

## Topic of Interest

### **Disparities in healthcare: a focus on Native American Women's health and the system that is failing them**

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#### **Introduction**

Women's health care has always been a hotbed for public attention. The upcoming presidential election and new state-level laws targeting reproductive rights have only brought these issues into greater prominence. While reproductive rights are an important topic on their own, we also need to talk about a subset of the greater issue that is often swept under the rug, to talk about women's healthcare disparities on Native American reservations. Unless you live close to a reservation, you may have never thought to consider that a disparity even exists. Yet, as a female tribal member who has lived on the reservation most of my life, this issue is of paramount concern ethically, socially and morally.

Health disparities on the reservation - and particularly for women's health care - are comparable to those in third-world countries. Suicide rates are among the highest in the northern hemisphere and are four times higher than the national rate for persons aged 15-25. Native Americans are twice as likely to commit suicide than any other minority group.<sup>1</sup> Their life expectancy has the lowest rate in the United States, ranking only above Haiti in the western hemisphere, with women living an average of 52 years.<sup>2</sup> The infant mortality rate is five times the national average, and the prevalence of cervical cancer is five times higher.<sup>3</sup> Over half of Native American women are under the age of 20 when they become pregnant with their first child, with a shocking rate of 1 in 3 women having

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been raped in their lifetime.<sup>4</sup> Native American women also suffer five times the murder rate of non-native women with a 40% domestic violence rate.<sup>5</sup> In 1994, a South Dakota Native American Youth Behavior Survey indicated that 81% of high school seniors reported having had intercourse, but of those seniors who had, 92% reported the encounter to have been forced upon them.<sup>6</sup> One may want to assume that these issues are caused solely by a lack of resources or lack of education, and while this is in part true, it does not address the more nuanced truths behind the inequality of health care and particularly women's health care. The problems are myriad, and I would like to explore a few of the most concerning. Based on my personal experience as a tribal member and as a medical student outside of the reservation, and on facts about the nature of the health care that is actually provided, I want to show you a system that is failing the Native American people.

### **Socioeconomic Burden**

Reservations, especially those in South Dakota, are some of the most poverty-stricken areas in North America. In this essay I would like to focus on the reservation that I am a member of, the Pine Ridge Indian Reservation, home of the Oglala Sioux Tribe. A 2005 study done by Colorado State University provides some shocking statistics about the tribe. Approximately 97% of the Oglala people were living at or below the poverty line. The average annual income was \$6,286 USD. This level of income stands in stark contrast to the national average of \$56,957 USD per capita. The tribal unemployment rate is 85%-95%

with an absolute paucity of industry, technology or commercial infrastructure to minimize the employment gap. The dropout rate for both grade school and high school is over 70% with little enforcement of a state-mandated law requiring mandatory attendance until the age of 18.<sup>7</sup>

Tribal members have been reliant on government assistance since their reservation was established in 1851. Generation after generation of people have become entrenched in programs that were designed to support their relocation. My family likes to refer to it as the "welfare cycle", a term which was actually referenced by Gurr in her article regarding reproductive justice and Native American Women.<sup>8</sup> Our people have known no other way to exist other than at or below the poverty line for the last 163 years. My own friends, who tried to break the cycle by picking up extra shifts or by taking raises they deserved, find their best efforts undermined by the loss of or increase in cost of the childcare they so heavily rely on as single mothers. As a result, their ability to rise above the cycle of poverty they have been living in becomes increasingly unattainable. This example is just one simple demonstration of a system in place to keep our people in "the cycle".

