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The Process of Reclaiming Tribal Sovereignty Through Healthcare Autonomy

Karolina A. Serhan

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The Process of Reclaiming Tribal Sovereignty Through Healthcare Autonomy

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Abstract

This honors thesis explores the complex interplay between health status, healthcare, and tribal sovereignty among native communities in the United States. These relationships are explored through analyzing the paradoxical and condescending nature of the Federal Trust Responsibility in relation to government-organized healthcare programs for natives. In establishing this relationship, the thesis goes on to illustrate how native communities have effectively fought to regain sovereignty through reclaiming autonomy of their healthcare systems through the use of the 1975 Indian Self-Determination and Education Assistance Act. The impact of tribal-led healthcare systems is further explored through an in-depth case study conducted regarding the healthcare system of the Eastern Band of Cherokee Indians in Cherokee, North Carolina. Ultimately, this thesis argues that tribal healthcare autonomy has significantly contributed to the fight to reclaim tribal sovereignty because it breaks the condescending nature of the federal trust responsibility and it serves as an effective model to improve health trends among native communities.

Table of Contents

Introduction	6-13
Chapter I. Contemporary and Historical Health Disparities among Native Americans.....	14-24
Chapter II. The Federal Trust Responsibility and Government Funded Healthcare.....	25-40
Chapter III. 20 th Century Health Services: The I.H.S. and the Push for Tribal Representation and Autonomy.....	41-62
Chapter IV. Case study of the Eastern Band of Cherokee Indians Healthcare System.....	63-78
Chapter V. Health Trends of the EBCI Tribe: The Efficacy of a Tribal-Led Healthcare System.....	79-89
Conclusion. Reclaiming Sovereignty through Health Care Autonomy.....	90-97
Appendix	98-105
a. Note on Terminology: Native American vs. Indian vs. Native	
b. Research Methods	
c. Interview Guide	
Bibliography	106-111

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“We have given up way too much... from this day forward we must pledge to not allow any more of our rights to be eroded, we must not be moved a single inch, not a single inch.” – Wilma Mankiller¹

¹ Wilma P. Mankiller, “‘Tribal Sovereignty Is a Sacred Trust’: An Open Letter to the Conference,” *American Indian Law Review* 23, no. 2 (1998): 479–80, doi:10.2307/20068896.

Introduction:

“...The rights of the original inhabitants [Indians] were, in no instance, entirely disregarded; but were necessarily, to a considerable extent, impaired...Their rights to complete sovereignty, as independent nations, were necessarily diminished.”²

Supreme Court Chief Justice John Marshall uttered these words in the final court case decision of *Johnson vs. McIntosh* 1823. This quote exemplifies the first of many instances in which the United States government continually worked to limit expressions of tribal sovereignty. Many court cases like this created opportunities for the U.S. government to define and redefine tribal sovereignty based on the political climate and environmental circumstances of the time. Although this particular quote pertains to the early development of the United States, this dominant understanding of tribal sovereignty has changed very little throughout history. Centuries of turmoil, both physical and cultural genocide, ethnic cleansing, warfare, destruction, and racially charged legal battles exercised by the United States illustrates how Native American tribes were not, and are not, treated or seen as sovereign nations.³ These many heinous acts committed against tribal nations in this country clearly indicate that the inherent sovereignty of tribal nations has been intensely challenged and threatened throughout history.

Inherent tribal sovereignty refers to the power of a tribe to govern its people based on their status as the original inhabitants of North America.⁴ This inherent sovereignty has been challenged throughout history, and today, arguably exists in a warped form of

² “*Johnson vs. McIntosh*. 22 III.21 U.S. 543, 8 Wheat. 543, 5 L.Ed. 681 (1823)”.

³ Russell Thornton, “Native American Demographic and Tribal Survival into the Twenty-First Century,” *American Studies* 46, no. 3/4 (2005): 23–38.

⁴ Algeria Ford, “The Myth of Tribal Sovereignty: An Analysis of Native American Tribal Status in the United States,” *International Community Law Review*, no. 12 (2010): 397–411.

sovereignty as delegated and granted by the federal government.⁵ Prior to colonial contact however, North America was inhabited by hundreds of different tribes with various languages, cultures, life-styles, and governing structures. Pre-colonial tribes freely expressed sovereignty through intricate governing structures, tribal leaders, trading systems, medical practices, and sustainable and self-sufficient food systems.⁶ This way of life drastically changed upon colonial contact, and with the impact of colonialism there was also a sudden shift in the expression of inherent sovereignty.⁷ With the centuries leading to the formation of the United States, colonial actions caused massive depopulation, shifts in tribal cultural, and a wave of forced assimilation.⁸ This destructive and convoluted history only continued with the development of the United States, and tribal sovereignty in particular, became a source of tension and dispute.

Sovereignty is broadly defined as, “the authority of a state to govern itself or another state.”^{9,10} Today, tribal sovereignty refers to a tribe’s right to govern itself, define tribal membership, manage tribal property, determine tribal law, and regulate tribal business and domestic relations.¹¹ These expressions of tribal sovereignty have been hard won and only recently achieved; this is due to the complex and unequal distribution of power between the United States government and tribal nations. Specifically, with the formation of the United States, the founding fathers attempted to maintain that tribes were independent political structures in order to continue previously established trading

⁵ Ibid.

⁶ Howard S. Russell, *Indian New England Before the Mayflower* (University Press of New England, 1983).

⁷ Thornton, “Native American Demographic and Tribal Survival into the Twenty-First Century.”

⁸ Ibid.

⁹ L. Scott Gould, “The Consent Paradigm: Tribal Sovereignty at the Millennium,” *Columbia Law Review* 96, no. 4 (1996): 809–902, doi:10.2307/1123429.

¹⁰ Amanda J. Cobb, “Understanding Tribal Sovereignty: Definitions, Conceptualizations, and Interpretations,” *American Studies* 46, no. 3/4 (2005): 115–32.

¹¹ “Tribal Sovereignty,” *The Leadership Conference on Civil and Human Rights*, accessed March 31, 2017, <http://www.civilrights.org/indigenous/tribal-sovereignty/>.

relationships.¹² This attempt to do so came through the defining of tribal sovereignty in terms of commerce in both Article I of the Constitution in 1775 and the Supremacy Clause of the Constitution.¹³ The Supremacy Clause in particular establishes that federal statutes and treaties are the supreme law of the land. This is particularly significant as from 1778 to 1868, over 360 treaties with native tribes were ratified, most of which included the exchange of tribal lands and natural resources for a promise of protection, peace, and healthcare.¹⁴ Together these constitutional statements both established tribal nations as sovereign entities and established the premise for the federal trust responsibility, later codified by the *Cherokee Nation vs. Georgia* landmark Supreme Court Case in 1832.¹⁵ This original language surrounding sovereignty, as utilized in the Constitution and the Supremacy Clause, greatly contradict both the later rhetoric expressed by many Supreme Court cases and the federal trust responsibility.

The federal trust responsibility, which is discussed in depth in chapter II, is a legal obligation in which the government has outlined its moral obligation to provide financial aid to defend treaty rights, tribal lands, assets, resources, and healthcare to certain recognized tribal nations. This trust responsibility is rooted in the hundreds of treaties ratified during the late 1700s and early 1800s, in which tribal lands were exchanged for certain benefits, many of which were never received. Despite the seemingly positive language of the trust responsibility, it was in fact created under the presumption that tribes were incompetent and uncivilized and therefore, incapable of acting as independent

¹² Mark Savage, “Native Americans and the Constitution: The Original Understanding,” *American Indian Law Review* 16, no. 1 (1991): 57–118, doi:10.2307/20068692.

¹³ Ford, “The Myth of Tribal Sovereignty: An Analysis of Native American Tribal Status in the United States.”

¹⁴ Donald Warne and Linda Bane Frizzell, “American Indian Health Policy: Historical Trends and Contemporary Issues,” *American Journal of Public Health* 104, no. Suppl 3 (June 2014): S263–67, doi:10.2105/AJPH.2013.301682.

