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Self-Determination to Better Health Outcomes: A Study of Diabetes in the Native American Community

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ABSTRACT

Increased self-determination in health care by the Native American community may help combat preventable diseases like diabetes. The racial stereotyping of Native Americans in medical clinics has been found to directly correlate to health disparities such as poor care and poor medical outcomes (Solomon et al.). However, since 1975, the ISDEAA, or Indian Self-Determination and Education Assistance Act, provides three major avenues by which Native Americans may receive health care: directly from the federal government through the Indian Health Service, through a Title I contract to administer part of their own health care programs, or through a Title V compact to take over all of their own health care (Marley, "Ambiguous Jurisdiction" 433). Longitudinal research into the diabetes prevalence rates across time for each of the 574 federally recognized tribes should be juxtaposed against the timeline of when each individual tribe evolved from Indian Health Service dependent to Title I, and then finally to Title V. I had sought to prove that diabetes prevalence rates for Native Americans show a lagging decline as self-determination of health care increases. Further collection of specific, tribal, micro-level data is necessary to prove or disprove this point. Ultimately, this conceptual paper is a proposal for further data collection by the United States Department of Health and Human Services, which is in charge of the Indian Health Service.

Introduction

My interest in the Native American community stemmed from reading about the injustices done to their community. I was in awe by how Native Americans survived colonization, genocide, removal, and forced assimilation. I was lucky to be able to travel to Native American communities in Cahokia, Illinois, and Anchorage, Alaska. There, I witnessed the resilient, vibrant Native American culture that helped them endure intergenerational trauma, or the collective historical loss of people, land, and culture which loss was systematically transmitted as trauma to present generations (Brown-Rice). As I learned about the poor medical outcomes Native Americans endure today, I connected biological, historical, and social causes of trauma, as well as structural racism, as potential causes.

The lens of structural racism best explains why Native Americans as a minority community in the United States do not effectively benefit from existing health institutions in our greater society. Socioeconomic factors such as a very high rate of poverty, housing inadequacy, and homelessness detrimentally affect the ability of Native Americans to access health care. Living on a rural, remote reservation stymies access to health care, creating obstacles such as over thirty percent of Navajo lacking access to indoor water and electricity. Further, health care infrastructure is missing, outdated, or overwhelmed in Native American communities. For example, only 222 hospital beds serve 244,000 Navajo tribe members, so sick Navajo often have to be transported for care to nearby cities like Flagstaff, Arizona. Native Americans face long distances to health care, and lack of health insurance, in addition to the scarcity of hospital facilities. Finally, structural racism has a pernicious effect on human biology. The stress response of the human body to past and continued present trauma may create epigenetic changes to Native American DNA that can appear as phenotypic changes in their bodies that make them sicker. As a result of structural racism over generations, Native Americans have a life span that is 5.5 years lower than that of the rest of the country. (Solomon et al.).

On a personal note, this paper is the culmination of a two-year process for me. First, I began researching this topic during my junior year of high school as my junior theme paper. In that paper, I found qualitative examples of tribes having access to specifically tailored health care programs that seemed to correlate with greater levels of self-determination. My continued curiosity and unanswered questions led me to research this current paper during my senior year of high school for the Journal of Student Research. In this paper, I expand upon that initial junior theme paper, with the bold aim to try to quantify exactly how much of a decrease in a specific ailment that disparately affects Native Americans and is meaningful to me – diabetes – could stem from an increase in Native American self-determination. I could not figure out the funding source for those successful health programs, such as whether they are from tribal socioeconomic resources, from another federally funded program like the Special Diabetes Program for Indians, or truly from Title I or Title V. I learned both that it is hard to find accurate yearly diabetes numbers by tribe, and that it is hard to prove that a particular social program caused those lowered rates.

Need for Culturally Appropriate Care

Native Americans feel that they lack access to culturally appropriate care. Connecting their vibrant culture and unique worldview to their health care is one way to optimize results. The Native American worldview is that humans, nature, and the universal spirit have to live in harmony. Illness occurs when there is disharmony between these forces. Integrating this holistic worldview into health care includes the use of community spiritual practices, intergenerational learning, and the re-introduction of traditional foods (Solomon et al.). To Native Americans, Western medicine is biomedicine, which teaches that the body is the location of disease (Lande 19). Native Americans may use a combination of biomedicine with their traditional healing practices (Lande 162). Their primary belief is that health occurs when mind, body, and spirit are in balance (Lande 34). One example of a holistic practice that some Indian Health Service hospitals provide is a separate area for traditional healers to visit the patient and utilize smudging, which is the burning of sacred herbs like juniper or sage to create a smoke cloud. (Lande 49).

