001). Neel collected the blood samples in order to examine “how the conditions regulating survival and reproduction had changed. In his words, “We must understand the biology of pre-civilized man much better” (Neel 1994:118-119). Implicit in this statement is the belief that “primitive” people’s biology is different from the biology of “civilized” populations. The stereotype of the “primitive” Indian is based on the hegemonic ideology served to dehumanize Indians during the colonial period (Mihesuah1996:37-45). This stereotype is a social construction and is not one based in biology. Creating racial categories based on phenotypic traits serves to reify existing social constructions of race.

**The “Thrifty” Genotype**

Based on his construction of "primitive" and "civilized," Neel in 1962 introduced his “thrifty” gene hypothesis. The “thrifty” gene hypothesis was Neel’s only work on diabetes. Prior to publishing his hypothesis, his research had been on radiation survivors of Nagasaki and Hiroshima. Considered a classic among geneticists, it is still widely cited fifty years later. Neel’s hypothesis suggested
that a “thrifty” genotype was responsible for the persistence of diabetes. Neel hypothesized it was the body’s ability to quickly turn food into fat that predisposed individuals to diabetes. This would have been advantageous for individuals during the Pleistocene times of feast and famine because whenever a steady supply of food was found, it would have been advantageous to quickly turn the food into fat, storing it for needed energy in times of famine. In developed western society today, this same “thrifty” gene has become disadvantageous to Native Americans because famines are no longer experienced. Neel suggested that the “thrifty” gene increased fat storage and this was accomplished by increased secretion of insulin in response to food. Neel hypothesized that the introduction of a steady food supply to people who have evolved a “thrifty” genotype may lead to progressive obesity with high concentrations of insulin in the blood and impairment of insulin action, which may eventually result in diabetes (Neel, 1962). To test his hypothesis, Neel suggested, “Studies on the level of anti-insulins (and insulin) in the serum of primitive hunters and gatherers are called for” (358). Neel and other researchers of the time viewed Native Americans and Alaska Natives as the only surviving populations of primitive man and a valuable resource for study. Neel viewed the problem of diabetes as an ethical dilemma of modern medicine.

If the dietary and cultural conditions which elicit the relatively high frequency of diabetes in the Western World are destined to spread and persist over the entire globe, then, to the extent that modern medicine makes it possible for diabetics to propagate, it interferes with genetic evolution. But if, on the other hand the mounting pressure of population numbers means an eventual decline in the
standard of living with, in many parts of the world, a persistence or return to seasonal fluctuations in the availability of food, then efforts to preserve the diabetic genotype through this transient period are in the interests of mankind” (359-360).

Neel concludes his article with a section on “Eugenic Considerations.” At the time when Neel’s article was published, diabetes was not categorized into insulin and non-insulin types.

In a later article (Neel, 1982) Neel, refined his hypothesis to focus on non-insulin dependent diabetes mellitus. While Neel’s causation for diabetes has changed over the last fifty years, the idea of a “thrifty” genotype has remained a convenient explanation for other scientists. Noel Boaz states,

Neel’s “thrifty” genotype hypothesis for the causation of diabetes mellitus has thus been modified by newer research, but it still stands as an important heuristic explanation for the disease (2002:132).

While Neel himself believed that lifestyle changes were implicated and not genes alone, many researchers have focused on genes in a changing environment and genetic variation to explain the rates of diabetes.

The thrifty gene hypothesis has served as a convenient narrative that ignores social and structural inequality while it simultaneously assumes that not all societies have experienced periods of starvation. In Neel’s view "primitive" natives were maladapted to the conditions of civilization. Central to his hypothesis is the fallacy that civilization provides access to food and resources to everyone. Although the contribution of environmental and other factors is widely accepted in scientific discourse regarding disease causation, genetic
explanations are nevertheless often prioritized and divert away from non-genetic factors (Hedgecoe 2001:875-911).

Neel’s article stands as a classic in anthropological literature, and has often been cited as fact. In the thrifty gene hypothesis, we see that regardless of narratives that position scientific/medical research as existing outside of social relations, there are many sites in their production, interpretation, and use that transform them from conveyors of objective, authoritative knowledge into socially situated objects that construct the body in complicated ways (Young 1993:108-128). Such discourse is used to naturalize the object while, at the same time, depending on ideology to provide an institutional base. In this view, discourse and ideology are separate but intersecting systems of knowledge. “Authoritative knowledge” is the knowledge on which decisions are made and actions taken “either because they explain the state of the world better or because they are associated with a stronger power base (Jordan 1993:152). The reality of authoritative knowledge is that it is not necessarily correct, nor evidence based; rather, it is influential and more powerful (Jordan 1997).

Authoritative knowledge in this case is simply the knowledge that decisions and actions are based upon. The knowledge that is valued most within any particular society or sub-culture becomes the dominant narrative. Browner and Press suggest that structural factors, such as the distribution of economic political and institutional resources, are made meaningful through these cultural
processes such as ideologies, norms and beliefs (Browner and Press 1996:141-156).

I argue in this chapter that Neel's hypothesis worked to create and maintain a certain type of "native" body: static, "primitive," and inherently diseased. I argue that it is through this imaginary that diabetes becomes a Native American disease. Native Americans were seen as immune to such diseases of civilization, and with no reports of diabetes prior to the 1950s in Native Americans, Neel's work makes diabetes visible in Native nations. By "visible," I mean that the narrative of a primitive genotype, maladapted to the conditions of civilization fit within the cultural stereotypes of Native people held by many Anglo-Americans of the time. Neel's hypothesis has been central to diabetes research and has been used to explain the high rates of type 2 diabetes in populations such as Native Americans, African Americans, Pacific Islanders and Australian Aborigines (American Diabetes Association, 2002). Native Americans are not the only group to have developed a "thrifty" gene in this narrative; P. Zimmet and K. O'Dea postulate that it appears that other populations such as Australian Aborigines and Polynesians evolved a similar "thrifty" gene (1993). Typically these populations have experienced a higher rate of type 2 diabetes than those of European or Asian descent.

**The Thrifty Gene Legacy**

How does the narrative of a "thrifty" gene become a common narrative? We have only to look to the number of times Neel's original paper has been cited
in order to understand its influence. For decades, citations have represented a fundamental unit of measure for assessing the influence of authors and their scholarly works. Citations provide links to the intellectual heritage foundation for the citing paper, and helps provide the historical context for displaying the unique contributions of the citing paper. Looking at the intellectual heritage of citations is probably the most important consideration when viewing citations as a measure of research impact. The act of citing acknowledges the contributions made in previous works that the citing work builds on, and serves as an affirmation (or refutation) of the cited work (Ajiferuke, Lu and Wolfram:2010, Kostoff 1998).

Neel’s original 1962 article on the “thrifty” gene has been cited nearly 1200 times according to the Web of Science. A Google search shows that the original article has been sited over 2000 times. With well over 1000 citations of the 1962 article, it is easy to see how influential Neel’s hypothesis has been in the scientific community since its original publication. This is not to say that all of the works that have cited Neel's article agree with the hypothesis; rather, it is the scientific debate that reify it as a valid imaginary. The following citation map serves as a visual representation of the influence in the production of knowledge regarding diabetes in Native Americans. Each thread from the original article represents a single citation. If we looked at how many of those articles were then cited, we would be talking about somewhere around 20,000 citations (far too many to be accurately displayed).
The goal of this research is not to prove or disprove Neel’s hypothesis; rather, it is to show how diabetes, a disease that Native Americans were at one time considered immune to, became one in which Native Americans were genetically predisposed to by the late 1960s. What I am arguing is that evidence from a variety of sources has shown thus far that diabetes in Native American communities was largely “unseen” by public health officials and researchers in
the first half of the twentieth century due in part to the racialization and imagining of diabetes as a disease of race and affluence. Further, I show how Neel's hypothesis became part of the common discourse over the last fifty years.

To understand how Neel's hypothesis became a dominant narrative, I argue that the authoritative status of scientific knowledge enables knowledge to travel from one place, the original place where data was gathered, to another place where that knowledge is represented, generalized and translated (Meyer 2007). This knowledge then becomes public narratives that are medically defined and held by social groups larger than the individual (Cheyney 2008). In the case of Neel's "thrifty" gene, narrative researchers move to look for evidence of a gene. With millions of possibilities, the lack of a gene or genes after 50 years does nothing to prove or disprove the hypothesis. Thus, Neel's meta-narrative communicates culturally constructed expectations and refers to traditions in which scientists and their social relations are "embedded as contemporary actors in history" (Somers 1994:619).