¹⁵ More on this in chapter II

and effective governments.¹⁶ The trust responsibility is therefore condescending in its promises to protect the native right to inherent sovereignty. Additionally, the trust responsibility is rooted in a trade-off that requires the loss of rights to land ownership. This is a crucial point as it innately undermines the concept of sovereignty: in order for a tribe to be recognized as sovereign it must be federally recognized, which requires land rights to be placed in the hands of the U.S. government.¹⁷ This compromise creates a paradox within the trust responsibility and sovereignty: sovereignty can only be expressed through the loss of land and the trust responsibility, which ultimately serves as a platform to make tribal nations dependent on the federal government. This trade-off is a primary example of the way in which tribal sovereignty has been threatened and restricted. This, coupled with Supreme Court cases such as *Johnson vs. McIntosh*, have led many to believe that tribal sovereignty is in fact an illusion.¹⁸

Many scholars such as historians and legal experts believe that tribal sovereignty, and the United States' respect for that sovereignty, is non-existent. The arguments for this are rooted in evidence that appears throughout the history of the relationship between tribal nations and the United States government. In particular, certain legislation has been enacted that purposely limits tribal governing structures. For example, the Major Crimes Act, outlined in Section 1153 of Title 18, removed the authority of tribal nations to prosecute offenders of major crimes in "Indian Country".¹⁹ This type of legislation is specific to prosecution of federal crimes, and most often than not, non-natives are not

¹⁶ Kevin Gover, "An Indian Trust for the Twenty-First Century," *Natural Resources Journal* 46, no. 2 (Spring 2006): 317–74.

¹⁷ Ibid.

¹⁸ Robert A. Fairbanks, "Native American Sovereignty and Treaty Rights: Are They Historical Illusions?," *American Indian Law Review* 20, no. 1 (1995): 141–49, doi:10.2307/20068787.

¹⁹ Get constitution citation

subject to tribal law under statutes outlined by the U.S. government. This type of protection from external bodies of law does not exist with any other country-to-country relationships, and therefore serves to undermine tribes' ability to exercise sovereignty.²⁰ Furthermore, various Supreme Court decisions have labeled tribes as "domestic dependent nations", such as in *Worcester vs. Georgia*, 1832.²¹ This type of rhetoric has been echoed through various court cases and has produced the arguments for the quasi-nature of sovereignty that tribal nations have experienced throughout the 18th, 19th, and 20th centuries.

Despite the many legal cases that have actively restricted tribal sovereignty, there have also been some Supreme Court cases that grant tribal nations certain authorities to maintain independence such as the abilities to regulate commerce, liquor licenses, and civil court cases.²² Yet, because the federal court granted this "independence", scholars argue that it is simply another source of evidence to argue against the existence of tribal sovereignty.^{23,24} Despite the overwhelming evidence regarding the limited status of tribal sovereignty, in which it is apparent that sovereignty has been restricted, I argue against views of native sovereignty that portray it as illusionary or non-existent today. It is clear that tribal sovereignty has been both intensely threatened and often times non-existent for certain tribal nations, however I argue that tribal nations have fought to reclaim their sovereignty since the development of the U.S., and have become successful in doing so through the avenue of reclaiming authority over their healthcare.

²⁰ Ford, "The Myth of Tribal Sovereignty: An Analysis of Native American Tribal Status in the United States."

²¹ "Worcester v. Georgia. 31 US 515 (1832)".

²² Ford, "The Myth of Tribal Sovereignty: An Analysis of Native American Tribal Status in the United States."

²³ Ibid.

²⁴ Fairbanks, "Native American Sovereignty and Treaty Rights."

At the start of the 1970s there was a groundswell of tribal dissent regarding limited sovereignty; it was no longer tolerated, and the fight to regain inherent tribal sovereignty gained national movement and has persisted today.²⁵ This unified struggle to reclaim sovereignty, under the banner of the American Indian Movement, called for changes in legislation.²⁶ These changes led to an era, during the Nixon administration, in which federal “Indian” policy transitioned from a policy agenda that was working to terminate tribes to instead actively work to enhance tribal authority and sovereignty.²⁷ This switch in federal policy began in the realm of healthcare policies. This is significant because many of the traumas that mark the historical relationship between the U.S. government and tribal nations relate to poor health, intense disease burden, and underfunded and negligent healthcare.²⁸ Health status and healthcare have been heavily discussed in terms of disparities, yet rarely are health and healthcare discussed in how they relate to tribal sovereignty and independence. This relationship seems obvious from a public health lens where the health of a population is necessary for stability, economic growth and prosperity, and independence, yet these factors are rarely discussed in the realm of native studies in combination with sovereignty. This thesis exclusively examines the complex interplay between health status, healthcare and tribal sovereignty. In particular, I aim to illustrate how, in the 21st century, the ability of a tribe to control their healthcare system is one important avenue in which tribes can reassert sovereignty.

²⁵ Dean J. Kotlowski, “Alcatraz, Wounded Knee, and Beyond: The Nixon and Ford Administrations Respond to Native American Protest,” *Pacific Historical Review* 72, no. 2 (2003): 201–27, doi:10.1525/phr.2003.72.2.201.

²⁶ Erich Steinman, “Settler Colonial Power and the American Indian Sovereignty Movement: Forms of Domination, Strategies of Transformation,” *American Journal of Sociology* 117, no. 4 (2012): 1073–1130, doi:10.1086/662708.

²⁷ Kotlowski, “Alcatraz, Wounded Knee, and Beyond.”

²⁸ David S. Jones, “The Persistence of American Indian Health Disparities,” *American Journal of Public Health* 96, no. 12 (December 2006): 2122–34, doi:10.2105/AJPH.2004.054262.

Throughout history, healthcare for native communities was delivered and funded by the U.S. government as mandated by the federal trust responsibility.²⁹ This healthcare however was culturally inappropriate, chronically underfunded, and ineffective.³⁰ It ultimately worsened poor health conditions, exacerbated the cultural genocide occurring across the nation through various other legislative policies, and was actively negligent in providing equitable care.³¹ These factors both negatively affected the health status of native communities and severely hindered tribal sovereignty despite the policies' stated intentions to maintain sovereignty. Thus, I argue that tribal-led healthcare, facilitated via the passing of the 1975 Indian Self Determination and Education Assistance Act, the first in a series of tribal self-determination policies, is an expression of independence that actually contributes to the fight for tribal sovereignty. Furthermore, native healthcare autonomy reasserts sovereignty as it breaks the paradoxical and limiting nature of the trust responsibility; it creates opportunities for improved healthcare, accessible care, and improved health status among tribal members of participating tribes thereby illustrating the competence and efficacy of tribal self-governance.

In order to effectively support this argument, I will begin by discussing the importance of health and the long-standing presence of health disparities among native communities. From there I will discuss the role of government-led healthcare in native history and how it has impacted tribal sovereignty. These chapters will also more thoroughly outline the basis of the federal trust responsibility, analyze the dramatic changes within native appropriated medical care, and discuss the rise of the Indian Health

²⁹ This concept will be discussed in depth in chapter II.

³⁰ David Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955* (Lexington Books, 2008).

³¹ Ibid.

Service. In discussing government-funded and led healthcare, I will also mention some of the monumental legal policies that have impacted healthcare for natives, these legal changes impacting healthcare will be accompanied by a case study analysis of the Eastern Band of Cherokee Indians healthcare system. Furthermore, in analyzing the history of government funded healthcare and the Indian Health Service, I will illustrate the ways in which tribal sovereignty has been severely hindered due to the harmful impact of government led healthcare: it limited the freedom, health, and independence of native peoples through negligence, severely underfunded services, culturally insensitive services, and a general lack of providing equitable healthcare. This point is strengthened when later illustrating how the 1975 ISDEA, which officially established support for tribes to assume responsibility of their healthcare systems, has resulted in a regain of sovereignty. These chapters, coupled with the case study analysis of the Eastern Band of Cherokee Indians healthcare system, a tribe who has successfully assumed responsibility of their healthcare system, ultimately illustrate how healthcare autonomy creates a path for reclaimed sovereignty in the twenty-first century. Although centuries of trauma cannot be erased, the many social injustices and violations of human rights inform tribes in how they should best address health issues among their communities today, and ultimately this process enhances the fight for sovereignty and exemplifies the resiliency and competency of tribal nations.