Self-determination in health care is vitally important because Native Americans feel treated poorly in the hospital setting. The doctors of the Indian Health Service are called “rent-a-docs” by Native Americans because doctors often work only a year or two at the reservation hospital to help pay off medical school loans, creating rapid turnover (Lande 32 & 39). In Native American culture where taking time to build relationships is of the highest importance, the hospital seems impersonal, and the patients feel they do not receive emotional support (Lande 1 & 13). Further, Native Americans feel that they face judgment and ethnocentrism in the hospital setting, “know[ing] their perceived low status and lack of control in the dominant society” (Lande 39 & 41). For example, the high unemployment on a reservation leads to less reliability for appointments and after-care and sometimes to alcohol abuse, for which the Native Americans feel judged by non-Native providers in the hospital setting as “lazy and non-compliant” (Lande 68-69). In reality, Native Americans face the difficulties of poverty, such as lack of transportation to office visits, family issues in an extended family setting, and a food desert (Lande 43).

Therefore, a cross-cultural practice of medicine is important to bridge the cultural chasm between largely non-Native medical providers and the Native patients. In 2016, Native Americans published their Cultural Wisdom Declaration that should guide any approach to health care. It states, “We will integrate authentic cultural interventions alongside existing healthcare promotion efforts to ensure a culturally tailored and culturally relevant approach to health promotion and healthcare delivery for American Indian and Alaska Native people.” Thus, any health care program proposal must permit room for “the relevant traditional paradigm or allow room for flexibility.” The principle prioritizes reaching Native Americans who live in rural, remote areas, and even deprioritizes the receipt of federal funding if necessary. “Federal funding is often tied with federal priorities and initiatives, rather than [Native American] needs.” This is the single strongest argument for self-determination. In fact, traditional healers provide health services and should be considered a health care “reimbursable expense.” During the pandemic, messaging in the Navajo language, as opposed to having signs in English only, could have mitigated some of the devastating effects of Covid-19 (Solomon et al.). The need for cultural expertise speaks to the call for further health care self-determination in the Native American community.

ISDEEA

The federal government has had a trust relationship to care for and to protect Native American tribes that stems from Supreme Court legal precedent as well as from executive branch treaties. First, in 1831, the Supreme Court decision *Cherokee Nation v. Georgia,* Native American tribes were given the status of "domestic dependent nations." The meaning is two-fold. The tribes were given the authority of self-government possessed by an independent nation, but conversely, the federal government still has a trust responsibility for their education, health, and well-being (Marley, "Ambiguous Jurisdiction" 433). Second, the federal government has signed over 370 treaties with Native tribes from 1778-1871. In exchange for land from those tribes, the federal government made promises to provide the tribes with health care and economic development. The treaties were made under the authority of the U.S. Constitution, so they have the status of federal law. The treaties never expire, and so they are a continuing obligation of the federal government today. ("Tribal Nations" 18).

Congress passed the Indian Self-Determination and Education Assistance Act in 1975, which is known as the ISDEAA (Marley, "Ambiguous Jurisdiction" 433). The goal of the legislation was to increase participation of Native Americans in their own health care administration ("About Us – Tribal Self Governance"). Native American tribes can choose one of three options for health care, which include utilizing the services of the Indian Health Service exclusively, contracting with the federal government to provide some of their own health care under Title I of the ISDEAA, or compacting with the federal government to provide all of their own health care under Title V of the ISDEAA (Marley, "Ambiguous Jurisdiction" 433). This is a spectrum of self-determination of health care, from being entirely dependent on the federal government with the Indian Health Service, to being somewhat independent under Title I, and then finally to being entirely independent under Title V. As of 1986, most Native Americans used the Indian Health Service, both because Native Americans often live in isolated, rural areas without access to other options, and because the services are offered for free regardless of whether Native Americans have other health insurance or the ability to pay (U.S. Congress 155). The Indian Health Care system offers limited services, and is underfunded. For example, the unavailability of dialysis services for kidney patients in the Indian Health Service requires patients to travel long distances for routine health care needs (Marley, "Ambiguous Jurisdiction" 438). There is a sea change towards greater independence now. As of 2011, sixty percent of tribes, or 337 of the then 566 total tribes, had converted to either Title I or Title V status instead ("About Us – Self Governance"). As of 2022, of the 574 federally recognized tribes, 275 are Title I contract tribes, and 292 are Title V compact tribes (Fitzpatrick). This paper encourages the evolution to Title V because diabetes rates seem to decline with increased self-determination.