The thrifty gene hypothesis has served as a convenient narrative that ignores social and structural inequality while it simultaneously assumes that not all societies have experienced periods of starvation. In Neel's view, "primitive" Indians were maladapted to the conditions of civilization. Central to his hypothesis is the fallacy that civilization provides access to food and resources to everyone. Neel's hypothesis shifts the view of diabetes from a disease of affluent and civilized society to a primitive maladaptation of genes to civilization
and modernity. The social and biological meanings of race shape the biomedical production and representation of this diabetes knowledge.

The following section follows how this narrative is picked up by researchers over the past fifty years. In doing this, it is not to say that Neel's hypothesis has been whole heartedly accepted but rather that his hypothesis is still used to explain the rates of diabetes in Native Americans, and has become a common discourse that ignores history and inequality while simultaneously producing knowledge about diabetes and Native Americans.

The Evidence

Neel's article was published in 1962, and by 1963, physicians were already using it to describe the newly recognized epidemic of diabetes in Native American communities. Throughout the 1960s, research from physicians, geneticists and physical anthropologists began to describe the conditions in which selection for a “thrifty” genotype would happen (Dobzhensky, 1963; Neel et al. 1964; Neel, 1966). In 1964 Johnson and McNutt report on a study among the Alabama-Coushatta Indians located in Polk County, Texas. The reservation is described as consisting of mostly full-bloods, and a dietary survey was taken. According to the survey,

The men who worked took lunches with them while school age children ate lunch at school cafeterias. Between-meal snacks were common, consisting of fruit, candy, soft drinks, sandwiches, cake and meal leftovers. Children are permitted a great deal of candy and soft drinks. Few, if any native dishes have survived the acculturation process; some of the recent past such as “fry bread” and perhaps some others, are prepared occasionally. Little food is grown on the Reservation, and home
canning is irregular. The nurse estimated that one half of the families had refrigeration (113).

While describing the historical and structural stress the community had undergone, their food habits, and high rates of unemployment, the report finds that the “de novo” appearance of diabetes suggests a genetic maladaptation to recent conditions (123).

From an evolutionary perspective, it is believed that the human genome has adapted to Pleistocene conditions. It has also been argued that it was with the beginnings of agriculture that cultural adaptations and the human genome came out of sync with each other. The first evidence of agriculture dates to 10,000 years ago, but prior to that time, humans lived in small bands of forty to fifty people and practiced hunting and gathering as a subsistence strategy. Over the last 10,000 years, humans have dramatically changed their environment. The change from hunting and gathering to agriculture is responsible for such a dramatic lifestyle change. Cultural evolution has occurred much faster than our evolving genome. Linda Gerber stated,

Changing environments and lifestyles have contributed to improved life expectancies and changes in life expectancy have acted to reveal ancient genes that today contribute to the etiology and pathogenesis of chronic degenerative diseases" (1999:444).

In this narrative, the genetic component of Native American’s diabetes would seem to have become fixed at an earlier time when these diverse populations shared a common gene pool, perhaps at the time of migration to the Americas (Long, Lorenz, 2002).
By the 1980s and throughout the 90s, the hope of genomic medicine fueled scientific research looking for the “thrifty” gene in Native American populations. The hunt included research that suggested that during the Pleistocene it would have been advantageous for those individuals who possessed the “thrifty” genotype because natural selection would favor a thrifty gene. The Pleistocene migration of anatomically modern humans reached the New World within the last 20,000 years. According to this narrative, the ways in which it happened were most likely a wave of migration over the land bridge Berengia. The Bering Strait was covered by seawater sometime between 10,000 and 14,000 years ago; at a minimum, these inhabitants were cut off from the Old World from 10,000 years ago until large scale European colonization (Relethford, 2003). It has been reasoned that this isolation by distance contributed to some of the genotypic characteristics of Native Americans. For instance, Relethford (2003: 128) describes phenotypical similarities like straight black hair, lack of facial hair, and broad cheekbones as widespread across all Native American groups. As Relethford states, when the new Americans spread through North, Central, and South America, they retained a common ancestry and today still share classic genetic markers (2003).

The first Americans were big game hunter-gatherers who survived the harsh Upper Paleolithic Ice Age through a diet high in protein, low in carbohydrates, low in dietary fiber, and low in fat and sugar. At the same time, energy demands were high in order to produce body warmth and maintain
activity levels. Brown and Konner (1987) observed there would have been no realistic possibility of becoming obese. Such narratives ignore or minimize the recent history of colonialism, lack of resources, and for that matter, the fact that much of Europe had experienced the same conditions. In this narrative, the genetic component underlying Native American diabetes would have originated early in history, perhaps at the time the Americas were settled (Long, Lorenz, 2002).

Michael Wendorf postulated that it was during the peopling of North America that Paleo-Indians experienced episodes of famine and feast. During this time, selection for a “thrifty” gene would have been advantageous. Wendorf believed there was evidence in the archeological record of such feast and famine events. According to Wendorf, a 10,600 year-old burial in Buhl, Idaho, supports the idea of times of feast and famine during the Pleistocene. Wendorf noted Harris lines in the distal segment of a Buhl woman’s right femur. Harris lines are thought to be a result from under-nutrition during a person’s growth and development (1999:176). According to Wendorf, these Harris lines could indicate the famines that would induce selection for a “thrifty” gene. It should be noted that one skeleton is not sufficient evidence for famines, let alone selective pressure. Such narratives represent a common ideology of the Native people as having inherently a primitive genome that is maladapted to modern life. This is reflected in Neel’s statement in regards to the Yanomami:
Males were collectively the most superb physical specimens I had ever seen. Our view of health among Amerindians has been unduly influenced by the findings on Indians huddled around Missions or Indian Services, or herded into reservations, 50 to several hundred years after first contact, when alcoholism, tuberculosis, and venereal disease have already begun to erode health (2000:126).

For Neel and fellow researchers, Native Americans living in North America had encountered a relative recent evolution from primitive to civilized that allowed for the epidemic rates of diabetes seen in tribal groups. This is best illustrated in the discussions of the role of environment and the adaption to agriculture. In this view structural inequality is ignored. In Neel’s envisioning, the “Modern Indian” had been betrayed by its primitive biology unable to be fully “modern.” By the close of the twentieth century, the narrative the “thrifty” gene hypothesis was well entrenched in scientific research of Native American diabetes.

Admixture

If the 1960s were the decade of describing the “thrifty” gene, and the 1970s served to find evidence of the “thrifty” gene in Native American populations, the 1980s were the beginning of admixture studies. Admixture studies focused on diabetes in admixed groups in populations of European and Native American descent. Admixture with Native Americans, it was theorized, led to higher rates of type 2 diabetes. Researchers believe that colonization of the Americas by Europeans and subsequent admixture of European and Native Americans has led to higher risks of diabetes in modern Latino populations. In 2004 biological anthropologists set out to study the relationship of type 2 diabetes risk to individual admixture of a Hispanic population in Colorado. They
concluded that risk of type 2 diabetes increased with increased Native American ancestry, but they acknowledge that relationship is confounded by socioeconomic factors (Parra et al. 2005).

The role of socioeconomic economic status (SES) has not been adequately examined in the search for a “thrifty” gene. Recent studies are now beginning to examine the role of socioeconomic status and its role in high rates of diabetes in admixed populations. Desmond et al. assessed the role of SES, Native American ancestry and “21 candidate gene loci” in type 2 diabetes. They concluded that SES was a stronger predictor of type 2 diabetes than genes (2012). Increasingly, studies have established the relation between SES and the prevalence of type 2 diabetes (Connolly et al. 2000; Florez et al. 2009; Agardh et al. 2011).

Different mutations arise in different populations, and the longer the populations have been isolated, the more genetically different they become. According to Kenneth Weiss, “One need think only of the millions of American Blacks and Hispanics to realize how important such populations are. Admixture between such populations may constitute an informative natural experiment that can approximate the effects of crosses between inbred strains (1993:196).