Chapter I. Contemporary and Historical Health Disparities among Native Americans

In order to understand the ways in which healthcare autonomy enhances tribal sovereignty, it is first essential to discuss the significance of health disparities among native communities. Throughout history, health disparities have overwhelmingly existed among the native population, and these disparities can be linked to the devastating effects of colonialism as well as the paternalistic and genocidal tactics of the United States government.³² When tracing federal Indian policy throughout history it is evident that many of the laws and policies created health issues among tribal nations, and are the source of the continued health issues today.^{33,34} This chapter will explore these historical health trends among natives, as well as contemporary trends, specifically addressing how the present day health issues among natives are directly linked to the haunting past of mistreatment, health disparities, and negligent healthcare.

This chapter aims to illustrate how historically, health status has been a barrier for expression of tribal sovereignty, and ultimately shows that health, and specifically a healthy population, is necessary for independence and stability of a nation. These topics lay the foreground to show that equitable and accessible health care is the way to improved health status, and with changing healthcare we see changing health status, both of which allow for the ability to express tribal sovereignty. It is important to note that many of the events discussed in this chapter coincide with the government-led healthcare programs; the basis of this government-led healthcare will be discussed in depth in chapter II.

³² Thornton, "Native American Demographic and Tribal Survival into the Twenty-First Century."

³³ Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

³⁴ Jones, "The Persistence of American Indian Health Disparities."

To begin, some context regarding health disparities in the United States must be explored. The word disparity generally defines a “great difference”, and in the realm of public health, it has become intimately used in the discussion of accessibility, racial discrepancies, and equitable healthcare. Health disparities are broadly defined as differences in the rates of disease occurrence and disability between socio-economic and/or geographically defined population groups.³⁵ Health disparities are attributed to and exacerbated by inadequate care, lack of access to care, socio-economic status, race and ethnicity, geographic location, and educational status. Health disparities are clearly seen in a global context, yet they also exist internally within a country. The United States is a prime example of a country with intense health disparities despite the presence of a highly complex healthcare system.³⁶

The United States spends more on healthcare services than any other country in the world. Spending \$9,086 per person per year, the United States spends two and half times more than most developed nations around the world, including some of the richest and healthiest European nations like Norway, Sweden, and the United Kingdom.³⁷ Yet, despite dedicating over 17.1% of the country’s Gross-Domestic Product towards healthcare, the United States struggles with some of the most pervasive health gaps across the developed world.³⁸ The complex neoliberal healthcare system, coupled by lack of accessibility and inequity across treatment, leaves room for gaps to develop in disease prevalence, death rates, and morbidity. Furthermore, these gaps are worsened disparities

³⁵ HRIC- health disparities website

³⁶ National Center for Health Statistics (US), *Health, United States, 2015: With Special Feature on Racial and Ethnic Health Disparities*, Health, United States (Hyattsville, MD: National Center for Health Statistics (US), 2016), <http://www.ncbi.nlm.nih.gov/books/NBK367640/>.

³⁷David Squires and Chloe Anderson, “U.S. Health Care from a Global Perspective,” October 8, 2015, <http://www.commonwealthfund.org/publications/issue-briefs/2015/oct/us-health-care-from-a-global-perspective>.

³⁸ National Center for Health Statistics (US), *Health, United States, 2015*.

in socio-economic status and racial barriers.³⁹ Specifically, certain reports indicate that these factors disproportionately affect minority groups in the United States, in particular African Americans and Native Americans.⁴⁰ This chapter will focus on providing context, both contemporary and historical, regarding health disparities among native communities. It is important to note that there is a vast amount of literature on this topic, and this section will only cover a few key points; touching on the historical roots of these disparities, as well as the roles that intergenerational trauma, economic development, educational development, and race play in exacerbating these health disparities. Lastly, this chapter will serve as an informative background to lay the foundation to illustrate the ways in which health and healthcare have intervened in tribal sovereignty and prosperity.

In order to dive into the historical roots of these disparities it is first essential to highlight the disparities that exist currently. It is important to mention that there are various organizations that report on health statistics by race, yet reports specifically regarding health trends among Native Americans are released very infrequently; in some cases they are sporadic and span across a 10-year gap. These reports can be problematic as well, as they often times perpetuate non-physical violence as they misclassify race, underreport on population statistics, and, in the past, have used unethical forms of data collection.^{41,42} These factors play into the difficulties of obtaining accurate health

³⁹ Joseph J. Sudano and David W. Baker, "Explaining US Racial/Ethnic Disparities in Health Declines and Mortality in Late Middle Age: The Roles of Socioeconomic Status, Health Behaviors, and Health Insurance," *Social Science & Medicine* 62, no. 4 (February 2006): 909–22, doi:10.1016/j.socscimed.2005.06.041.

⁴⁰ "CDC Health Disparities & Inequalities Report (CHDIR) - Minority Health - CDC," accessed December 17, 2016, <https://www.cdc.gov/minorityhealth/chdireport.html>.

⁴¹ Melissa A. Jim et al., "Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area," *American Journal of Public Health* 104, no. S3 (April 22, 2014): S295–302, doi:10.2105/AJPH.2014.301933.

statistics regarding native tribes in the United States. These factors also create barriers in attempting to combat health issues, as health data are required in order to effectively address the needs of a community. Despite these limitations, there are a few reliable organizations that release health reports regarding native tribes. Among them are the Centers for Disease Control and Prevention (CDC), the National Center for Health Statistics (NCHS), the Indian Health Service (I.H.S.), and the American Health Foundation. These health reports however only report all-encompassing statistics pertaining to natives of federally recognized tribes in the United States⁴³; health statistics regarding specific tribes are very rare. This lack of reporting, and unreliable reporting, leaves room for making inappropriate assumptions as well as designing ineffective health campaigns, both of which exacerbate poor health.

The lack of accurate data reporting coupled with the infrequent nature in which the reports are conducted are two of the largest barriers in addressing health disparities among native populations. This point is quite evident as the CDC's most recent report regarding health statistics of native communities was released in 2013; similarly the I.H.S.'s most recent health report was released in 2009.^{44,45} Prior to the release of these documents, the I.H.S. released a health report in 2005, and the CDC released a report in 2011. In addition to the inconsistency in data reporting, these reports group all natives as "American Indian/Alaskan Native, AI/AN". This is incredibly problematic as there are

⁴² Robert N. Anderson, Glenn Copeland, and John Mosely Hayes, "Linkages to Improve Mortality Data for American Indians and Alaska Natives: A New Model for Death Reporting?," *American Journal of Public Health* 104, no. S3 (April 22, 2014): S258–62, doi:10.2105/AJPH.2013.301647.

⁴³ Federal recognition will be discussed in chapter 3, but of the 3.7 million individuals who identify as native, only 2.2 million are members of federally recognized tribes.
(<https://www.ihs.gov/newsroom/factsheets/disparities/>)

⁴⁴ "CDC Health Disparities & Inequalities Report (CHDIR) - Minority Health - CDC."

⁴⁵ Indian Health Service, "Disparities | Fact Sheets," accessed December 18, 2016, <https://www.ihs.gov/newsroom/factsheets/disparities/>.

over 567 federally recognized tribes across the nation, all of which come from vastly different cultural, historical, geographic, and economic backgrounds. This lack of health reporting, coupled with the one label terminology, makes it very difficult for public health professionals to properly address the health issues among specific communities. Thus, due to the lack of recent reports, this section on contemporary health disparities will reference figures published in 2013 by the CDC and from the I.H.S. in 2009.