Transportation provides an example of an even greater issue that limits the ability of those living at or below the poverty line and in relatively isolated areas (as is the case on reservations in South Dakota) to seek adequate health care. Vehicles are not readily available on the reservation. A few families can afford to share a car or truck, but, in fact, most of the time families cannot afford a

vehicle at all. The Pine Ridge reservation is approximately 3,468 square miles, making it larger than Delaware and Rhode Island combined. Despite the very large land area, only two clinics and one hospital are located inside the boundaries of the reservation. The Aberdeen Area Health Services Master Plan of 2003 states that facilities at a travel distance equal to 30 minutes are considered “accessible” for primary care and that a 2 to 3 hour drive to receive “appropriately tiered, shared, and culturally sensitive specialty services” is “accessible” for Indian Health Services clients.<sup>9,10</sup> In actuality, the primary-care clinics are 40 miles from each other, and the one IHS facility capable of emergency and specialty services is over 90 miles away from the clinic located in Wanblee, SD. While these distances fall within the Indian Health Services “accessible” category, they are, in fact, a colossal limitation to Native American women needing timely, regular, emergent or, frankly, any health care whatsoever beyond basic clinic visits. Thus, for women needing even basic clinic care, the clinics they need to use are 45 – 60 minutes from each other by car. When taking into account the large number of women living more than 20 minutes away by vehicle but with no real means of transportation, it is easy to imagine that most would have trouble getting to the clinic at all.

Finally, the link between low income and poor health needs to be considered. Poverty is a primary risk factor for a variety of health concerns such as teenage pregnancy, sexually transmitted diseases, domestic violence, premature death, diabetes and a list that goes on and on. This relationship has been

extensively studied and persists across cultures, showing that there is a link between this economic group of people and burden of disease. In fact, I postulate that increased health risk for low income populations results from a combination of factors that are associated with poverty, including lack of quality education and lack of access to greater financial resources.

I have lived in an area where almost everyone is below the poverty line and where, growing up, almost all my friends were in this socioeconomically burdened class. As a result, I have witnessed firsthand the sequelae that come from living on the reservation. I went to a small country school located on the northeast corner of Pine Ridge Reservation. We had countless lice checks, with some of my best friends being sent home time after time, only to come back with shaved heads, until the school nurse would eventually delouse the children herself. As I got older, I noticed that some of the poorest kids had “fend for yourself” attitudes and would steal anything they could get their hands on. A large majority of parents and caregivers had severe alcohol and drug addiction, and their children would come to school day after day in the same clothes, or maybe even wearing shorts in wintertime. As we grew older, my friends became calloused. Girls were molested, dropped out of school and became teenage mothers when their own mothers were barely in their 20’s. It is a sad song my people sing. Only by exposing these painful truths about life on the reservation can we ever seek to make change.

### **The role of the United States Government and Indian Health**

## **Services**

The Indian Health Service (IHS) became a federal entity in 1955, drawn from roots in the early Treaty period. IHS has been consistently underfunded by the Congress and the President. It has historically been funded at lower levels than similar programs within the Department of Health and Human Services such as the Veteran's Affairs system and Medicaid. The United States Commission on Civil Rights stated, "the anorexic budget of the Indian Health Service can only lead one to deduce that less value is placed on Indian health than that of other populations and, further, that the failure of Congress and the President to meet the government's obligations and responsibilities to Native people in the provision of health care can only be attributable to either intentional discrimination or gross negligence".<sup>10</sup>

Having received care at IHS facilities for the majority of my life, I have lived firsthand the consequences of this gross underfunding. While there have been some improvements in recent years due to a \$500 million-dollar grant given to update the utterly outdated facilities, the harsh truth is that these facilities have been in a state of neglect since they were built in the 1950's. The problem reaches further than just facility updates and medical equipment, though. Due to the nature of its relationship with the federal government and the limited funding it receives, IHS funds are discretionary in nature. Therefore, IHS provides healthcare services only to the extent that appropriated funding allows.<sup>4</sup>

In the article *No Exceptions Made: Sexual Assault against Native American*

*Women and the Denial of Reproductive Healthcare Services*, author Rebecca Hart states, "That is to say, due to the extraordinarily low level of federal funding for IHS, there is no guarantee IHS will pay for doctor visits, test, and/or procedures deemed necessary because IHS may not have sufficient funds to pay for the service".<sup>4</sup> The United States Commission on Civil Rights found that IHS operated with only 59% of the funds it needed to provide adequate health care and, adjusting for inflation, IHS per capita spending on health care has fallen. The same group also stated that the government spends 50% more on healthcare services for prisoners and those on Medicaid than it does for Native Americans.<sup>11</sup> In fact, IHS has been known to force neighboring facilities to the brink of collapse from failure to reimburse emergency room visits.