The hypothesis has been advanced that the excess occurrence of type 2 diabetes, obesity, and gallbladder disease in this ethnic group may be genetic in origin and results from genes derived from Native Americans, rather than similar environmental and social realities. Researchers view evidence that the
interaction of cultural and genetic factors is responsible for the high prevalence of diabetes in Native Americans, Mexican Americans and Mexicans. Only after World War II did the prevalence of these diseases increase, coinciding with "westernization" in dietary habits of these populations (Weiss et al, 1984, Bennett, 1999). Researchers believe the evidence in support of this view is the positive correlation between diabetes prevalence and Native American admixture in Mexican-American populations. Latinos in the Americas are genetically admixed with Native Americans. The hypothesis has been advanced that the excess occurrence of type 2 diabetes, obesity, and gallbladder disease in this ethnic group may be genetic in origin and results from genes derived from Native Americans.

Mexican-Americans are the result of the admixture process that took place when people of primarily Native American and European ancestry met in the New World, a process that began five centuries ago. Researchers have argued that the correlation between diabetes and percentage of Native American contribution strongly points to the presence of risk alleles of Native American ancestry in Mexican and Mexican-American populations. In accordance with these findings, a recent study has indicated that, among the Gila River Indian Community of Arizona, persons with European admixture have a statistically significant lower prevalence of type 2 diabetes (Williams et al., 2000).

A study by Lisker, Ramirez, and Babinsky (1996), found that modern upper-class Mexicans have more European genetic admixture while lower-class
Mexicans have more Indian genetic admixture. These ethnic class divisions are a result of the decades of European expansion into Mesoamerica, and help to explain why lower-class Mexicans, more likely to migrate to the U.S., have a closer relation to Native Americans than do upper-class Mexicans who can afford to stay in Mexico. The work of Stern (1999) echoes this by demonstrating that the rates of type 2 diabetes in Mexican Americans in San Antonio, Texas, fall into class categories. Lower-class individuals have more Native American admixture and higher rates of diabetes than higher-class individuals. Such studies do not take into account environmental, social and political factors.

Michael Montoya, in his work on diabetes research among Mexicans living in Sun County, Texas, recounts the debates that took place among scientists when selecting a control group for research in Sun County. The debates revolved around the extent of Native American admixture among Puerto Ricans and Mexicans. Montoya argues that while Native Americans, Alaska Natives, African Americans and Latinos are considered at greater risk for diabetes, the absolute number of whites affected is 1.6 times higher than all of these groups combined. Yet prevalence estimates are used and minority groups are then viewed as biologically more vulnerable. Scientists and physicians inscribe race onto biology as they seek to make sense of illness (Montoya 2007:94-128).

Emoke Szathmary gave another possible hypothesis. She worked with the Dogrib people of Canada. Szathmary postulated that an adaptation to a low carbohydrate, cold environment would have selected for individuals in whom
gluconeogenesis and free fatty acid release and utilization were enhanced (1989, 1994). Szathmary believed that Neel’s model presupposed a nutritional environment that produced carbohydrate in excess of daily energy requirements. Szathmary noted that the Paleo-Indian environment during the migration southward was Arctic and Subarctic for most of the year. To test this hypothesis, Szathmary sought to determine whether carbohydrate ingestion on the day preceding the oral glucose tolerance test had any influence on glucose tolerance, insulin level, and insulin response to oral glucose challenge in the Dogrib Indians. The results, according to Szathmary, indicated,

If one accepts the “thrifty” gene model as an adequate explanation for the existence of NIDDM in Indians, one would expect that the high carbohydrate intake hyperglycemic would be the ones showing elevation in basal insulin and not the reverse” (1989:347).

While the “thrifty” gene hypothesis saw its greatest relevance in the literature during the 1990s, today it is still being cited and debated among researchers. Today the worldwide epidemic of diabetes has called into question the continued racialization of a “thrifty” gene in diabetes causation.

Like population geneticists, Mulligan et al. suggests that Native peoples in the Americas experienced a reduction in population size twice: first with the peopling of the Americas, and again during the European invasion. Mulligan et al. suggests that the peopling of the Americas is a more important determinant of “the genetic variation underlying common complex diseases, and especially diabetes.” They go on to state,
It now appears that the increase in prevalence of NIDDM since the 1940s is shared by most, if not all, Native Americans and has an inherited basis that traces back to a common founding population. Since the early 1960s, researchers have hypothesized that this suite of metabolic characteristics arose as an adaptation for efficient food utilization in post-Beringian environments. The adaptive process by which these traits evolved is still poorly understood. Although the adaptive process occurred along with a major bottleneck during the peopling of the Americas, it was undoubtedly more complex than a loss of rare alleles by accelerated genetic drift.

The authors conclude that regarding complex diseases in Americans Indians, it is unclear if “biogeographic ancestry” (race) will improve understanding of complex disorders such as diabetes. The authors conclude that studies such as population studies on the genetic history of Native Americans will likely decrease due in part to lack of Native American interest in studies that do not contribute to better health outcomes (Mulligan et al., 2004:308).

Since its inception, the “thrifty” gene has been used to explain the high rates of diabetes, obesity, and gallstones in Native American populations. In 2002 physician Martin Carey and researcher Beverly Paigen, suggested that epidemiological studies have developed a reference to “dissect out both ‘nature and nurture’ issues” that cause the high rates of gallstones. The authors point to the “intensely studied” ethnohistory and geographic origins of Native Americans to examine Native American’s genetic predisposition to gallstones. In this article, the narrative of the “thrifty” gene becomes the imaginary of the “primitive” Indian come to life.
Paleo-Indians were big game hunters who became trapped by mountainous cliffs on one side and glaciers on the other within the frozen tundra of an isolated Beringia for an amazing 20,000 year period, spanning the nadir of the last glacial epoch. In this secluded area several times the size of present-day Alaska there was scant food, and survival depended on hunting-gathering strategies. It has been suggested that this bleak, desolate, and inhospitable environment saw 10 to 11 months of harsh winter and was unlike any climate known on Earth today... Moreover, current thinking is that the highly seasonal nature of food sources led to the likelihood that successful survival and indeed reproduction, depended on genes that produced a favorable advantage principally by efficient fat storage. The hypothesis that “thrifty” genes facilitated survival in the Pleistocene era, whereas today the same genes cause cholesterol gallstones, obesity, and non-insulin-dependent diabetes mellitus, is intriguing (2002:785).

Using racial categories that includes Mongoloids and Europeoids, the authors are reflective of how the “thrifty” gene hypothesis became a common narrative.
While in scientific circles there is still much debate about the relevance of the “thrifty” gene in explaining the high rates of diabetes in Native American populations, the narrative has become a common “truth.” In May of 2011, The Venture, a multi-university online collegiate Latino newspaper with over 4000 subscribers, ran an article on diabetes in Latino populations.
Discussion

Scientists today fall between two paradigms: genetic determinism and research in epigenetics that is just taking shape. While type 1 and type 2 diabetes have been viewed since the late 1960s as two separate diseases with two very differ pathogenic routes, they lead to similar metabolic problems and complications. Scientists have implicated epigenetic and environmental influence in each type. Epigenetics is the study of inherited changes in phenotype or gene expression caused by mechanisms other than changes in the underlying DNA. These epigenetic traits are a stable inherited phenotype that is the result of changes in a chromosome, not in the DNA sequence. While the connection between type 2 diabetes and a high-calorie diet and sedentary lifestyle is well known, scientists are still unclear as to whether these factors cause the initial resistance to insulin. This is due to the fact that between 75-80 percent of obese people never develop type 2 diabetes. Researchers believe that they have identified more than forty genes associated with type 2 diabetes, but they only account for ten percent of the apparent genetic causes (Jonietz 2012). Epigenetic studies indicate that poor diet during pregnancy may affect the expression of genes that influence fetal fat-cell development, making it harder for fat cells to store excess lipids effectively.

Some researchers examining epigenetics are interested in the idea of a “thrifty phenotype.” The idea is that being deprived of nutrients in the womb, but then exposed to a high-calorie and low-exercise life, leads to a person
developing diabetes. The fetal environment triggers changes in DNA switches, which turns genes on or off, and that is the epigenetic effect. The environment in utero affects the expression of genes that code for enzymes that regulate blood sugar (Stöger 2008; Shetty 2012).