According to the CDC 2013 health disparities report, the infant mortality rate for natives was almost double that of non-Hispanic whites: 8 deaths per 1,000 live births for AI/AN whereas for non-Hispanic whites it was 4.5 per 1,000 live births. Similarly, the rates of diagnosis for diabetes were twice as high among natives when compared to non-natives: 15.9% for AI/AN versus 7.6% for non-Hispanic whites.⁴⁶ Furthermore, according to the Indian Health Service, the life expectancy for American Indians/ Alaska Natives is 4.4 years lower than the U.S. all races population life expectancy: 73.7 years compared to 78.1 years respectively. This lower life expectancy is coupled with higher rates of chronic liver disease, diabetes mellitus, unintentional injuries, suicide, cardiovascular diseases, and chronic lower respiratory diseases. The disparity ratio for these diseases, comparing AI/AN rates from 2007-2009 to U.S. all races of the same period are as follows: chronic live disease: 4.7 times higher in AI/AN, diabetes mellitus: 2.8 times higher, unintentional injuries: 2.4 times higher, cardiovascular diseases: 1.2 times higher, and self-harm/ suicide: 1.6 times higher.⁴⁷ These statistics simultaneously highlight the key health issues present among native communities as well as illustrate how they disproportionately affect native populations when compared to non-native populations. However, as stated, these

⁴⁶ “CDC Health Disparities & Inequalities Report (CHDIR) - Minority Health - CDC.”
5/15/17 10:17 AM⁴⁷ Indian Health Service, “Disparities | Fact Sheets.”

reports discuss health trends and disparities as they relate to all native tribes, thus it is important to note that some tribes are experiencing these health issues at different intensity levels.

These health disparities stem from a plethora of inequalities, among them socio-economic status and educational status have been investigated thoroughly in relation to natives and the current state of health disparities. Many public health scholars have identified a bidirectional relationship that exists between health status and economic and educational development.⁴⁸ Specifically, with strong health and wellbeing there is increased opportunity for economic prosperity and stability. Conversely, poor health serves as a barrier in achieving economic stability and advancing in educational status.⁴⁹ This relationship is crucial as it serves as an exacerbating factor for native health; more than one quarter of Native Americans are currently living in poverty, a rate that is double that of the general population.⁵⁰ Furthermore, the U.S. Census Bureau statistics indicate that 27% of native families with children live in poverty; this is also more than double that of the general population. This gap in wealth correlates directly to education levels: statistics reveal that many fewer native individuals possess a high school diploma or GED when compared to their all race counter-parts (71% vs. 80%), or a bachelor's degree (11.5% vs. 24.4%). The educational discrepancies as well as poverty levels are coupled with soaring unemployment rates that range from 14% to as high as 35% in some native communities.⁵¹ It is important to note, that these statistics represent individuals

⁴⁸ "Health and Wealth," *The Economist*, November 20, 2008, <http://www.economist.com/node/12637080>.

⁴⁹ Ibid.

⁵⁰ Michelle Sarche and Paul Spicer, "Poverty and Health Disparities for American Indian and Alaska Native Children: Current Knowledge and Future Prospects," *Annals of the New York Academy of Sciences* 1136 (2008): 126–36, doi:10.1196/annals.1425.017.

⁵¹ "CDC Health Disparities & Inequalities Report (CHDIR) - Minority Health - CDC."

who identify as American Indian/Native Alaskan, yet not all American Indians/ Native Alaskans fit these statistics; some tribal members fare much worse than others, while other tribal members fare much better. These differences in wealth arise from differences in economic opportunities, geographic location, and educational status. Ultimately, these gaps in wealth and education status play an integral role in the barriers halting the alleviation of health disparities among native communities.

In addition to increased rates of poverty, lack of education, and health disparities, many native communities are struggling with severe mental health disparities. Many of the issues in the realm of mental health are related to the intergenerational trauma experienced by native communities.⁵² Intergenerational trauma and violence is the concept that trauma experienced by the first generation of survivors is transferred from one generation to the next. Intergenerational trauma has been identified as a plaguing issue among native communities; this is due to the fact that members of native communities are much more likely to experience a range of traumatic and violent events in their lifetime.⁵³ This includes intergenerational trauma, violent victimization, sexual assault and rape, and unintentional injuries/self-harm. Many authors have noted that these experiences are linked to factors that are typically listed as “risky” behaviors, such as engaging in substance use and abuse, vandalism, stealing, and suicidal thoughts and attempts, among many others.⁵⁴ Furthermore, reports have shown that native children are more likely to be killed in a motor vehicle accident, to be hit by a car, commit suicide, or

⁵² Teresa Evans-Campbell, “Historical Trauma in American Indian/Native Alaska Communities: A Multilevel Framework for Exploring Impacts on Individuals, Families, and Communities,” *Journal of Interpersonal Violence* 23, no. 3 (March 1, 2008): 316–38, doi:10.1177/0886260507312290.

⁵³ Ibid.

⁵⁴ Sarche and Spicer, “Poverty and Health Disparities for American Indian and Alaska Native Children.”

drown compared to their non-native counterparts.⁵⁵ These statistics are often coupled with reports discussing the prevalence of alcohol related deaths and morbidity, which are significantly elevated among native communities.⁵⁶ Despite the alarming statistics presented above, these rates are astonishingly better than those recorded prior to 2000. The explanation for these improvements is discussed in depth in chapter III in conjunction with the changing tides of the Indian Health Service.

The health disparities present today are not a recent phenomenon; native communities have been battling extensive health disparities since colonial contact nearly 500 years ago.⁵⁷ The origin of these health disparities begins with the massive depopulation that occurred upon colonial contact. Throughout the colonial period, war, violence, and foreign diseases wreaked havoc among costal tribes of New England and the North Eastern regions. Among these foreign diseases, smallpox was particularly devastating, acting as the primary contributor in the massive depopulation of native tribes during the 15th-18th centuries.⁵⁸ Many theories have been published regarding what was deemed as “increased susceptibility” to this disease, the most famous of these theories: Alfred Crosby’s, “Virgin-soil Theory”, stated that the population at risk had no previous contact with the disease in question and thus were immunologically defenseless.⁵⁹ Alongside this theory, many other theories have tied in genetic differences, racial differences, and cultural practices as contributing sources of increased susceptibility. Regardless, of the controversial theories, infectious disease such as smallpox, measles,

⁵⁵ Ibid.

⁵⁶ Ibid.

⁵⁷ Jones, “The Persistence of American Indian Health Disparities.”

⁵⁸ Kristine B. Patterson and Thomas Runge, “Smallpox and the Native American,” *The American Journal of the Medical Sciences* 323, no. 4 (April 1, 2002): 216–22, doi:10.1097/00000441-200204000-00009.

⁵⁹ Native Voices, ““Virgin-Soil” Epidemics Devastate Native Populations,” accessed December 17, 2016, <https://www.nlm.nih.gov/nativevoices/timeline/183.html>.

and mumps to name a few, initiated the beginning of a heavily extended period of disease and poor-health for native communities.

In addition to lack of immunity and prior exposure to these infectious diseases, colonialism and warfare forcibly altered the many diverse traditional lifestyles of native tribes. Throughout the 1600s and 1700s hundreds of treaties between European settlers and various native tribes were signed.⁶⁰ These treaties later resulted in an era of “Federal Indian Policy” under the United States, which led to increased land cessation and “civilization” policies. These policies led to a multitude of issues, including lack of food security, which collectively created a platform for further susceptibility to infectious diseases. Most famously documented are diseases such as trachoma and tuberculosis, which became rampant during the “reservation era” from the late 1800s to the early 1900s. This era is specifically described as the period in which many tribes were removed from their native lands onto reservation boundaries.⁶¹ These movements both expedited the loss of traditional lifestyle and simultaneously facilitated the spread of diseases, and generally worsened the health of native populations. Reservation lands lacked sources of clean water, sanitation, and sustainable food sources. The impacts of these conditions were exacerbated by lack of proper housing and the deliberate ban on the practice of traditional healing and medicine. Chapter II will discuss specifics on this reservation era as it relates to government-funded healthcare, illustrating how these programs in fact exacerbated health conditions rather than alleviating them.

⁶⁰ Donald Warne and Linda Bane Frizzell, “American Indian Health Policy: Historical Trends and Contemporary Issues,” *American Journal of Public Health* 104, no. Suppl 3 (June 2014): S263–67, doi:10.2105/AJPH.2013.301682.

⁶¹ Everett R. Rhoades and Dorothy A. Rhoades, “The Public Health Foundation of Health Services for American Indians & Alaska Natives,” *American Journal of Public Health* 104, no. Suppl 3 (June 2014): S278–85, doi:10.2105/AJPH.2013.301767.