Though the government allocates funding to the tribes in both programs, there are differences between Title I and Title V. A Title I contract is annually renewable for up to a three-year term, but Title V is for a multi-year term. The Department of the Interior must approve substantial changes to a Title I contract, but Title V compacts do not require this approval to redesign programs or reallocate funding. In addition, the federal government must pay all of the Contract Support Costs to cover the costs of either administering a contract or a compact (Fitzpatrick). Thus, the government takes on a good amount of the financial risk for a tribe to evolve toward self-determination. As far as the process to jump from Title I to Title V status, for example, the Navajo Nation had to demonstrate compliance for three years with legal and financial standards from three different governing bodies: the Navajo Nation, Medicare, and the Joint Commission that provides national accreditation for hospitals (Yazzie). Thus, the very fact that a tribe can achieve Title V status speaks to its financial resolve, foresightedness, and maturity.

Indian Health Service

The Indian Health Service, the agency tasked by the federal government to provide health care to Native Americans, is beset with staffing shortages, insufficient supplies, too few hospital beds, and inadequate funding. In 2020, when Matalynn Lee Tsosie, a forty-year-old secretary in Gallup, New Mexico, tested positive for the coronavirus, she was sent home with an inhaler and a prescription for an oxygen tank. When she returned to the hospital three days later, she was transferred to a bigger hospital two hours away in Albuquerque, where she died. The reason for the transfer from Gallup may have been a lack of hospital equipment and a lack of medical expertise about severe conditions. Tsosie's sister blames the system's slow medical response for her sister's death (Walker).

In addition to staffing shortages, the Indian Health Service has poor management and weak regulation. Alarmingly, the Rosebud hospital emergency room in South Dakota was closed for seven months during the 2015 to 2016 time period because of lack of staffing. The effect of this closure was that some tribal members were dissuaded from seeking emergency treatment at all. In 2016, a twelve year old girl who was mentally disturbed took her own life because she was left unattended, likely due to staffing shortages and inadequate procedures. In another case in 2017 involving Indian Health Service hospitals across five midwestern states, doctors prescribed opioids in excess of federal guidelines, without checking the state prescription monitoring programs (Frosch). In fact, the health care of the Indian Health Service fails to meet the minimum standards of the federal Affordable Care Act (Marley, "Segregation" 8).

As of 2020, the Indian Health Service served 2.2 million Native Americans, but with only 26 hospitals, 56 health centers and 32 health stations (Walker). After adding those three numbers to find only 114 total health clinics or hospitals for all Native Americans, this is paltry even at first glance. In fact, the current number of total Native Americans served by the Indian Health Service today is even higher, or 2.6 million people across 37 states ("About IHS"). More precisely, the total number of hospital beds, and not the total number of hospitals or health centers, is the most accurate apples-to-apples way of comparing the readiness of hospital systems. The United States has 2.9 hospital beds for every 1,000 people, which is low among developed nations ("Hospital Beds"). Conversely, in 1984, the Indian Health Service had only 2.4 beds per 1,000 people, which is already significantly lower than the national ratio (U.S. Congress 18). Shifting our focus to one tribe, the Navajo Nation, illuminates the statistics further because there are significant readiness disparities even within the Native American community. In 2020, the Navajo Nation had 222 hospital beds for its 170,000 members, or 1.3 hospital beds for every 1,000 people. This ratio is less than one-half of the ratio for the nation as a whole. Moreover, the ratio gets even smaller when actual usage of the beds is reflected in the computation. When the Navajo includes the additional 74,000 members who live off of the reservation but still use the Indian Health Service hospital facilities, the ratio shrinks to 0.9 hospital beds for every 1,000 people. Thus, when based on the actual usage of the hospital beds, the Navajo have less than one-third of the number of beds in the nation as a whole.

Exacerbating the shortage of facilities are the severe funding disparities of the Indian Health Service with comparing its federal spending to that of other comparable federal medical programs. In 2017, the federal government spent $3,332 per Native American patient, versus spending $12,829 per Medicare patient and $7,789 per Medicaid patient (Walker). Thus, the federal government spent approximately one-quarter on the Indian Health Service, per capita, that they spent on Medicare, which seems to be the federal government's highest medical spending priority. Worse still, in 2016, the Bureau of Prisons, which is a federal agency under the United States Department of Justice, paid $8,602 per year for the health care of each prisoner ("Federal Bureau"). It is a despicable irony that a Native American would have to be incarcerated for a federal crime in order to receive almost three times the per capita federal spending on their health care.