Genetic researchers today are still looking for evidence of the “thrifty” gene. In 2009, Southam et al. looked for support of the “thrifty” genotype hypothesis using proven loci. They concluded there were “no consistent patterns of selection that provide[d] conclusive confirmation of the thrifty genotype hypothesis” (2009:1846). Yet geneticists in 2010 suggested that they had found a gene variant associated with low HDL cholesterol, evidence of positive selection for a thrifty gene in Native Americans (Acuña-Alonzo et al.). Epidemiologists also believe that they found good candidate genes that might qualify as “thrifty. In this study, researchers focused on the angiotensin-converting enzyme (ACE) gene as a possible candidate. They concluded that the ACE gene could be identified as a thrifty allele (Xiao et al.).

Conclusion

Population genetics as a field really came into being during the 1920s and 1930s. Population geneticists of that time were interested in integrating natural selection with Mendelian genetics. Through the use of mathematical models of gene frequency, population geneticists attempt to draw conclusions about patterns of genetic variation in populations. Natural selection is really the cornerstone of population genetics. Natural selection occurs when life forms
have a trait that enables them to out-reproduce other populations of their kind as a result of being better adapted to the environment, or “fitter” (Okasha 2012). This presumes that fitness is at least partly due to genetic differences and that gene frequency will change over time.

Critics of population genetics have argued that devotion to the development of new theoretical models has come at the expense of testing those models against empirical data. Other critics have included the lack of insight on the evolutionary process and that few phenotypes are controlled by a single gene. Defining evolution as a change in gene frequency implies that all evolutionary phenomena can be reduced to changes in gene frequency. In this way, the “thrifty” gene theory does not reveal the genes involved in diabetes in different populations; rather, it is a story of how those genes may have arose within a population.

So while the “thrifty” gene hypothesis made visible type 2 diabetes in Native American communities due to its use as a racialized discourse, it also made invisible the health disparities that exist for Indian people. Native people are constructed by the dominant discourse that may not coincide with their self-identity. Representations of Native people as “primitive” and “risky” are stabilized through the discourses of the “thrifty” gene. It is at these discursive levels that dominant discourses are constructed (Takeshita 2001:269). In focusing on a long dead ancestor rather than access to high-quality food, health care and
structural inequality the “thrifty” gene hypothesis gets us no closer to lowering the rates of diabetes in these communities.

By the end of his career Neel was pushing for what he termed a euphncs approach to health (Neel 2000). Euphncs has been defined as the study of how genes and the environment interact. As type 2 diabetes rates continue to rise in all populations, discussion has moved from genetic reductionism to an increased acknowledgement of the role of environment and lifestyle. Through this narrative, we see that by approaching health from the vantage point of categorical identity, other ways in which health risks are distributed in society are ignored. The focus on group obscures individual level difference, and as Stephen Epstein suggests, “raising the risk of improper ‘racial profiling’ in health care” (2007:11). The emphasis on difference encourages and naturalizes the belief that race and gender are biological in their essence and that social inequalities are best remedied by attending to those biological particularities.

To date, Neel’s “thrifty” gene has not been found in humans. Kenneth Weiss and William Schull, in *Perspectives Fulfilled: the work and thought of J.V. Neel (1915-200)*, stated, “[Neel] cautioned that the most serious health problems faced by our species should not be approached as if they have a genetic solution” (2002:46). Yet Neel’s hypothesis has focused scientists on causation rather than cure. Narratives such as the “thrifty” gene are thought to eliminate the uncertainty of disease and to provide a definitive explanation of a person’s condition as located in their body. Through these practices, genes become an
actor, one who provides access to unseen parts of the body. Human beings are nowhere to be found in these accounts.

I guess I don’t get how this happens. I mean I know that I shouldn’t eat sugar and bread and stuff but the genetics part. I mean I know they say the genetic stuff is right and you know I get that part but I don’t know, though I’m not a full-blood I have Mexican and white family too. I think Indians just get it no matter how much Indian blood you got ‘cause we eat a lot of stuff that we didn’t used to. So is it like that cancer gene?

In examining Neel’s hypothesis, its history and the cultural assumptions tied to it we see that, as Marks suggested, “Normative human genetics is not value neutral and is not disconnected from contemporary social and cultural politics. Indeed, it has commonly been more of an applied science than an abstract theoretical one, while, nevertheless, rarely if ever confronting its track record as applied science” (2012:170). In this case anthropology’s value is in exploring the cultural assumption of genetic production and interpretation of genetic data. For doctors, it may be that it is easier to talk about genes and long dead ancestors than to talk about lifestyle and diet.
Chapter 5

The Indian

Alas! for them their day is o'er,
No more, no more for them the wild deer bounds,
The plough is on their hunting grounds;
The pale man's axe rings through their woods,
Beyond the mountains of the west
Their children go to die.
Charles James Sprague 1921

Introduction

In the previous chapters, I argued that type 2 diabetes in Native Americans was largely invisible to physicians, researchers and health policy makers during the early twentieth century due to a racialized discourse of disease etiology based on essentailized traits. Further, I contend that with Neel’s thrifty gene hypothesis, diabetes becomes an Indian disease through a racialized discourse that views Native American DNA as inherently “primitive” and maladaptive to civilization. This chapter examines the phenomenon of risk as it pertains to genetic predisposition of type 2-diabetes in Native Americans, and the role risk plays in contemporary social life and subjectivities of Native American diabetics.

Previous work on risk has shown that throughout human history, risk has often stemmed from the natural world—for example, famine, weather events, and natural catastrophes. In contrast, much of what we see as risky today is attributed to humans. People are seen as both the cause of risky behavior and
are held to be responsible for its minimization (Lupton 2006:13). In this sense, risk imposes morality on people’s actions because they are held responsible for its avoidance, while it simultaneously lacks a moral component. Risk is used as a means of what David Lyon calls “social sorting” (2003:1). Social sorting focuses on the social categories by which individuals deemed “risky” are surveilled. In this sense, information can then be used to create divisions within and between populations (Lyon 2003:1-2).

My interest in risk is in how populations are seen as risky through a particular discourse. In particular, how did a view that Native Americans were inherently “diseased” arise and become a predominant discourse that impacted research and policy? Such discourse on genetic risk shifts the focus away from both the historical and social relations that have contributed to the high rates of disease and is rarely included in discussions of Native American health. Thus, being genetically predisposed to type 2 diabetes serves to ignore both social and political inequality.

With the focus on genes, risk becomes embodied. Rather than locating the risk outside of the body (such as an environmental risk that happens to a person, or a lifestyle risk that occurs because of something an individual does or does not do), embodied risks say something about who the individual is. In this way, risks are identified as characteristics of their body (Kavanagh and Broom 1998). This is seen in the discourse of diabetes among Native Americans.
As an anthropologist, I am interested in how these historical processes worked to shape the experience in day-to-day living to show how discourse, policy and history are embodied in a system of inequality that directly impacts health equity for Native American people today. My interest follows the work of Michael Foucault, Margret Lock, Paul Rabinow and Nikolas Rose. It builds on Michael Foucault’s work on biopower and biopolitics. Biopower, Foucault believed, was the way in which capitalist states exerted control over people to better promote life. The major means of control were through statistics and probabilities.

The State focused on the ways in which people could most probably be controlled and directed in all aspects of life. What then emerges with the introduction of biopower as a practice is the notion of a social body as the object of government. Biopolitic’s focus, therefore, is with populations as a political and scientific problem. It is a biological issue in the exercise of power. In this sense, biopower does not act on the individual as a subject of discipline. Rather, it acts on the population in a preventative manner. It is legitimized because of its preoccupation with optimizing life chances, and operates through surveillance for the prevention of epidemics and disease.

In the Foucaultian view, risk is understood as one of the many ways of states disciplining power by which populations and individuals are monitored and managed. Norms of health status and behaviors are identified and individuals are compared to those norms. Those who are determined to fall outside of that
range are considered an “at risk” population or individual. In this view, risk is seen as controllable as long as expert knowledge can be brought to bear upon it (Lupton 1999:4-5).

Nicolas Rose has argued that biopolitics today is risk politics. Seeking to classify, identify and eliminate or constrain individuals with a defective constitution is no longer the question, nor is promoting the reproduction of those whose biological characteristics are most desirable in the name of the overall fitness of the population. Indeed, there were a variety of strategies that attempted to identify, treat, and manage or administer individuals, groups or localities where risk was seen to be high. The distinctions of normal and pathological, which were central to earlier biopolitical analyses, Rose suggests are now organized at a number of levels. There are actuarial or epidemiological strategies that seek to reduce aggregate levels of risk across a population. There are strategies for the management of high risk groups. And, increasingly, there are strategies based on identification of and preventive intervention for risky individuals (2008).