Collectively, these historical as well as contemporary events and statistics highlight two key concepts. The first is that poor health among native communities has been persistent throughout history and the second is that the socio-economic disparities, rooted in racist and genocidal tactics hidden within the structural system, have only worsened health over time. These health disparities exist due to the great disparities in wealth, power, and resources in this country and these relationships illustrate the ways in which health status and government controlled healthcare impact tribal stability and therefore, tribal sovereignty. Without healthy populations, it is nearly impossible to create structure and stability within a community. Poor-health has plagued many tribes, successfully inhibiting their abilities to express independence, recreate functioning societies, and maintain stability. These conditions therefore have suppressed tribal sovereignty. Furthermore, as discussed throughout the chapter, and more in-depth in chapter II, the presence of these diseases and health issues are tied directly to the negligent government-funded healthcare and the convoluted tribe to federal government relationship. Ultimately, colonization and the subsequent paternalistic treatment by the United States government brought disease, poor-health, instability, and death to tribal nations across the country. This history, as well as the intricate relationship between health and sovereignty, provides the context to explore the ways in which tribal autonomy of healthcare plays a crucial role in the process of reclaiming tribal sovereignty in the 21st century.

II. The Federal Trust Responsibility and Government Funded Healthcare

As outlined in the previous chapter, health and healthcare are intimately connected to the expression of tribal sovereignty. Without a healthy population it is nearly impossible to escape economic deprivation, create powerful governing structures, and effectively act as a sovereign nation. This relationship between health and sovereignty is critical as it sets the foundation for understanding how regained healthcare autonomy contributes to the fight for tribal sovereignty. Ultimately, this argument cannot be supported without first discussing the ways in which healthcare autonomy was forcibly taken, among many other things, from tribal nations upon the formation of the United States. This chapter will explore the origins of this transition to government-funded healthcare, illustrating the ways in which this system has inhibited tribal sovereignty.

Government-funded healthcare for federally recognized tribal nations was a result of the hundreds of treaties that were made between the forming United States and various tribes during the late 1700s and early 1800s.⁶² These treaties created the foundation for the particular tribal-federal relationship as outlined in the Constitution of the United States. These treaties collectively created the special “trust” relationship that exists between the United States government and Native American tribes. As mentioned in the introduction, this trust relationship loosely acknowledges federally recognized tribes as sovereign nations within the United States.⁶³ Furthermore, it mandates that the United States government protect tribal lands, assets, resources, burial grounds, treaty rights, and

⁶² Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

⁶³ Mary Frances Berry et al., “Broken Promises: Evaluating the Native American Health Care System” (U.S. Commission on Civil Rights, n.d.).

provide health care.⁶⁴ This trust relationship however was based on treaties involving the cessation of land and the assumption that native tribes were incompetent and incapable of economic development, and although it utilizes the language of “moral obligation.... To protect” it in fact served as a vehicle of plenary power that the U.S. government used to disenfranchise and deprive tribal nations.⁶⁵

The trust relationship developed into a trust-responsibility that was through three Supreme Court cases, which effectively defined and redefined tribal sovereignty during the 1800s. Specifically, these Supreme Court cases are known as the “Marshall Trilogy”. They are a series of three cases led by Chief Justice Marshall during the early 1800s that established tribal sovereignty by federal standards.⁶⁶ The first of these cases, *Johnson vs. McIntosh* 1823, resulted in Chief John Marshall ruling that natives were unable to convey land to private parties without the consent of the federal government. The Court reasoned that, after conquest by Europeans and the establishment of the United States, tribes were no longer completely sovereign nations and thus did not possess the power to dispose of their lands.⁶⁷ This particular case established that tribes possessed a form of limited sovereignty and Congress and the Supreme Court would dictate the extent of this limited sovereignty.

Despite this discouraging outcome, the other two cases of the trilogy actually enhanced tribal sovereignty. Furthermore, these two cases were of key importance in establishing the legitimacy of the federal trust-responsibility. Both of these cases involved the Cherokee Nation filing suit against the state of Georgia in the 1830s. At the

⁶⁴ “About IHS | Indian Health Service (IHS),” accessed November 29, 2016, <https://www.ihs.gov/aboutihs/>.

⁶⁵ Gover, “An Indian Trust for the Twenty-First Century,” Spring 2006.

⁶⁶ PHILIP J. PRYGOSKI, “FROM MARSHALL TO MARSHALL: The Supreme Court’s Changing Stance on Tribal Sovereignty,” *Complete Lawyer* 12, no. 4 (1995): 14–17.

⁶⁷ *Ibid.*

time, the state of Georgia had stripped local Cherokees of their rights to their land and resources. The state was acting in line with a series of laws promoted by Andrew Jackson under the Indian Removal Act. The Indian Removal Act of 1830 authorized the president to grant unsettled lands west of the Mississippi in exchange for Indian lands east of the Mississippi. This however required the relocation of five primary native tribes: the Cherokee, the Choctaw, the Seminole, the Chickasaw, and the Creek. The Indian Removal Act of 1830 was absolutely devastating for these five particular tribes, and resulted in forced relocation, war, and genocide.⁶⁸ During these tumultuous times, the five tribes mentioned above, also commonly referred to as “The Five Civilized Tribes”, worked tirelessly to resist relocation. In particular, Cherokee Nation in 1831 filed suit against the state of Georgia in, *Cherokee Nation vs. Georgia*. Here, Cherokee Nation called upon the Supreme Court to review the forcible actions of the state of Georgia. The tribe hoped that the Court would rule in their favor, stating that Georgia had no legal right to forcibly remove them from these lands as they were secured under multiple treaties formulated between the tribe and the U.S. government many years prior. The Court ruled that they had no jurisdiction over the case, as tribes were “domestic dependent nations” and their relationship to the United States “resembled that of a ward to his guardian.”⁶⁹ This court ruling was highly controversial; it explicitly stated that tribes were not foreign nations as they were bound by geographic restraints, which ultimately restricted the exercise of their sovereignty.

⁶⁸ Alfred A. Cave, “Abuse of Power: Andrew Jackson and the Indian Removal Act of 1830,” *Historian* 65, no. 6 (Winter 2003): 1330–53, doi:10.1111/j.0018-2370.2003.00055.x.

⁶⁹ PRYGOSKI, “FROM MARSHALL TO MARSHALL.”

Despite the poor outcome of this case, it resulted in upheaval and increased resistance.⁷⁰ In 1832, Samuel Austin Worcester, a missionary living peacefully among the Cherokee, refused to obtain the newly required state license that was deemed necessary for non-natives to live among these lands. These required licenses were part of a larger series of laws passed by Georgia to remove the Cherokee from the state and grant their land to white settlers. With this act of resistance, Worcester was indicted by a Georgia court and was convicted. Worcester then appealed to the U.S. Supreme Court, in the famous *Worcester vs. Georgia 1832* lawsuit, claiming that the state of Georgia had no authority to convict him. The Supreme Court ruled in favor of Worcester stating that the state of Georgia lacked authority to rule within Cherokee Nation, as Cherokee Nation was a separate political entity that was exempt from state regulations and state tax systems. Furthermore, the Court ruled that only the United States federal government could negotiate the terms of Indian lands with tribes, and that states lack the constitutional power to deal with such nations at all.⁷¹ These three cases, and specifically the latter, were landmark Supreme Court cases that established the basis for interpreting federal “Indian” law. They collectively affirmed that native nations are separate political entities that can exercise certain forms of sovereignty, yet they are seemingly dependent on support from the United States in order to express that sovereignty. This dependency, as explicitly stated in *Cherokee Nation vs. Georgia 1831*, created the groundwork in establishing the federal trust-responsibility.⁷² The federal trust responsibility, although

⁷⁰ Reid Peyton Chambers, “Judicial Enforcement of the Federal Trust Responsibility to Indians,” *Stanford Law Review* 27, no. 5 (1975): 1213–48, doi:10.2307/1228040.

⁷¹ Alex McBride, “The Supreme Court . The First Hundred Years . Landmark Cases . Cherokee Indian Cases (1830s) | PBS,” *Supreme Court History*, 2007, http://www.pbs.org/wnet/supremecourt/antebellum/landmark_cherokee.html.