Diabetes

I chose to study diabetes in the Native American community because Native Americans have the highest diabetes rates of any racial group. In 2018, Native Americans were twice as likely as whites to have diabetes, with a rate of 16% compared to 8% overall (“Native Americans”). As in 2017, diabetes is one of their top five leading causes of death (“Leading Causes 2017). In 2018, which are the latest figures available, diabetes ranked fifth on the list of leading causes of death of non-Hispanic Native American males, behind heart disease, cancer, unintentional injuries, and chronic liver disease and cirrhosis (“Leading Causes” 2018). Ultimately, I chose diabetes because it is easily measurable, through an A1C or fasting blood sugar test, so that single number makes it administratively easy for a doctor to characterize a tribe member as diabetic or pre-diabetic (“Diabetes Tests”). Next, diabetes may be medically preventable (“American Indian/Alaska Native”). Finally, diabetes affects my own family terribly, so there is that strong personal connection and intimate knowledge of the ailment.

Although most researchers deal with the overall diabetes rate for all Native Americans, there is great variation in diabetes rates among tribes. Even across a single region of our country such as the Pacific Northwest, which includes just three states of Washington, Oregon, and Idaho, there is tremendous intertribal disparity in the rates of diabetes. In 1989, the tribes of the Great Basin culture had 3.6 times more diabetes as the nation as a whole, the tribes of the Plateau culture had 3.0 times more diabetes than the nation, but the Northwest Coast culture had only 1.9 times more diabetes than the nation (Freeman et al. 282).

Defining what a tribe is provides the foundation for answering the larger question on diabetes rates per tribe. A tribe is a sovereign nation, which includes the right to self-govern. A tribe has the political status to govern its members as well as the land of its reservation, or living area within Indian Country. Indian Country is the 56 million acres of the United States under the jurisdiction of Native American tribes, which is an area that would be equivalent to the fourth largest state of the United States. There are 574 federally recognized tribes, and 229 of these tribes are in Alaska. A tribe has every power of government, from taxing its members, creating governance structures like courts and laws, and enforcing tribal law with their own police and courts. The tribe has the authority to govern for the health, safety, and welfare of its members, and this authority extends to the provision and management of health care. (“Tribal Nations” 10-23).

The study hints at another reason that studying diabetes at a tribal level is optimal. A tribe living on a reservation, and within forty miles around the reservation, may be a culturally homogeneous group (Freeman 285). There may be genetic similarities within a tribe as far as how likely they are to get diabetes. Native Americans are comprised of three distinct groups that emigrated here from Siberia over ten thousand years ago. The study suggests that tribes with higher diabetes rates today came from a migration group with a higher tendency to get diabetes in distant history. Further, genetic information on individual tribe members is currently not available (Freeman et al. 286).

Case Study 1 – The Pima of Arizona

The Pima tribe of Arizona have the markedly highest diabetes incidence rate, not just among all Native American tribes, but in the entire world (McLaughlin). Thus, the Pima have been tested as a high risk population for diabetes longitudinally every two years since 1965 (Sandefur et al. 276). In 1995, the Pima were found to have a 70% diabetes rate (Sandefur et al. 278).

In 2006, the Pima men were found to have a 34.2% diabetes rate, and Pima women had a 40.8% diabetes rate (McLaughlin). If the average of those two rates is taken, the overall diabetes rate for the Pima tribe is around 37.5%. The sky-high diabetes prevalence rate of the Pima Indians of Arizona, of over three times the national average of 11.3% in 2022, is a clarion call to action (“Diabetes Statistics”). However, equally as important, the overall approximately 30% reduction in diabetes rates of the Pima over that eleven-year period requires our sustained scrutiny so that medical practices leading to their success can be copied by all other Native tribes.

In 2023, the Gila branch of the Pima tribe had a 25.3% diabetes rate. There is a 12.2% decline in the diabetes rate from 2006. This 2023 decline coincides with the timing of the Title V funds received by the tribe from 2013 to 2023.