Such was the case in Bennett County, South Dakota, in 2013. Bennett County is a non-reservation county located between the Pine Ridge and Rosebud reservations in southwestern South Dakota. A small hospital is located 45 miles away from Pine Ridge, in the middle of a large Native American population. Emergency room visits to this hospital are crucial to the indigenous population. In 2013, Indian Health Services was in debt to the Bennett County hospital for millions of dollars for years of backdated ER visits. The main response from IHS to the Bennett County Hospital claims was that hospital providers should have only treated "non-emergent" patients and that the patients with unpaid claims should have been sent to the larger Pine Ridge facility, which is much farther away. Thus, the Aberdeen Area IHS denies

reimbursement believing that, although Bennet County Hospital has been able to provide care for such persons, emergent patients must travel further by ambulance at greater risk to seek treatment in an overcrowded hospital that, through no fault of its medical staff and providers, requires long emergency room waits in a location where patients have died before receiving emergency assessment or care simply because “that’s the way the system works”. In other words, the use of outdated metrics, underfunding, understaffing and lack of compassion at IHS has basically closed the doors to medical care for low-income Native Americans that lack their own transportation in a geographically isolated area. This is just one example of how bureaucratic failures, administrative mismanagement and federal ignorance affect health and safety outcomes for a population that has seldom had access to the same healthcare options available to the rest of America.

Poverty, lack of transportation and limitations created by the current IHS system affect all levels of Native American communities -- including women’s health care. And, when women’s health care suffers, families suffer. Countless issues exist, including limited birth control options, increased rates of surgical sterilizations and a paucity of sexual assault resources, to name a few. The limitations on these resources in the year 2019 are frankly overwhelming.

The Indian Health Care Improvement Act outlines the United States government’s long-recognized trust, treaty-based, statutory obligation to provide health care for Native American populations and, as

such, it is subject to a variety of legislation that affects the disposition of relevant funds and policy. In 1976, the United States Congress attached a rider to this Act called the Hyde Amendment, which was updated in 1996 and which is renewed on a yearly basis. The Hyde Amendment prohibits the use of federal funds for abortion unless the pregnancy results from rape, incest or health issues that pose a threat to the mother’s life.<sup>12</sup> Since IHS is completely funded by the government, the Hyde Amendment effectively bans abortion for Native American women for any other reason than those stated above, which only deepens the crisis of unwanted pregnancy.

To compound this problem, the Native American Women’s Health Education Resource Center reports that 85% of IHS facilities are not in compliance with IHS and Hyde Amendment regulations.<sup>12</sup> This means that they either do not have abortion services available or will not refer to abortion providers even for women who meet the rape, incest or personal safety criteria. Furthermore, pharmacies at IHS facilities do not keep medications on hand for medical abortion even though they claim to provide all FDA approved medication. Therefore, even if a woman becomes pregnant due to rape or incest or if her pregnancy endangers her health, she will, most likely, not be able to receive appropriate abortion care at her local IHS facility. In South Dakota, this means either taking the chance that the assault did not result in pregnancy or driving 6 hours to Sioux Falls to seek treatment that may not be covered by IHS funding. This means that, given the transportation problems inherent on the reservation, women who

were criminally impregnated or whose lives are at risk as a result of pregnancy have very little chance of getting legal, appropriate, life-saving medical care. The injustice here demonstrates the ongoing failure of both Indian Health Services and the federal government to meet the terms and promises of the contract they made with the tribal people over 150 years ago. It also highlights how a government can, either by omission or intent, deprive a unique but marginalized ethnic minority access to the same rights and privileges afforded to anyone else, including not only other citizens but also prison inmates, the institutionalized mentally ill, immigrants and international guests.