⁷² PRYGOSKI, “FROM MARSHALL TO MARSHALL.”

designed to provide protection for tribal lands, assets, peoples, healthcare, and governing structures, is in fact detrimental for tribal sovereignty. Inherent in its design, the trust responsibility assumes that tribes are incompetent and fragile, thereby implying that they are incapable of handling their own affairs, and thus effectively restricting tribal sovereignty.⁷³

It is important to note here that federal recognition is the crux of the federal trust responsibility: without federal recognition, a tribe is not considered a sovereign nation, nor will it receive the present day protective standards set in place by the United States government to ensure that sovereignty.⁷⁴ However, entangled within this recognition and trust responsibility relationship is the issue of property rights to land. Specifically, the trust responsibility relationship between tribes and the United States relies on the fact that tribal lands are “held in trust” by the U.S. government. Essentially what this means is that the U.S. assumes ownership of the land, and then by placing it “in trust”, they designate that land (a reservation) as tribal land to be governed by the specific tribal nation. This trade of land for “protection” is grounded in the hundreds of treaties from the 1700s and 1800s. Yet, it is with this paradox of land ownership that tribal nations engage in the federal trust responsibility and thereby exhibit sovereignty as separate political entities within the United States.^{75,76} This paradoxical relationship is important to note due to the fact that almost every tribe in the country was forcibly designated a reservation and in

⁷³ Kevin Gover, “An Indian Trust for the Twenty-First Century,” *Natural Resources Journal* 46, no. 2 (April 1, 2006): 317.

⁷⁴ US Department of the Interior, Indian Affairs, “Indian Affairs | Office of Federal Recognition,” accessed April 12, 2017, <https://www.bia.gov/WhoWeAre/AS-IA/OFA/>.

⁷⁵ Vickie Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting, tape recorded, March 8, 2017.

⁷⁶ Sarah Sneed, EBCI relationship with I.H.S. and tribal compacting, March 8, 2017.

return received certain freedoms to express sovereignty.⁷⁷ Despite the intention of protection under the responsibility, the paradox forces tribal expression of sovereignty to come at the steep price of loss of land-ownership, which inherently undermines what it means to be a sovereign nation.

Although the Marshall Trilogy are considered the founding Supreme Court Cases in establishing both federal “Indian” policy and the federal trust responsibility, there have been multiple court cases and laws throughout history that have further complicated the notion of tribal sovereignty and the trust responsibility. Specifically these entities, although designed to protect tribal nations, further contributed to disbanding and destroying tribes.⁷⁸ For example, the Dawes Act of 1887 was particularly devastating. The Dawes Act of 1887 was designed based on the idea that the institution of private property would “civilize” native tribes and lead to dissolution of tribalism.⁷⁹ This land allotment act, although not the first of its kind, authorized the president of the United States to divide up reservation lands into 160-acre lots for each native family to own; this however resulted in the unethical buying and selling of native lands.⁸⁰ Thousands of acres of land were lost during the 47-year period that the law was in effect. With this loss of land, as well as the forced dismantling of traditional community-based life, exacerbated the state of despair many tribes were already facing. This law is just one example of many where the federal government, with the agenda of forced assimilation and civilization, completely disregarded tribal sovereignty.

⁷⁷ Fairbanks, “Native American Sovereignty and Treaty Rights.”

⁷⁸ Samuel Lyman Tyler, *A History of Indian Policy* (Bureau of Indian Affairs; [for sale by the Supt. of Docs., U.S. Govt. Print. Off.], 1973).

⁷⁹ Imre Sutton, review of, *The Assault on Indian Tribalism: The General Allotment Law (Dawes Act) of 1887*, by Wilcomb E. Washburn, *Pacific Historical Review* 45, no. 2 (1976): 293–94, doi:10.2307/3638513.

⁸⁰ Leonard A. Carlson, “The Dawes Act and the Decline of Indian Farming,” *The Journal of Economic History* 38, no. 1 (1978): 274–76.

Despite the many instances throughout history where federal law and policy have resulted in increased destruction of native communities, native communities have resisted this destruction in many ways. This native resistance often comes in the form of filing lawsuits against the federal government in attempts to highlight the Constitutional obligation to honor and respect native tribes. In particular, one major court case involving the Seminole Nation of Florida and the United States further established the constitutional obligation and responsibility of the government to provide funds for land protection, education, and healthcare. In 1942, the Seminole Nation filed suit against United States in *Seminole Nation v. United States*, as the tribe noticed that federal employees were mishandling funds granted by Congress. The Supreme Court ruled in favor of the tribe, highlighting the obligation to provide government appropriations for tribal development and protection.⁸¹ Cases such as this one are crucial to include in this discussion as they continue to enhance the significance of the federal trust-responsibility while simultaneously working to solidify the notion that tribes are independent nations capable of demanding respect and governing their affairs. This history regarding the controversial nature of trust-responsibility is essential to cover in order to explore how the federal to tribal relationship impacts healthcare and health status among native communities.

Although the federal trust responsibility was officially established through the Marshall Trilogy in the 1830s, healthcare programs and services administered by the government date back as early as 1802.⁸² Specifically, starting in 1802, Army physicians,

⁸¹ “SEMINOLE NATION v. UNITED STATES.,” *LII / Legal Information Institute*, accessed December 4, 2016, <https://www.law.cornell.edu/supremecourt/text/316/286>.

⁸² Abraham B. Bergman et al., “A Political History of the Indian Health Service,” *The Milbank Quarterly* 77, no. 4 (December 1999): 571–604, doi:10.1111/1468-0009.00152.

as part of orders from the Department of War, took “emergency” measures to halt the spread of highly contagious diseases, smallpox and measles, among native tribes.⁸³ These measures however were often designed to protect the spread of diseases to nearby stationed soldiers and gain crude mortality rates and population statistics of native tribes.⁸⁴ These early interventions can arguably be considered militaristic actions rather than rationed healthcare. This statement is further supported by the fact that many of the early healthcare programs after these military actions were implemented under a law called the 1819 “Civilization Act”. This act was allegedly designed to provide services and funds to combat the decline of native tribes: “for the purpose of providing against the further decline and final extinction of the Indian tribes”.⁸⁵ This act officially established the United States’ attitude towards native competency: in assuming the responsibility of healthcare, as well as education, the United States made it clear that tribes were unable to provide for their peoples. Furthermore, this law, like many others, assumed responsibility of various systems and services that a sovereign entity would normally control, thereby actively stripping certain rights from native tribes.

Although the Civilization Act was enacted in 1819, it was not until 1824 that the government created an official board to direct native affairs: the Commission of Indian Affairs. Following the establishment of the Commission, the first official healthcare program began in 1832.⁸⁶ With this first program, Congress appropriated money to the Office of Indian Affairs to combat health-specific issues. Yet this funding was under estimated: in 1832, Congress appropriated \$12,000 for smallpox vaccinations in “Indian

⁸³ Ibid.

⁸⁴ Berry et al., “Broken Promises: Evaluating the Native American Health Care System.”

⁸⁵ Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

⁸⁶ Ibid.

country”.⁸⁷ This underfunding resulted in the failure of many of the healthcare campaigns throughout the 1800s. These programs were designed to tackle the on-going smallpox epidemic, yet disease rates of trachoma, cholera, measles, and tuberculosis were also increasing daily, and thus began a viscous cycle of poor-health, non-specific healthcare, and uninhabitable living conditions.

Furthermore, the physicians assigned to work with native populations had incredibly high patient loads coupled with very low pay and absent medical resources. In 1879, the Commissioner of Indian Affairs Report noted that, “67,352 Indians were treated by a medical corps of 59 physicians—an average of 1,142 cases per physician”, an incomprehensible patient load, that most certainly resulted in poor care.⁸⁸

Additionally, an 1890 Commissioner of Indian Affairs report compared how much was spent per type of individual being treated by the military medical corps: \$21.91 per soldier, \$48.10 per sailor, and \$1.25 per Indian.⁸⁹ This astonishing calculation clearly indicates the lack of funding appropriated for “Indian Health” during the late 1800’s. These conditions only worsened throughout the turn of the 20th century as native rights were increasingly seen as unimportant due to the ignorant belief that the race was vanishing; these sentiments further fueled inadequate government aid.⁹⁰

Following the era of military-implemented healthcare, the federal government transferred healthcare responsibilities to the Department of Interior in 1849, which also resulted in a name change to the infamous Bureau of Indian Affairs (BIA). The BIA, just like the Commission of Indian Affairs, was designated orders to “assist” native tribes, yet

⁸⁷ Ibid.