Native Americans having been seen as inherently “unhealthy” and at risk have often been seen as a good population for research based on this view.

The Indian, without his knowledge or consent, offers us a human experience in immunology as well as epidemiology which we can ill afford to ignore. The material is conveniently located, the data are or should easily be made available for record and study, and the results applied to regulative measures of control (Burns 1932).
Historically, Native Americans have been painted as inherently pathological, prone to disease, much like the “thrifty” gene hypothesis views Native Americans as maladapted to modernity. These characterizations range from the justification of manifest destiny and discourses of the “dying race” to being genetically predisposed to alcoholism and diabetes. Predisposition as it relates to illness and disease stems from the eighteenth century when physicians and lay people began discussions about individual “constitution” and its relationship to disease vulnerability (Jasen 2002:17-43).

In many communities, diabetes is seen as an “Indian problem” related to genes in changing environment, but how do we understand genetic risk? How are ideas of risk and genetic predisposition culturally constructed and tied to ideas of race and genes? Deborah Lupton has identified previous work on risk as generally falling within three types of theoretical frameworks: Mary Douglas’ cultural/symbolic; Ulrich Beck and Anthony Giddens’ work on “risk society”; and Michel Foucault’s governmentality. These theoretical approaches, by taking into account the larger social, cultural and historical contexts in which concepts of risk arise, differ from “techno-scientific approaches to risk wherein risk is a measure of the probability of adverse effects (Lupton 1999).

In *The Taming of Chance*, Ian Hacking writes of the rise of probabilities, which he argues could have only come about in conjunction with the census, computation and the expansion of literacy. With this comes the ability to divide people into different groups and populations. Deviant groups that did not “fit” in
with society were the first to be divided. Later, states included citizens in the division of populations. Hacking believed that these “technologies of data collection” were connected to the growth of the “research mentality” that was seen in Europe and the United States at the turn of the twentieth century (Hacking 1990).

While originally the risk concept was value neutral, over time it has come to be associated with adverse consequences. Lupton and others have argued that the treatment of risk in the fields of medicine and epidemiology are treated “as a taken for granted objective phenomenon” (Lupton 1999:1). In this way, “risk information” is distilled of various elements and given importance in the course of medical care. People’s confusion about how this information is assembled and what it means persists, largely due to the fact that individualized risk estimates “are abstractions inferred from population data, though they are presented to individuals as personal” (Lee 2010:102). Surveillance links notions of risk to individuals through the enumeration of risk factors and a calculation of probability (Lee 2010). The growing awareness among anthropologists is that risk is socially constructed and that, as Nelkin stated, “Risk perceptions depend less on the nature of a hazard than on political, social, and cultural contexts” (2003: viii). Measures often hold little meaning for those considered “at risk.”

In the fields of economics, public health and epidemiology, the focus on identification of risks and causal factors in developing predictive models for future interventions that limit the effects of risk neglect to recognize how understandings
of risk are produced and function at the level of situated experience. How do people singled out as “at risk” respond to imperatives on behavior from expert knowledge? In particular, how do Native Americans understand, contest and experience being genetically predisposed to type 2 diabetes?

**Native Americans and Risk**

The discourse of type 2 diabetes, genetic predisposition, and race are embedded in the historical, political and economic processes. L. A. Whitt has argued that “transforming science involves vitalizing “indigenist” theoretical perspectives that aim to analyze the legacy of western science, the political role it plays and its implications for indigenous peoples” (In Poundrier 2007:243). With that in mind, the aim of this work is to enhance current understandings of the influence of racial/ethnic discrimination in health care delivery and its association with disease incidence, treatment and outcomes among Native Americans.

Diane Weiner’s research with clinicians and Native Americans has shown that the concept of genetic predisposition has diverse meanings for clinicians and their patients (Weiner 2001:108-133). Native Americans are often told they are genetically predisposed to diabetes. Predisposition serves to absolve the individual and the environment by placing blame onto diseased ancestors. Such reductionism ignores the situational and socio-political environment in which they are embedded.
A History of Risk

Beginning at the turn of the twentieth century, assumptions by non-Natives regarding Native American susceptibilities to certain diseases and immunity to others shaped public policy. As Mary Ellen Kelm suggests, since the beginning of the last century, non-Native assumptions of Native bodies were naturalized, ignoring the extent to which Native bodies and what happened to them were made by history (1998:xvi). Leaders in Indian country have situated social and physical pathologies outside themselves as being part of the European contribution to the North American epidemiological scene.

Native “ill-health” was created not just by faceless pathogens but by the colonial policies and practices of the United States government. At the end of the nineteenth century, medical professionals put Native bodies under close study, hypothesized that racial contact was dangerous, and argued that massive medical, cultural and social intervention was necessary to save the so-called dying race. It was within this context that a certain type of knowledge about the Native body was produced. Today Native bodies are not just the result of forces of colonization and resistance, but have emerged from the body politic of twentieth century U.S. Indian policy “molded by patterns of subsistence, education, belief, and healing that were at once, centuries old and rapidly changing” (Kelm:1998, xix).
A Vanishing Race

In understanding how the western discourse that has viewed Native people as primitive and maladaptive to civilization became a common narrative we can look to the common binary discourse of Native Americans as the noble and ignoble savage. The noble and ignoble savage constructs were part of European exploration used to characterize indigenous peoples in which they met. In each of these constructs, Native groups were portrayed as the antithesis of European civilization. The construction of the noble savage was a romanticized view that viewed indigenous people as “free from the oppressive bonds of civilization” (Borsboom 1988:419). The noble savage lived in a natural state of existence, while the ignoble savage is characterized as degenerative, pathological, and primitive. Both contributed to the idea of Indians as a “risky population.”

During the sixteenth and seventeenth centuries, many Anglo-Americans viewed Native Americans as beastly, “more brutish than the beasts they hunt,” A pastor in Virginia described Native Americans as “bad people, having little of humanity but shape.” In these views, Native Americans were largely seen as monstrous and savage, while many other Anglo-Americans simultaneously viewed Native Americans through a much more romantic lens. Columbus described Native people as “loving people, without covetousness, and fit for anything… they love their neighbors as themselves, and their speech is the sweetest and gentlest in the world” (Olsen 1906:201). Many Anglo-Americans
followed who saw in the Native American an idealized man-child, serene, generous and full of dignity (Berry 1960). Yet both of these groups agreed on one thing: Native Americans will disappear. For Indian people, the only salvation lay in becoming “civilized.” The extinction of the Indian was viewed by some as the best answer to a tough problem, and by others as a tragedy.

By the turn of the twentieth century, Native American people were seen as a remnant of human history that was passing away. Writings from this period often emphasized the biological aspects of the “dying race.” Popular literature of the time bemoaned the passing of the Native American, while simultaneously extolling their nobility and the belief that Native Americans no longer posed a threat to the Anglo-American civilization (Kelm 2005).

Sociologist and demographer Russell Thornton found that at the time Columbus landed in what is today San Salvador, there were seven million Native people living in North America (Russell 1987:32). At the turn of the twentieth century, the Native American population stood at 250,000 its lowest point. Well before 1900, Anglo-Americans believed that Native Americans were a “dying race.” Some of this was due to decreasing population but also to the fact that Native American’s land base in the United States had gone from 156 million acres in 1881 to 48 million by 1934 (Mihesuah 1996:74).

Many government officials argued that rather than dying out, Indians were merging into the general population (Kelm 2005). In 1905, anthropologist Henry W. Henshaw argued that the idea of Native Americans as a “dying race” was one
of the population fallacies respecting Indians. Henry Knox, the first federal official to have responsibility for Indian Affairs stated, "It is painful to consider that all the Indian tribes existing in those states now the best cultivated and most populous, have become extinct. If the same causes continue, the same effects will happen… and, in a short period, the idea of an Indian on this side of the Mississippi will only be found in the pages of the historian.” While Knox prediction of the eminent extinction of Native American people east of the Mississippi did not come to pass, Anglo-Americans across the United States held similar views. Andrew Jackson in his annual address to Congress in 1830 noted,

> Humanity has often wept over the fate of the aborigines of this country, and philanthropy has been long busily engaged in devising means to avert it, but its progress has never for a moment been arrested, and one by one have many powerful tribes disappeared from the earth.