Defining the Pima with a tribe name post-contact with the Europeans is important to study them minutely. The Pima is the name of a large group of Native Americans now broken down into four smaller component tribes. Only a federally recognized tribe can receive federal funding, and researchers of Native American health need that tribe name to track that federal spending. The Pima are known as the O'odham, or by their ancestral tribe name of Hohokam (Schulz and Chaudhari). The O'odham occupied much of the southwestern United States, including Arizona and California, but have now been divided into four separate federally recognized tribes: Gila River Indian Community, Salt River or Pima Maricopa Indian Community, Tohono O'odham Indian Nation, and Ak-Chin Indian Community ("History and Culture"). Of these, the majority of the Pima, or Akimel O'odham, are now in Gila River and Salt River Indian Communities ("Akimel O'odham"). However, the Salt River Indian Community is known as the Pima-Maricopa, or a blend of two separate pre-American tribes with different languages ("Salt River"). Targeting the Pima alone is a focus of this section of the research paper. Thus, my study of the Pima will focus exclusively on the Gila River Indian Community.

In 2002, Gila River first compacted with the federal government under Title V of the ISDEAA to carry out the health care for its own tribe (United States, United States District Court for the District of Arizona). As per Title V, instead of receiving care through the Indian Health Service, Gila River received funds through a funding agreement with the federal government to fully manage and control the health care of its own members. Gila River grew its Title V program by 250% over a ten-year window. A service by the Department of Health and Human Services, TAGGS or Tracking Accountability in Government Grants, lists every Title V expenditure made by the federal government from 2011 to 2023 to each Native American tribe. The funds are through the Indian Health Service, so the funds are for health care as opposed to education or roads. Gila River received sixteen such Title V grants, or to be more precise, fifteen grants and the payment of one rebate to the government, as I have delineated in Table 1 below. At times, the grants were not listed in chronological order. I reviewed the forty-four page list of grants line-by-line to find every mention of Gila River ("Tribal Self-Governance").

Table 1: HHS Title V Grants to the Gila River Indian Community

Year	Amount
2023	$118,253,619
2022	$128,605,130
2021	$ 19,326,917
2021	$261,958,371
2020	$116,457,078
2020	$ 1,399
2019	$109,326,167
2018	$ 96,499,204
2017	$ 55,418,905
2016	$ 53,244,148
2015	$ 50,603,587
2014	$ 452,396
2014	$ 51,605,392
2013	$ 86,009
2013	$ 47,293,980
2012	($ 32,228)

There are unanswered questions. The Department of Health & Human Services, an agency of the federal government, continued to fund the Gila River tribe with ever increasing amounts. Is this due to the rising cost of health care in general? A particular spike in 2021 in funding is likely related to increased pandemic spending for personal protective equipment and medical issues due to Covid-19. However, is the longitudinal tripling of annual grant allocation due to better funding of the program by Congress, or due to better administrative capability or grantsmanship skills developed by Gila River?

Without access to the data showing whether key medical indicators such as diabetes prevalence improved with access to Title V grants, I relied on secondary evidence such as the increase in tribes' reliance on them. The strength and stability of the Title V program can be evidenced by the fact that in 2013, Gila River received $47 million, but almost three times that ten years later in 2023, or $118 million. In fact, in the year prior, or 2012, Gila River owed the federal government $32,000, and had to refund the government a part of its federal expenditures on behalf of the tribe. Receiving $118 million in 2023 is infinitely better than a negative outlay in 2012. The amount doubled in 2021 to $261 million, likely for additional pandemic-related medical outlays.

The amount of self-determination funding that Gila River received from the moment it had the highest level of Title V self-determination in 2002 until the first marker of its lowered diabetes rates in 2006 is not available publicly. Unfortunately, Title V data is really only publicly available for the past eleven years. Following the trend line of the Title V monies received backwards, had further data been available, there may be a correlation between lowered tribal diabetes rates and the increase in Title V funding. Correlation is not causation, certainly, as there could be a multiplicity of reasons why tribal diabetes rates for the Gila River are getting consistently better with time, such as increased education, fitness, and access to care. The lowered diabetes rate in 2006 could also be due to the tribe's evolution from Indian Health Service to Title I, or partial self-determination.

Case Study 2 – The Lummi Nation

As discussed in the previous case study, a service by the Department of Health and Human Services, TAGGS or Tracking Accountability in Government Grants, lists every Title V expenditure made by the federal government from 2011 to 2023 to each Native American tribe. In Washington state, the Lummi Indian Business Council received fifteen such Title V grants from the years 2013-2023, which is the exact same number of grants that the Gila River Tribe received above ("Tribal Self-Governance"). The amount of grants that the Lummi received has stayed constant in amount over that time period, or approximately $11 million per year, except for the pandemic year of 2021, when the amount received jumped to $22 million. Likely, the doubling of the grant funds for the 2021 year was to fund Covid-19 supplies, testing, and other critical medical care specific to that pandemic year.