⁸⁸ Ibid.

⁸⁹ Jones, “The Persistence of American Indian Health Disparities.”

⁹⁰ Jean M. O’Brien, *Firsting and Lasting: Writing Indians out of Existence in New England* (University of Minnesota Press, 2010), <https://muse.jhu.edu/book/24468>.

its initiatives were rooted in racist and genocidal tactics.⁹¹ Specifically, the BIA's programs were designed to facilitate assimilation to "white culture", destroy native culture, and increase tribal dependence on western medicine. In reference to the last point, the federal government explicitly decreased the influence of traditional native healers through banning traditional healers from practicing.⁹² These programs continued throughout the 20th century, and the BIA was in charge of appropriating its own funds for healthcare programs, yet often times these funds were used for other programs, such as "educational programs" ie: the establishment of Indian Boarding Schools.⁹³

The BIA held control of health services from 1849 to 1955 and this period can be broken down into two phases of involvement: the reservation period from 1849-1900 and the post-allotment period from 1900-1955. During the "reservation period", tribes across the country were being relocated and interned on reservations. The subsequent healthcare services provided by the BIA were primarily bound by concerns of providing smallpox vaccinations for tribal members. There were occasional provisions for constructing hospitals, however often times health services were run by a single physician with massive responsibilities, duties, and very limited resources. This period has been previously classified as a 'containment of infectious diseases' period, as the majority of protocols designed by physicians were aimed at reducing infectious diseases like

⁹¹ Rose L. Pfefferbaum et al., "Providing for the Health Care Needs of Native Americans: Policy, Programs, Procedures, and Practices," *American Indian Law Review* 21, no. 2 (1997): 211–58.

⁹² Holly T. Kuschell-Haworth, "Jumping Through Hoops: Traditional Healers and the Indian Health Care Improvement Act" 2, no. 4 (1999).

⁹³ Indian Health Service. *Compilation of Authorities, Treaties, Federal Statutes and Substantive Legislation*. Rockville, MD: US Department of Health Education and Welfare, Indian Health Service, Division of Program Formulation; 1980

smallpox, pertussis, measles, and even malaria.⁹⁴ Although this classification is specific to native tribes, the United States as a whole had similar programs aimed at reducing infectious diseases during this time.

With the turn of the century however, healthcare across the nation saw noticeable changes. The application of science to medicine brought new discoveries, along with increased regulations for medical procedures, and a more institutionalized and standardized approach for educating healthcare professionals.⁹⁵ However, BIA programs during the early portion of the 20th century were still focused on combatting infectious diseases among natives; tuberculosis had now become a national epidemic, and it was particularly prevalent among native tribes, claiming the lives of thousands, and similarly trachoma, a highly contagious eye-infection that can lead to blindness if left untreated, was also wreaking havoc among natives.⁹⁶ Specifically, in 1925 tuberculosis mortality in the general U.S. population hovered around 87 deaths per 100,000 individuals, yet in the general native population the mortality rate was 603 deaths per 100,000 individuals, and in some tribes, such as the Navajo, the rate was above 1,000 deaths per 100,000 individuals.⁹⁷

These alarming mortality rates called for a push for antibiotic therapies, as well as widespread immunizations, yet healthcare services were underfunded: in 1912 Congress appropriated just \$12,000 for native healthcare, this number eventually grew to \$350,000

⁹⁴ Rhoades and Rhoades, “The Public Health Foundation of Health Services for American Indians & Alaska Natives.”

⁹⁵ Kuschell-Haworth, “Jumping Through Hoops: Traditional Healers and the Indian Health Care Improvement Act.”

⁹⁶ “‘If You Knew the Conditions...’ Health Care to Native Americans: Indian School Hospitals Under the Office of Indian Affairs (c.1883-c.1916),” Exhibitions, *History of Medicine*, NIH US National Library of Medicine, accessed December 4, 2016, https://www.nlm.nih.gov/exhibition/if_you_knew/ifyouknew_05.html.

⁹⁷ Jones, “The Persistence of American Indian Health Disparities.”

by 1917 and by 1925 it grew to \$596,000.⁹⁸ Despite the increase in funds, the money was not nearly enough to combat the health and humanitarian issues present both on and off the reservations. Particularly in the realm of health care, the Bureau of Indian Affairs miscalculated funds and did not properly distribute funds for healthcare programs, and this has remained the case to this day. Ultimately this lack in funding resulted in the fact that many BIA health stations could not provide the necessary services to treat patients.⁹⁹ This lack of funds, resources, physicians, and standard care exacerbated the already existing health gap that was present between natives and non-natives. It is important to note that although many historians and public health specialists have mentioned this gap in health, accurate quantitative data from this time period are rare and often inaccurate; therefore qualitative information has established the basis of this claim.

As health conditions worsened throughout the 20th century, it eventually became evident to a select few within the BIA, that unless the government intervened in a positive manner, it would only facilitate in the complete destruction of native tribes.¹⁰⁰ Furthermore, certain members of the BIA noticed that the reservation conditions, as well as overall conditions present among native tribes, were inhabitable and unbearable. Housing was inadequate, there was a lack of clean water, very little food security, and almost no opportunities for economic development.¹⁰¹ These conditions could not change unless the department began properly supporting various tribes via financial means.

⁹⁸ Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

⁹⁹ Ibid.

¹⁰⁰ Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

¹⁰¹ *The Problem of Indian Administration: The Meriam Report* (Johns Hopkins Press, Institute for Government Research, Studies in Administration, 1928), <http://www.narf.org/nill/resources/meriam.html>.

These conditions resulted in the authorization of the Synder Act of 1921.¹⁰² This act provided official authorization for native health care, and it formulated, for the first time, a broad approach to native health policy. The act also gave authorization for appropriations specifically designed to provide relief for the distress of poor health and design programs that aimed at conserving health, thus taking on a more proactive approach towards healthcare.¹⁰³ This resulted in a series of programs based on education reform, economic reform, and health care reform. A few years after the start of these programs, the BIA released the Meriam Report of 1928, formally known as *The Problem of Indian Administration*. This report highlighted the immense amount of poverty, unemployment, lack of sanitation and access to clean water present on reservations. Additionally, the Meriam Report tied these horrible conditions to the vast number of health issues present among native tribes across the nation. The report noted the ways in which poor health, little economic reform, and no education were limiting tribes in their ability to express what limited sovereignty they were granted at the time.¹⁰⁴ This report, along with many anecdotes from individual physicians and commissioners, resulted in a slow, but gradual increase in funding from Congress: in 1925 total BIA funding was \$596,000, and by 1935, it grew to \$2,980,000.¹⁰⁵

Although it would be wonderful to report quantitative statistics regarding mortality rates, morbidity data, life-expectancy rates, infant and maternal mortality rates, the data simply does not exist. The Meriam Report dedicates a whole chapter regarding the lack of statistical information on tribal health. The authors note the need for

¹⁰² Bergman et al., “A Political History of the Indian Health Service.”

¹⁰³ Ibid.

¹⁰⁴ *The Problem of Indian Administration: The Meriam Report*.

¹⁰⁵ Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

statisticians and health analyst in order to better understand the plaguing impact of lack of sanitation, clean water, housing, and healthcare facilities. The report does note that rates of trachoma remained exceptionally high among natives, and showed that it disproportionately affected this population, as it was nearly extinct among non-natives in the United States.¹⁰⁶ Furthermore, the report states that the infant mortality rate was soaring, to the point that many field physicians noted that there were more infant deaths than successful live births during the early 20th century.¹⁰⁷ The report was also the first instance in which a federal program acknowledged the need for native participation in designing effective healthcare programs. Thus, following the release of the Meriam Report, the BIA, which at the time was under the leadership of John Collier—famous for his efforts and advocacy for native rights—underwent a series of organizational and structural changes. Despite the efforts of John Collier and the sobering facts of the Meriam Report, it took the BIA another twenty-five years to enact change. Specifically, it was not until the 1954 Indian Health Transfer Act, which called for the transfer of the maintenance and operation of hospitals, health facilities, and services from the BIA to a newly created agency in the U.S. Department of Health, Education, and Welfare called the, Indian Health Service (I.H.S.).¹⁰⁸ This lag in action serves as a key point illustrating the negligent behaviors of the federal government: there was a clear understanding of the plaguing health issues present among native communities, yet nothing was done for one-hundred and fifty years.