Francis Parkman believed that it was the “vanishing” Indians rigidity and inability to embrace “civilization” that would ultimately lead to their extinction.

> Some races of man seem molded in wax, soft and melting, at once plastic and feeble. But the Indian is hewn out of rock… Races of inferior energy have possessed a power of expansion and assimilation to which he is a stranger, and it is this fixed and rigid quality which has proved his ruin. He will not learn the arts of civilization, and he and his forest must perish together.

Frontier accounts during the eighteen hundreds were of Indian captivity and had become a staple of the thrilling dangers of frontier hardships. Pearce suggests that the reader of the captivity narrative “was the price one paid for living in the vanguard of civilization, for trying to be a peace-loving farmer in the presence of bloody savages” (1988:58). For many Anglo-Americans, when they did see
Indians, it was Indians drunken, diseased, and degraded; they were told that
Indians beyond the frontier would sooner or later be in no better condition.
Anglo-Americans were of two minds about Native Americans: some believed that
the state of Native Americans was inevitable and "civilizing" the Indian population
would kill them; civilization would kill them.

Much of the discourse of the “Vanishing Indian” was based on the idea
that to be Indian was based on blood quantum. Full blood represented what was
meant to be Indian. In 1917, physical anthropologist and eugenicist Aleš
Hrdlička wrote in the journal, *Science*:

> The progress of miscegenation among many of the Indian tribes
> has progressed to a degree that is surprising even to those who for
> many years have been studying the Indian. While the total number
> of “Indians” as recorded by the census increases from decade to
> decade, the fact is that this increase is due wholly to that of mixed
> bloods; the full-bloods of pure strain are in most localities rapidly
> disappearing and in a considerable proportion of the tribes have
> become actually extinct or are on the point of extinction (1917:266).

For Hrdlička and other scientists of the time “purity” of blood or blood quantum
was what defined “Indian.” He went on to state:

> Thus two tribes, one of which was of considerable importance, may
> be regarded as lost to science, so far as pure-bloods are
> concerned. Only a few years ago according to local information
> there were still a number of old men and women living in both tribes
> who represented the pure strain. The genuine Indian is rapidly
> passing away and the work of the anthropologist who endeavors to
> record the physical type of the various tribes is becoming
> increasingly difficult (1917:267).
Native Americans, because they were viewed as a vanishing race, inherently diseased, primitive, and unable to adapt to civilization, were also viewed as the perfect research population.

**The Risk of Indian Blood**

In 1930, a publication titled *The Indian as a Life Insurance Risk* surveyed 153 insurance companies on their practices regarding Native Americans. In the introduction to the survey Hoffman writes:

> There is a natural apprehension on the part of life insurance companies of assuming risks on the lives of Indians of different degrees of racial intermixture... No exhaustive study of Indian mortality according to the degree of racial intermixture has ever been made, nor is such an investigation really feasible in view of the practical impossibility of ascertaining the number of persons exposed to risk and the decrease according to the same degree of racial intermixture (1930:48-49).

The results from the survey indicated that a quarter of those companies that responded did not insure Native Americans at all, and another quarter had no experience with Native Americans. Based on the location of those companies that did insure Native Americans, qualification was usually based on percentage of Indian blood. According to Hoffman, “Some companies take a reasonably liberal attitude and extend the benefits of life insurance to the better element of the Indian population, including, to a certain extent, full-bloods of an established status” (Hoffman 1930:83). “Full-bloods of an established status” were those Indians from the five-civilized tribes and Pueblo Indians of New Mexico. Both groups were often portrayed as “more civilized” than other Native American groups at that time. This was due to the focus of Anglo-Americans who viewed...
the permanence of settlements and agricultural based subsistence strategies as hallmarks of civilization.

In this, we see the taken-for-granted assumption that Native Americans are naturally “risky,” and that it is only through the possible assimilation through admixture that they may become less of a “risky” population. In this context, what is identified as a risk and risk issues are aligned to issues of power.

The Risky Genes

The Joslin Diabetes Center in Boston, in a special advertising section titled “Diabetes is it in your genes?”, discusses the genetic influence of type 2 diabetes in this way:

Type 2 diabetes has the greatest genetic influence and the most complicated genetics. While in a low percentage of families there may be a single genetic defect leading to type 2 diabetes is both polygenic and heterogeneous. This means that type 2 diabetes requires the interaction of two or more genes (polygenic), and in different individuals the genes involved can be different (heterogeneous). Furthermore, in contrast to type 1 diabetes, the most important or most common genes in type 2 diabetes have not yet been identified (In Time March 2005)

In such cases, a multifactorial inheritance pattern is affected by multiple genes, not just a single gene as in Mendelian inheritance, and the inheritance pattern is unclear. In such cases, having a parent or other family relative with the disease is a factor that will increase an individual’s risk for developing the disease, but there is no definite pattern over generations.

Most of the diseases that are claimed to be genetically transmitted are responses to environmental conditions and environmentally induced mutations as much as to genetic inheritance. For many genetically transmitted diseases,
an individual may seek genetic counseling after having witnessed generations of family with the condition, while for Native people, type 2 diabetes is a relatively new phenomenon, which has touched many people in the community, and there is no test to see if you carry the type 2 diabetes gene or genes. You are simply at risk because you are Native. Such reductionism ignores the internal and external environments in which they are embedded. It is not to exonerate the environment by the individual as possessing a “genetic predisposition” (Finkler 193). The notion of genetic predisposition is powerful because it is not easily refutable. For example, if one says a person has a drug addiction because he/she is predisposed to addictive behavior, it cannot be disproved. The outcome is the proof, exculpating the individual and the environment from responsibility” (Finkler 2000:193). Predisposition absolves the individual and the environment, but places blame onto diseased ancestors.

Embedded in the genetic risk discourse is a notion of risk in which concepts of “predisposition is central. Risk in this case is a statistical probability of a possible future occurrence of biological harm. This approach deflects attention toward individual predisposition and away from the social and structural factors that contribute to risk (Chapman 2006).

**Alternative Views of Risk**

When asked, “What do you think causes diabetes?”, Mae states:

Well, it just seems like… that we get it ‘cause, look, we have lived off government food; all that food is bad. There is lots of things we have gone through. I don’t think that kind of a….stress is good; it has something to do with it.
Julie believes, “We used to live different… moved around more, you know. We ate food that was good.” Rather than the risk of disease residing within the body, Mae and Julie see the etiology as residing outside of their body. Both attempt to locate the etiology to historical trauma, colonialism, and access to resources within a diabetes narrative. While these narratives are not explicit, they do reveal a relationship between health, the land, history, cultural knowledge, and diet, while simultaneously resisting biomedical reductionism. As such they link diabetes to social inequality, stress, and trauma. In this discourse, risk stems from social and political inequality rather than having a risky biology.

This is not to say that those interviewed did not also accept the idea of diabetes as having a genetic component; however, they did contest the narrative of diabetes as a result of a maladaptation. They based the etiology of the disease in an indigenous knowledge system that connected the relationship between their relationships with the world around them. A philosophical view held in common by many Native American groups is the belief that the Creator taught the people the proper relationship between humans and the world around them (Cajete 1999; Cordova 2007). “Native tradition looks to the primacy of direct experience, interconnectedness, relationship and reciprocity in the natural world” (Madrigal 2008:24). The implication is that when one’s relationship with the world around them is out of balance, individuals suffer. Anthony Madrigal suggests,
The Native view of the world considers the inter-relationships of all beings at all levels of existence and here differs from Western tradition where understandings of the natural world are often separated from the spiritual realm and are considered in a secular, compartmentalized manner (2008:24).

Such philosophical understandings of the world are seen in traditional land management practices but also encompass a view of health as relating to a whole living system that is interconnected.

Bio-medical understandings of genetic inheritance as a matter of random chance in which randomness of inheritance in the case of diseases is often subsumed under the notion of a risk factor. Regarding modern ideas of risk, Kaja Finkler states, “[Risk] recognizes on the one hand that events are random, and on the other that this very randomness can be controlled to attain certainty. The concept of risk based on mathematical probability permits modern humans to nurture the notion that they can control the future by controlling risks” (2000:7).