Indian Health Services is also failing the victims of sexual assault. The rate of sexual assault is 3.5 times higher in the native population than in the general population, and 1 in 3 women will be physically assaulted in their lifetime.<sup>12</sup> This issue is predominant enough to have been addressed in the Senate Committee on Indian Affairs. Nevertheless, residents of reservations do not have access to the same systems, resources or support as women in other segments of American society. Sexual assault takes both a physical and mental toll on its victims, and most communities have a comprehensive and structured system to address the needs of victims. This level of support does not exist in any functional capacity at IHS hospitals, despite the statistically high odds that a Native American woman will face a sexual assault in her lifetime. As a result, Native people have taken issues related to victims of sexual assault into their own hands, establishing organizations such as White Buffalo Calf Woman for support

and services outside of the Indian Health Service. A study done by in 2005 by the Native American Women's Health Resource reported that 30 percent of responding IHS facilities did not have a clear protocol in place for the treatment of sexual assault survivors or the collection of forensic evidence. Of those facilities that did have a protocol in place, only 56 percent reported that it was posted and accessible to staff members. The same study also found that 44% of the facilities lacked personnel trained to provide emergency care to survivors of sexual violence. This means that even if a woman who has been attacked on the reservation is able to find a way to travel to the main IHS hospital located 2 to 3 hours away, there is a good chance that the resources she needs will not be available once she gets there. Hence, the system once again fails Native American women.<sup>13</sup>

### **Perceptions of Health Care among Native Americans**

The failings of IHS and the United States government deepen the distrust of Native American people in the systems that were meant to serve them. Indian Health Service, particularly on the Pine Ridge Reservation, is viewed negatively by the same people who have no choice but to rely upon it. Due to both the geographical and financial restrictions that this population must live under, they are often caught in a game of "something is better than nothing". In fact, most tribal members that can receive health care elsewhere will. For example, if a tribal member has reliable transportation and private insurance, they will preferentially travel to non-IHS facilities to receive care, although these are guaranteed to

be over an hour away. In my time as a medical student, I have watched how hard many women will fight to be put in another underfunded government program, Medicaid, just to be able to get the care they need. Their willingness to be anywhere but IHS speaks volumes to the Native American perception of the health care that the government has forced upon them. Add to this a general distrust of the federal government due to the many other promises not fulfilled, and you have a very dissatisfied and underserved population.

Frustration with the IHS system occurs at every level of medical care. My own personal experience with the inadequacy of IHS has happened as a patient, as a sister and as a medical student in an outside facility. For example, when I was eight years old, I was bitten by a dog that tore a hole through my cheek. My parents, being reliant on IHS for medical care, drove me to Pine Ridge, two hours away, and, after waiting many hours in the emergency room, I was finally seen. I distinctly remember how overwhelming that ER was, and how there was not enough room for everyone. I also remember my mother screaming in rage as I was about to be placed on a blood-soaked cot. After my mother had forced the issue of a clean bed, I was stitched up almost 6 hours after arriving at the ER and 8 hours after I was injured. All in all, it was a long, frustrating, terrifying day for a little girl with a relatively minor injury.

But working with IHS services is not just problematic for patients needing emergency care. It is also difficult for patients with long-term medical needs. For example, I am the sister of a hearing-impaired brother. When he was young,

we traveled to Pine Ridge Hospital once a month to get audiology care. At that time, a provider came just one day a month to render these services. One audiologist, one time per month, for a reservation with a population of 30,000. Thus, despite our 8 a.m. appointment time, we would be there often until 4:00 p.m. before being seen. The burden on my parents with time missed from work, missed wages and stress was enormous. Once again, this highlights how “free” medical care comes at remarkably high cost under IHS policy and procedures.