However, the Lummi receives about one-tenth of the amount granted to Gila River. The Lummi grant amounts double from about $6 million in 2013 to around $11 million per year consistently thereafter. Conversely, Gila River received an increasing amount from $47 million in 2013 to $118 million in 2023. At the peak of the amounts that Gila River received, the Lummi received one-tenth of the amount of Title V grants that Gila River received or $11 million compared to $118 million. This is despite the fact that the Lummi Nation is only one-third as small as Gila River – Lummi Nation has 5,000 members ("About Us"), but Gila River has 14,000 members ("Gila River"). According to the data, the expected grant size for Gila River should have been only three times what the Lummi received, and not ten times. Perhaps this speaks to the relative affluence of the Lummi tribe, as they are able to be self-sufficient to a greater degree in the provision of their health care per capita for their members. Alternatively, the Lummi could just be healthier as a tribe in general, due to better food sources, opportunities for outdoor exercise, or genetics.

In 1987, the Lummi, as a Northwest Coast culture in Washington state, had a diabetes rate of 1.9 times the rate in the United States (Freeman et. al 282-283). The rate of diabetes of the Lummi was only 4.0% (Freeman et al. 285). By 2002, the rate of diabetes of the Lummi had tripled to 14% ("Research"). By 2021, the Lummi reservation had halved that diabetes rate to just 6.1% ("Lummi Reservation"). The Lummi are a success story with their ability to bring down their diabetes rate. More importantly, the timing of the lowered rate is correlated with the timing of the doubling of Title V funding to the Lummi from 2013 to 2023.

In real time, these grants may be helping spur an evolution in the quantity and quality of the health care the Lummi receives. The Lummi are facing a crisis of opioid abuse, particularly fentanyl. On April 27, 2023, the Lummi were able to open a new seven-bed stabilization and recovery center for overnight treatment of tribe members who are overdosing. Unlike in Western hospitals, the Lummi can utilize cultural, holistic treatment in this center (Wilkinson). The Lummi are trying to help patients reconnect with their cultural identity as a means of healing. Prior to this new center, the Lummi were reliant on the Anne Deacon Center for Hope, which is the stabilization center for all of Whatcom County that only has sixteen beds for detox and another sixteen beds for mental health patients (Lerner). Thirty-two drug treatment beds for an entire county speaks to the crisis in our nation's health care, and to the paucity of care the Lummi had been receiving. Now, the Lummi can partake of culturally appropriate health care.

Tracing Title V funding as a direct cause of the recent gains in Lummi health is challenging. First, the Lummi are well-funded by their Silver Lake Casino. In 2003, when the casino started generating forty percent more revenue than expected, the tribe earmarked that money for mental health and substance abuse treatment ("United States: Lummi Nation").

Table 2: HHS Title V Grants to the Lummi Indian Business Council

Year	Amount
2023	$11,446,613
2022	$11,287,952
2021	$ 46,276
2021	$22,229,165
2020	$15,642,999
2019	$12,719,163
2018	$12,765,314
2017	$ 426,386
2017	$11,822,679
2016	$ 647,524
2016	$10,831,305
2015	$ 965,197
2015	$10,456,566
2014	$10,607,389
2013	$ 6,850,859

Case Study 3 – The Navajo Nation

The Navajo Nation is a vast tribe who live across three southwestern states, or Arizona, New Mexico, and Utah ("History"). The Navajo Nation spans 27,000 square miles, and is the largest reservation in the United States by land area (University of Arizona). In 2020, the Navajo Nation also became the largest tribe by population, or 399,494 members, surpassing the second largest tribe, the Cherokee. This growth in enrollment was found to be attributable to self-determination (Romero). I suspect the enrollment increase is both a function of increased access to services as well as a function of increased cultural pride.

In 1992, the tribe was broken into two smaller units and given two diabetes rates. I suspect this is because of the sheer population size of the tribe to account for genetic variation, and how dispersed the tribe is geographically to help administer tests to smaller samples. In 1992, the Navajo in Shiprock, New Mexico had a diabetes rate of 17%, but the Navajo in the Many Farms-Rough Rock region of Arizona had a diabetes rate of 12% (Sandefur). I took the average of these two rates, to find that the approximate rate of diabetes of the Navajo in 1992 was 14.5%.