For some, the notion of risk gives a sense of control of the ability of precautionary measures, while for others, risk leaves a feeling of inevitability.

One result is the emergent figure of the individual “genetically at risk” such individual and their families [who] have taken unto themselves the responsibility for the government of their risky genes, in relation not merely to a secular norm of individual health, but an obligation to one’s kin, to those one loves, and to the future (Novas and Rose 2000:507 quote taken from Lock et al 2007).

While I would say that when I first began looking at diabetes in Native communities that there did seem to be a sense that many felt there was an inevitability of diabetes over the course of several years, I would argue that is
changing. That being said, some voiced concern for their children’s risk of developing diabetes. When asked what she fears about diabetes, Jenny said,

I don’t want my kids getting it..... you know. I mean I keep mine under good control but I know what it can do. Well, you know, I just don’t want that. Well…. I worry that my diabetes will get as bad as my mom’s. You know... she has a real hard time controlling hers. She’s nearly blind and doesn’t get around too good anymore. I worry about her. So I guess part of me …um part of me thinks about it like, is that what I’m gonna be like? I mean sick like that and, you know, sometimes I think, whoa what about my kids?

It was a beautiful fall day the first time I interviewed Jenny. I met her through a mutual friend at a child's birthday party and have asked if she would be interested in talking to me about diabetes and her experience. I came out to her home in the early afternoon. Jenny lives in a small three-bedroom home with her three children and her husband. Jenny lives in north San Diego County off reservation land. Jenny was diagnosed with type 2 diabetes in 2001 at the age of 31. Jenny has private insurance through her husband and typically doesn’t receive care through the consortium’s health clinic. When I came in, her youngest son was playing in the yard with another child and her middle child was playing a video game in the front room. During our interview, she said she first got diabetes in her third pregnancy, and then was diagnosed with type 2 diabetes when her youngest child was two. Jenny’s mother and aunt are both diabetic and Jenny said that so are many of her cousins on both her mother and father’s side of the family.

In subsequent interviews when asked, “Do you think Native people have a thrifty gene?” Jenny said,
“Ummm, I don’t think so. We have been [through] so much, ummm…lost a lot of things that …lost the knowledge. I mean part of me thinks how is it that if it’s in our genes, our ancestors didn’t get it, but I know lots of Indians have it now… so I don’t know, maybe its just what we eat and…?

When asked if her doctor had told her she was “predisposed” to diabetes, Jenny stated,

It wasn’t, no, no it was after I was told that I had it. The doctor told me that Indians get diabetes. It was when he told me how we have a gene that was useful to our ancestors so they wouldn’t starve but now it is making us sick.

Jenny’s story is not uncommon. When asked the same question, John replied, “The doctor asked if I was Mexican; when I said I was Native, he said, “Oh yeah, you should be tested for diabetes. I asked why and he said, “Native Americans have a gene [or something like that] that puts them at higher risk for diabetes…. He was right … I had it.” While both medical researchers and Native Americans believe that Natives are at risk for type 2 diabetes, medical researchers over the last century have naturalized Native American’s health risks and reduced those risks to a matter of race, while Native Americans I interviewed saw Indians as at risk due to history, politics and inequality.

At the turn of the twentieth century, what we see with the example of Native American Health and United States Government Indian Policy is a health policy linked to political concerns for the “fitness of the nation” and for personal “techniques for the care of self” (Rose 2001:3). Rose saw the change from the government’s interest in classifying, identifying, and eliminating or constraining individuals viewed as pathological to strategies that identify, manage and treat
those individuals and groups in those risky areas. “The binary distinctions of normal and pathological, which were central to earlier biopolitical analyses, are now organized at a number of levels. There are strategies for the management of high-risk groups. And strategies based on identification of and preventive intervention for risky individuals” (Rose 2001:7). Risk profiling, in effect, has served to naturalize disease and place it within the body rather than due to outside forces of access and structural inequality.

Margaret Lock et al. have argued that individuals considered genetically at risk to late-onset diseases is “fraught with uncertainty” (2007:256). Population derived epidemiological forecasts probabilities can predict with some certainty how many individuals in any given population will die in a year. However, such estimates cannot say who will die. Thus, uncertainty is produced through risk estimates when individuals must interpret probabilistic calculations.

**Conclusion**

Frequently in public health discourse, the concept of risk carries with it notions regarding agency or the lack thereof. Focusing on risk in this way keeps the focus on the individual’s sickness and prevention while ignoring larger social questions of history and inequality.

Predictions about who exactly is genetically at risk are problematic in part because genes alone determine nothing in the majority of diseases. As such, knowledge alone about such genes is not a good indicator of future risk.
Chapter 6

Introduction

I began this work introducing alternative narratives to diabetes etiology based on a model of historical trauma that views the rise of diabetes as rooted in history, land, and inequality. In the subsequent chapters, I developed how the rise of diabetes in the first half of the twentieth century was made “invisible” in Native American communities through the categorization of diseases as diseases of affluence or diseases of civilization in effect creating a narrative that there were some diseases that Indians got because they were primitive and uncivilized and diseases that they did not. I further went on to argue that it was through James Neel’s “thrifty” gene hypothesis that situates diabetes in the blood and genes of maladapted primitive biology that diabetes became an “Indian” disease. In this way I illustrated that the thrifty gene, viewed within its historical and cultural context, is not a closed and finished fact.

Bringing together health policy, genetic reductionism, and risk discourse situates diabetes in Native communities within the larger context of their status as a colonized people. Colonization has taken many forms, from the U.S. government sponsored policies of ethnocide and genocide to a focus on genes and the creation of an at risk population, an approach that has often ignored the historical and social processes that have led to Native American poor health. The objective here has been to enhance current understandings of the influence of racial/ethnic discrimination in health care delivery and its association with
disparities in disease incidence, treatment, and outcomes among Native Americans. The ongoing struggle for Native Americans in the United States exemplifies the relationship between health, policy, and research.

Native Americans I spoke with resisted biomedical ideology that placed risk on ancestors and diminished the role of social relations and structural inequality. In so doing they reflected on the complexity of the etiology of type 2 diabetes. While resisting a “thrifty” gene that places blame on a long dead ancestor, participants simultaneously acknowledged that diabetes runs in families. In the early twentieth century, physicians and scientists viewed race to include biology and culture that they collapsed into ideas of difference: civilization and primitivism. The story of diabetes and Native Americans becomes the story of transformation and of racialization in which scientists used disease to talk about difference.

As this research has shown, dominant ideological and social patterns in biomedicine are intimately related to hegemonic ideologies outside of western medical systems. This radical social constructionism, as Dona Haraway states, “seeks to deconstruct the truth claims of … science by showing the radical historical specificity, and contestability, of every layer of the onion of scientific… construction” (1991:186). As seen in the biomedical discourse of type 2 diabetes in Native Americans, scientific knowledge is produced under a particular and influencing set of cultural and historic conditions.
Historical Trauma

It has been argued here that the impact of colonialism had not only immediate effects on Native people but that it continues to impact Native people in distinct ways. The ongoing struggle for health equity for Native people exemplifies the relationship between health and the social relations within which they are based. For Native Americans, diabetes arose from the unequal social relations and through the experience of historical trauma.

United States Indian policy is intimately linked to cultural construction of Indians as primitive, pathological and lacking civilization. Biomedical practitioners of the time viewed diabetes as a disease of civilization and affluence, making invisible the rise of type 2 diabetes in the early twentieth century in Native communities. While history shows that ideologies that denigrated Native resources and practices have been and continue to be resisted Native American discourse of diabetes incorporates Native knowledge regarding access to land, kinship and identity.

Crucial to understanding how diabetes became an “Indian” disease is the understanding of bio-medical views regarding diseases of civilization. It was only once Neel developed his “thrifty” gene theory that located the disease in blood and genes that diabetes became an “Indian” disease. At the turn of the twentieth century, Anglo-Americans viewed diabetes as a racialized disease of civilization and affluence. In this light, Native Americans, viewed largely as incapable of the civilizing, would not in this view suffer from a disease that had largely been tied to
civilization. In the Anglo-American imaginary, civilization was theory to describe the transition from “a primitive condition to a more advanced one by means of moral, intellectual and social progress” (Patterson 1997:15). In this sense, civilization becomes a comparison civilized/uncivilized. What I have argued here is that diabetes in Native American communities during the first half of the twentieth century was made invisible due to western ideologies of civilization and disease. It was only once James Neel’s “thrifty” gene hypothesis linked diabetes to genes, blood and maladaptation to civilization, that diabetes in Native American communities became real.