Sad as these situations might be for patients requiring emergency or long-term care, the personal cost of IHS care is absolutely heart wrenching for those who are most fragile and who face life-or-death situations. As a medical student, I saw the failings of IHS and its policies firsthand. One example that sticks out in my mind occurred when I was at the Winner, South Dakota, hospital doing a rural rotation. I was on call when a possible bowel obstruction came into the ER. This was a very serious condition with very high morbidity and mortality if not addressed urgently. The patient had a history of bowel obstruction and consequent necrosis resulting in a previous partial colectomy. After being seen at the Rosebud IHS clinic with symptoms reminiscent of an earlier episode, he was transferred by IHS to Winner, which was an hour drive from Rosebud, with some very unusual medical orders. He was sent with the strict instructions to only perform ultrasound evaluation, which is the wrong imaging test for this condition. He was not to have a Computed Tomography scan or have a surgical consult, despite there being two general surgeons

available at the hospital. If evidence of necrosis and/or obstruction were seen on the ultrasound, he was to be sent back by ambulance to Rosebud, to then be flown to Rapid City Regional Hospital.

In other settings, this case might be seen as medical negligence at best or as malpractice at worst. First, the patient's care was delayed at least 6-7 hours by this unwarranted transfer to receive limited services at another facility. Secondly, the acuity of this condition was completely dismissed by the refusal of an available surgical consult. Lastly, although IHS cited funding issues as the reason for this bizarre procedure, no one at IHS seemed to have considered the fact that this patient would incur the cost of two ambulance rides and a plane ride during this encounter.

These three situations that come from my own experience are negligible in comparison to the many more that happen on a daily basis and speak volumes to the gross mismanagement of not only patient well-being and health, but also the allocation of funds. Situations such as these not only diminish the reputation of the IHS in the eyes the people it serves, but also in the eyes of outside providers, who are frustrated by the fractured care and the seemingly random services and processes employed. Overall, IHS providers express immense frustration with the system which they feel limits their ability to adequately do their jobs.

### **Possible Solutions**

In 2019, a small glimmer of hope for improved health care for Native Americans in South Dakota took place. In

an effort to reduce the inequities of the broken IHS system, the tribe took over management of an IHS hospital in Sioux City.<sup>14</sup> In theory, tribal management would reduce the cost to IHS for maintaining the facility, making more funds available for the costs of diagnosis and treatment. In most cases, privatization of hospitals allows leadership and care providers to incorporate better policies and practices, which help to improve both the quality and quantity of providers available at the facility. In actuality, however, years of neglect have left the Sioux City hospital in need of upgrades and refurbishments just to raise it above its sub-par standards. Because of the extreme poverty of the region and a general lack of supportive external funding sources, the tribe has had to develop a multi-year plan to improve the facility enough to meet even the basic needs of the reservation population. Once again, the local indigenous population is forced to wait and wait and then wait some more, just as they patiently have since 1955.

Based on my own experience, I would like to postulate a solution that, anecdotally, most people on the reservation seem to also agree with. As a tribal member, I would like to see IHS be discontinued, if not abolished completely. If this were to happen and the people IHS serves were placed on Medicare and Medicaid, this population would be free to receive health care at any facility they wished, ending the restrictions placed on them that effectively keep them contained to the reservation. In this way, members of the reservation population would not only have equal access to the same, minimal healthcare insurance as any other



resident of the United States, but they could also help bring an end to one of the last vestiges of systemic ethnic segregation in the American healthcare system.

### **Conclusion**

Federal provision of medical care for Native Americans is a complex issue with a long and drawn out history. Members of the U.S. government have spoken often and vehemently about healthcare reform in recent years. Too often, promises made are promises broken. When reform does occur, it is often a decades-long process to fill the gaps and fix the rough spots in legislation that may have resulted more from cronyism and ethnic stereotyping than from caring and careful research. In the meantime, people still suffer, and people still die.

As a result, health care on the reservation and especially that serving Native American Women is wrought with dysfunction, underfunding and absolute disregard for human rights. As a member of this community, I have seen firsthand how these issues are overlooked, disregarded and swept aside. The system has failed us. It has failed men, women, children, even entire families for generations. We can only hope that someday these injustices will be righted, and, to that end, we must strive to be a part of the solution. Nevertheless, I must admit, given the magnitude of the problem, we in the Native community have a sense of hopelessness that this will never occur, making the situation truly heartrending. Therefore, we Native American women must band together and continue to try to help each other as mothers, grandmothers, sisters and

daughters. We must continue to sing our song of woe, until perhaps, someday, someone will listen.

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