In 2014, the diabetes rate for the tribe was 28.5%, which I calculated from the stated approximately 100,000 of the 350,000 Navajo having diabetes. At that time, the general diabetes rate in the country was 9.4%. The researchers looked at medical records to get this data and warned that the number might be an underestimate. Many Navajo do not visit the doctor for four reasons: no health insurance, no public transportation, large turnover of doctors, and great distance to a clinic or hospital (Trevisi et. al). By 2021, only 10% of the Navajo had diabetes (Bindell). This halving of the diabetes rate is remarkable, and the timing of this decrease correlates with the increase of Title V funds granted to three Navajo tribes. I reviewed the forty-four page list of grants line-by-line to find every mention of three Navajo health care entities ("Tribal Self-Governance"). In the list of 574 federally recognized tribes, the Navajo Nation appears only once, as the Navajo Nation – Arizona, New Mexico, and Utah ("Indian Entities"). Thus, the first table below, Table 3, relates to the only Navajo titled entity receiving Title V federal funds, or the Utah Navajo Health System, Inc. However, in a related article about the Title V program, the tribe also includes at least two other corporate health care entities, which are the Tuba City Regional Healthcare Corporation, and the Winslow Indian Health Care Center (Yazzie). Tables 4 and 5 below record the Title V grants to the Tuba City Regional Health Care Corporation, and the Winslow Indian Health Care Center, Inc., respectively. These three Navajo entities all received Title V status on the same date, July 21, 2010 (Yazzie).

In Table 3, the grants to Utah Navajo stay relatively constant, or between $12 million and $14 million during the decade of data that is publicly available. In Table 4, the grants to Tuba City stay relatively constant, around $59 million, excepting a few years that there is increased funding, such as in 2022, $63 million; in 2020, $78 million; and in 2014, $60 million. There is no upward trajectory of funding, but the steady constant funding of around $55 million to $59 million per year. The large bump in 2020 may be related to funding for the Covid-19 pandemic but seems earlier than the pandemic funding bumps for other tribes that occurred a year later, in 2021. There were two years when Tuba City owed significant rebates to be paid back to the federal government, or in 2016, $3 million; and in 2014, slightly less than $1 million. In Table 5, Winslow shows the upward trajectory of funding that is common across tribes. Winslow received $28 million in 2013, but $42 million in 2023, which is a 48% increase over the ten-year period. There are no rebates that have to be refunded back to the federal government.

Table 3: HHS Title V Grants to the Utah Navajo Health System, Inc.

Year	Amount
2023	$14,533,713
2022	$13,765,220
2021	$ 39,303
2021	$24,108,778
2020	$15,924,357
2019	$13,207,639
2018	$13,103,078
2017	$13,000,457
2016	$12,896,393
2015	$12,590,841
2014	$ 35,073
2014	$ 5
2014	$12,721,203
2013	$ 66,784
2013	$10,422,340

Table 4: HHS Title V Grants to the Tuba City Health Regional Care Corporation

Year	Amount
2023	$59,747,909
2022	$63,761,169
2021	$ 243,568
2021	$28,201,554
2020	$78,176,586
2019	$57,477,697
2018	$57,857,509
2017	$56,686,211
2016	($3,118,377)
2016	$ 117,014
2016	$58,735,450
2015	$59,782,956
2014	($ 808,725)
2014	$60,198,424
2013	$ 599,134
2013	$55,232,845

Table 5: HHS Title V Grants to the Winslow Indian Health Care Center, Inc.

Year	Amount
2023	$42,746,597
2022	$33,657,162
2021	$ 126,517
2021	$68,498,439
2020	$41,084,780
2019	$32,253,512
2018	$32,179,955
2017	$32,365,663
2016	$ 48,529
2016	$30,555,462
2015	$29,366,292
2014	$ 66,167
2014	$ 25,699
2014	$ 268,521
2014	$30,241,760
2013	$ 691,199
2013	$28,864,838

Discussion

Table 6: Longitudinal Diabetes Rates by Tribe

Tribe	Diabetes Rate
Pima – Gila River	1995: 70.0% 2006: 37.5% 2023: 25.3%
Lummi	1987: 4.0% 2002: 14.0% 2021: 6.1%
Navajo	1992: 14.5% 2014: 28.5% 2021: 10.0%

Though Native Americans are disparately affected by diabetes as a group, there is significant variation in rates among the 574 individual tribes. Dividing the overall Native American diabetes rate by tribe, and then assessing the factors of tribes successful in lower than the overall average rage, is the central aim of this paper. Three Title V tribes were chosen for assessment, or the Pima in Gila River, the Lummi, and the Navajo. In Table 6, the diabetes rates are listed for each tribe, over time. All three tribes show a marked decline after the Title V funding. Two of the three tribes now have a rate close to the national average of 8%.