In tracing James Neel’s “thrifty” gene hypothesis, we find a new way for western understanding of diabetes etiology. Neel’s work is indicative of research knowledge of the time. In defining diabetes as a maladaptation to a modern environment, Neel presented a hypothesis that linked diabetes to the environment through a narrative of a gene or a people out of place in a civilized society.

This work has emerged out of the literature in the social construction of biological, genetic and health sciences. This study will contribute to a better understanding of how type 2 diabetes has become an epidemic in Native communities and constitutes contemporary racialized and politicized domains for the exercise of power. More broadly, it documents what epidemiologists are just recently beginning to understand as a new epidemiological transition: the co-occurrence of tuberculosis and diabetes (Trnovec et al. 2001; Magee, Blumberg
and Narayan 2010). This dissertation details the process in which information is gathered, disseminated and assimilated through dominant knowledge regimes.

Since the 1960s diabetes again has a racial profile, but Jews have been now been replaced by Native Americans. This racialized image is reinforced by the United States government’s policy of collecting racial/ethnic information but no other confounding factors. Attention to race on websites like that of the National Institute of Diabetes and Digestion and Kidney Diseases draws attention to incidence of diabetes among certain racial/ethnic groups but excludes socio-economic-status as a risk factor. What is being produced in the literature is indicative of the kind of data that is collected.

Alternatives

The “thrifty” gene has become a catch phrase that now encompasses more than just diabetes; it has been offered as the possible explanation of obesity, hypertension, diabetes and other Chronic Diseases of Civilization (CDC). After fifty years of research, the “thrifty” genotype has not been found in any human population. Robyn McDermott stated,

This limited concept of causation and a monopoly of concern with pathogenesis and treatment almost completely ignore the need to attend to environmental factors, including the socio-economic environment and prevention (1998:1190).

McDermott went on to argue that epidemiologists have limited the search for causality to genes and have not taken socio-economic factors into account. Is there enough evidence so far to support the genetic theory? In particular, do indigenous people and some other ethnic groups have a genetic and therefore
immutable, rather than merely a metabolically adapted and therefore changeable, susceptibility to diabetes? What does this mean for those individuals or populations? Diane Weiner spent six years researching how patients interpreted the ideas regarding genetics and inheritance. She interviewed two groups of Native Americans who suffered from diabetes, one group in California and a group in Arizona. The majority of individuals sought care from Indian Health Service facilities. Health care workers for IHS are given a patient-education booklet to help familiarize them with diabetes as it relates to Native Americans. In the 1993 booklet, type 2 diabetes was defined as a genetic disorder. Health care professionals believe in the “thrifty” gene, yet their patients are told it “runs in families”. Weiner noted that among both groups, medical professionals were seen as knowledgeable and rarely doubted. Yet, some individuals stated that if doctors could not control or cure diabetes why bother with treatment. As one elder put it:

Myself, I don’t go to the doctor and how would I typically say that? Cause I’m not interested in suppressing symptoms. Now if I crushed the tip of my finger, I’d go to the doctor and have him cut it off or do whatever had to be done. I’d always do that, but I wouldn’t be interested in having it hang there and take pain killers and aspirins and stuff that’s going to- it’s still there, but it’s not cured (127).

This statement exemplifies what McDermott stated as marginalization of certain populations because they have a genetic, therefore unchangeable, susceptibility to NIDDM. McDermott writes, “Thus diabetes in Aborigines (Indigenous populations) has been defined by scientists simply as a problem of “race” and
“genes” in a changing environment. ...repeated studies of disease take no account of socio-economic status, history, or culture” (1998:1193).

While we know more today about diabetes than we did fifty years ago, scientists are still not sure whether all populations throughout evolution expressed a “thrifty” genotype or if it evolved in only some populations. By examining a small random sample of the literature regarding Neel’s “thrifty” gene hypothesis, we can gain a better understanding of how his hypothesis has directed scientific research since its inception fifty years ago. A majority of the articles focused on revealing the genetic causation of diabetes. While they did acknowledge that environment played a role in selection for a “thrifty” gene, none of the articles examined how much environment, including socio-economic factors and culture, effect diabetes outcomes today.

For decades researchers have known that diabetes is a risk factor for TB. According to the World Health Organization, diseases associated with western living standards have become the fastest growing killers in low and middle-income countries. Diseases of affluence and poverty are interconnected; poor people are more vulnerable due to greater exposure to risks and decreased access to health services, while, at the same time, these diseases can push families into poverty or further into poverty (Ezzati et al 2005; Who 2005). Epidemiologists have called for clinical, public health practice, research and policy development that explore the knowledge gaps. They go on to urge for
screening of TB patients for diabetes, and diabetes patients for TB (Magee, Blumberg and Narayan 2010).

As the preceding chapters have shown, the discourse of the “thrifty” gene carries powerful hidden arguments with race as a subtext. Native Americans were viewed not as individuals with complex qualities and histories but rather as undifferentiated social categories. The sudden onset of diabetes in Native Nations was said to be because of their lack of “civilization.” This is a story about how history, policy and science are implicated in the rise of diabetes in Native communities, its racialization and narratives of difference.
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Appendix

Interview Instrument

Type 2 Diabetes Questionnaire

Date of Interview

Place

Time of interview

Basic demographic information

1. Full name.

2. Where were you born? City, State/ reservation

3. Month and year of birth?

4. Marital Status

5. _____married _____single _____divorced _____widowed _____other

6. How long have you been married?

7. Where was your spouse born?

8. How old is your spouse?

9. Ethnic identity of spouse?

10. Father’s place of birth

11. Mother’s place of birth

12. What language(s) did your parents speak?

13. Do you have children? How many?
Childhood

14. Where did you grow up?

15. Would you describe the house you lived in.

16. Describe the sort of food you ate. How many meals a day? Where did you eat your meals?

17. How much variety was there?

18. Would you describe the games you played as a child.

19. Did you suffer any childhood illnesses? What was the treatment?

20. Did your family use home remedies? If so, what? Over the counter medicines? If so, what?

Education

23. Where did you go to school?

24. How many years did you go to school?

Leisure

25. What did you do in your spare time when you were young?

26. How do you spend your spare time now?

Locality

27. Has your local environment changed in your lifetime? How? How will it change in the future, do you think?

28. How would you describe the community you live in?
General understandings of health: I’d like to begin by asking some general questions about health.

29. How would you say your health is in general?

30. What kinds of things do you do to stay healthy? If they say diet, ask them what kinds of food are in a healthy diet. If they say exercise, ask them what kind of exercise they are doing.

31. Why do you think some people get sick and others don’t?

32. Are there any illnesses or diseases that you think Native Americans are more likely to get than other people? What are they? Why?

33. How would you say your health is compared to your grandparents’ generation? Why do you think that?

34. How would you say your health is compared to friends or family?

Type 2 Diabetes in general: Now I’d like to ask you some questions about diabetes.

35. What do you think of when you hear the word diabetes?

36. What is diabetes?

37. What do you think causes diabetes? Probe: Anything else?

38. Why do you think some people get diabetes and others don’t?

39. Do you know anyone who has ever had diabetes?

If yes: Who? What type?

Now I’m going to ask you some questions about genetic predisposition.

40. When you hear “genetic predisposition” what do you think?
41. What is genetic predisposition?

42. Are some individuals genetically predisposed to type 2 diabetes? Why?

43. How do you think genes influence health? a. If yes, what types of problems?

**Now I would like to ask you about your experience with type 2 diabetes.**

44. Why do you think it started when it did?

45. What do you think type 2 diabetes does? How does it work?

46. What do fear most about type 2 diabetes?

47. Do you have type 2 diabetes?

48. When were you diagnosed?

49. What did the doctor tell you about diabetes?

50. In what ways has diabetes changed your life?

51. How many doctors do you see for your diabetes care? (eye doctor, foot doctor, etc.)

52. What would you like to know about diabetes?

53. What would like to tell people about diabetes?