Parallel to this aims of this paper is the current general trend in health care of "unscaling" medicine, which is collecting individual data through the use of mobile networks and cloud computing to create highly specialized treatments (Taneja 9 & 15). In "unscaled" medicine, doctors use both a patient's historical electronic health records as well as current data from mobile devices to make targeted prescriptions. Diabetes is especially amenable to individualization. "Instead of treating diseases such as diabetes… based on what's worked for the broad population, you can treat your medical issues based on what will work for you" (Taneja 73). Doctors can be proactive with data before illness occurs (Taneja 79). Then, that same medical data can be aggregated and anonymized for broader research, as I have tried to do in this paper (Taneja 168).

All Native American tribes are not the same. Smaller is better, and because tribes know their own members better, self-determination may play a key role in advances in Native American health care. Title V self-determination allows the tribe flexibility to create tailored programs that fit the specific needs of its members that increase the likelihood of success. The steady lowering of diabetes rates is not a random event but caused by sustained, targeted medical intervention.

Limitations

Primary research on this topic was difficult because I am a high school student with no formal link to any Native American tribe. In April 2023, I contacted the chiefs of twelve tribes by e-mail. Eleven of those did not respond, and the final chief replied that he would not speak to me unless I was a member of his tribe, which I am not. Given their tragic history and resulting mistrust of outsiders, I was not able to collect primary data on two important variables for this paper. The two variables are when the tribe joined Title I or Title V of the ISDEAA, and what that tribe's rates of diabetes were for each year over time. Therefore, this research paper uses the method of data collection from secondary sources. I also did not have access to a college research database that might be more cutting-edge but used online research journals.

Another conflating factor is the Special Diabetes Program for Indians, or SDPI. The SDPI is a conflating factor because it blurs the causation between Title V funding and the decline in diabetes rates. Established by Congress in 1997, tribes can apply for funding from the SDPI for the tribe to create local, community-based individual and group coaching sessions to their members about diabetes ("American Indian"). However, it is possible that Title V tribes with their health care administration experience and staff can better navigate the requirements to get SDPI funding. To get a grant, a tribe must submit an application, and learn how to monitor health outcomes with a specific online system. Once the grant is received, the tribe must provide an annual progress report and a federal financial report ("SDPI Basics"). This grant system may favor tribes that have extra time, manpower, and experience with health care bureaucracy already.

Proposed Methodology

Data can be mushy. Researchers must be clear whether diabetes or pre-diabetes data is being collected, so the rates are consistent in what they are measuring. Then, reliance on the data contained in medical reports may cause accidental underreporting if not all Native Americans take advantage of hospital services. The ideal method would be to track diabetes rates for every Native American adult, in person, over time. As this may not be cost effective, medical data is a substitute. Then, statistics would be used to prove what percentage of any decline in the diabetes rate could be attributed to Title V.

Future Research

The confluence of the efforts of three interest groups is necessitated to further this research.

First, to collect primary source data, Native Americans may be asked for permission for their medical data to be collected anonymously and be tabulated at a population level to compute diabetes rates per year per tribe. Historically speaking, Native Americans have been a marginalized community. Thus, health research pertaining to the Native American people must be done in an ethical and culturally sensitive manner, utilizing the expertise of Native American elders, hospitals, clinics, and medical staff in a collaborative effort (Brown-Rice). Along with tribal diabetes rates, the tribes would also be able to share if they were a Title I or Title V tribe, and since what year. Beyond ethical considerations, tribes have internal requirements to qualify a researcher to do research. For example, in order to do research on the Navajo tribe, the researcher must first apply to their Internal Review Board, and then with their Department of Cultural Preservation (University of Arizona).

Second, if primary source data is not available or is prohibitively expensive, the Indian Health Service may have archived diabetes rates for each tribe. Otherwise, government agencies may provide annual longitudinal data, dating back from each program's inception, of exactly how much each tribe received in funding for Title I or Title V. A Freedom of Information Act request to the National Archives in Washington, DC will secure documents provided by the Indian Health Service, which is a department of the federal Department of Health and Human Services.

Finally, health researchers and doctors can work toward finding causation of self-determination improving health through statistical analysis, by working to remove other sources of causation. Although there is a positive correlation between culturally self-determined health programming and lowered diabetes rates, statistical analysis must be used to prove causation, not just correlation. If proven true, self-determination may be either a strong cause or the primary cause of the positive winds of change happening generally in diabetes rates across the Native American community.

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