¹⁰⁶ *The Problem of Indian Administration: The Meriam Report.*

¹⁰⁷ Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955.*

¹⁰⁸ Rhoades and Rhoades, “The Public Health Foundation of Health Services for American Indians & Alaska Natives.”

With creation of the Indian Health Service, the department conducted an initial health survey. This health survey was initiated in order to help achieve the goal of the I.H.S., which was, and still is today, to provide healthcare services to the American Indian/ Alaska Native peoples in order “to raise their health status to the highest possible level”.¹⁰⁹ The health survey found that total mortality among natives was 20% higher, life-expectancy was 10 years lower, infant mortality was three times higher, and infectious diseases and accidents were much more prevalent.¹¹⁰ These statistics remained true into the 1970s where a similar health survey by the Indian Health Service showed that infant mortality was still 1.5 times higher, diabetes incidence was two times higher, dysentery was 40 times higher, rheumatic fever was 60 times higher, suicide was three times higher, tuberculosis was 14 times higher, and gastrointestinal infections was 27 times higher than their white-counterparts.¹¹¹ Following the release of this second report the Indian Health Service began receiving critique from tribes across the nation. These critics highlighted the notion that in order to better native health, the services and programs offered by the Indian Health Service must be designed by native members in conjunction with government officials. This outcry led to a transition within the Indian Health Service that resulted in increased tribal representation within the Indian Health Service. This transition is the key to many of the health improvements that have been made since the 1980s and it will be discussed in depth in the following chapter.

Ultimately the history of government-funded healthcare highlights the intimate connection between federally funded healthcare, health status, and the controversial topic of tribal sovereignty among native communities. This interplay demonstrates the ways in

¹⁰⁹ “About IHS | Indian Health Service (IHS).”

¹¹⁰ Jones, “The Persistence of American Indian Health Disparities.”

¹¹¹ Ibid.

which improvements in health can serve as a platform to strengthen tribal sovereignty. As illustrated throughout this chapter as well as chapter I, natives have faced, and still do today, a whole slew of debilitating health disparities that are rooted in the very nature of government-funded healthcare. The failures of the I.H.S., and more broadly government-funded care, can be marked throughout history and are clearly connected to the persistent health disparities seen among native communities today.¹¹² These events ultimately led to an emphasis to provide healthcare that resulted in improved health. This emphasis was coupled with extensive changes within the department that led to a shift in federal policy aimed at creating opportunities for tribal self-determination and self-governance with the hopes of designing effective healthcare programs. The progression to tribal autonomy of healthcare will be discussed thoroughly in the following chapter, outlining the clear association between increased tribal representation and control and the improvements in native health.

¹¹² Berry et al., “Broken Promises: Evaluating the Native American Health Care System.”

Chapter III. 20th Century Health Services: The I.H.S. and the Push for Tribal Representation and Autonomy

The creation of the Indian Health Service (I.H.S.) in 1955 was accompanied by a series of instrumental changes that led to the restructuring of the delivery of care for native communities. From 1955 to present day, this era of change resulted in increased tribal representation in both the I.H.S. and the BIA, which was subsequently followed by tribal autonomy in designing effective healthcare programs.¹¹³ This chapter exclusively examines the beginnings of the Indian Health Service, and the many changes it has undergone since 1955. This section will also touch on the ways in which native social movements fighting for sovereignty, coupled with I.H.S. leadership, resulted in the passing of crucial laws such as the Indian Self-Determination and Education Assistance Act of 1975.

In order to discuss the changes of the I.H.S., as well as the changing legal policies, it is first essential to provide some historical context regarding this time period of the 1950s. In 1953, the federal government passed legislation resulting in “termination” of native tribes.¹¹⁴ Termination policy called for the abolition of native reservations and removal of all federal oversight of native tribes. Although this policy seems to be the epitome of tribal independence, it had devastating effects on tribal autonomy, community, and economic stability.¹¹⁵ The adverse effects of termination are rooted in a combination of two issues. The first of these was the overbearing

¹¹³ Donald Warne and Linda Bane Frizzell, “American Indian Health Policy: Historical Trends and Contemporary Issues,” *American Journal of Public Health* 104, no. S3 (April 22, 2014): S263–67, doi:10.2105/AJPH.2013.301682.

¹¹⁴ Michael C. Walch, “Terminating the Indian Termination Policy,” *Stanford Law Review* 35, no. 6 (1983): 1181–1215, doi:10.2307/1228583.

¹¹⁵ Ibid.

guardianship-like involvement of the U.S. for over a century and a half, followed by the fact that termination resulted in the loss of tribal recognition as sovereign entities.¹¹⁶ This termination era caused upheaval and dissent among native communities, ultimately resulting in the official federal abandonment of termination in 1970 under President Richard Nixon.¹¹⁷

The infamous Watergate Scandal often clouds the era of Nixon, yet his presidency was monumental as it called for reform of federal “Indian” policy.¹¹⁸ This reform was coined by the slogan, “Indian self-determination without termination”.¹¹⁹ This era, coupled with the recent termination efforts, was birthed with the famous American Indian Movement and the Indian Sovereignty Movement.¹²⁰ Both movements were working to fight for tribal sovereignty. The efforts of these social movements greatly influenced the push for laws such as the 1975 Indian Self-Determination and Education Assistance Act.¹²¹ In the words of Tribal Contracting Officer, Sarah Sneed, JD, enrolled member of the Eastern Band of Cherokee Indians,

...Finally, why don't we give the money to the tribes and let the tribes decide how the money is to be spent and I don't have any secondary sources for this but the Indian Power Movement really had a lot to do with that because during that time all these young Indian people were really critiquing all of what had happened in Indian history, and I really think that [Indian Power Movement] had a lot to do with the redirection and thinking.¹²²

This historical context is crucial as it highlights the ways in which changing federal policy, which will be outlined in this chapter, was a result of natives fighting for tribal

¹¹⁶ Ibid.

¹¹⁷ Kotlowski, “Alcatraz, Wounded Knee, and Beyond.”

¹¹⁸ Ruth P. Morgan, “Nixon, Watergate, and the Study of the Presidency,” *Presidential Studies Quarterly* 26, no. 1 (1996): 217–38.

¹¹⁹ Kotlowski, “Alcatraz, Wounded Knee, and Beyond.”

¹²⁰ Ibid.

¹²¹ Steinman, “Settler Colonial Power and the American Indian Sovereignty Movement.”

¹²² Sneed, EBCI relationship with I.H.S. and tribal compacting.

sovereignty during the late '60s and '70s. Furthermore, detailing the history of the Indian Health Service, as well as outlining the many policy changes that have occurred throughout the last half-century illustrate the impact of tribal autonomy of healthcare and its relationship to tribal sovereignty.

As mentioned in the history and development of medical services for natives, the initial focus of government-funded healthcare for native populations was on infectious disease control. The programs focused on administering immunizations, vaccinations, implementing sanitation systems, and identifying secure food sources.^{123,124} However, despite their so-called efforts, these programs were ineffective. They were underfunded, paternalistic by nature, incapable of providing adequate care, and the intervention was primarily geared towards assimilating natives into white culture rather than reducing health issues.¹²⁵ Government officials ran the programs with little to no knowledge regarding tribal affairs, cultural differences that existed between tribes, the urgent needs of certain tribes, and the intricacies of the federal trust-responsibility. This inadequate organization slowly changed with the transition of healthcare responsibilities from the Commission of Indian Affairs within the Department of War to the Bureau of Indian Affairs within the Department of the Interior and finally to the Indian Health Service within the Department of Health, Education, and Welfare (now the Department of Health and Human Services). With these bureaucratic changes, tribal healthcare programs became increasingly systematic and organized. Although these transitions began as early

¹²³ Jones, "The Persistence of American Indian Health Disparities."

¹²⁴ Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

¹²⁵ Bergman et al., "A Political History of the Indian Health Service."

as the 1800s, this section will focus primarily on the changes that occurred within the Indian Health Service, thus looking at a time frame of 1955 to present day.

The first major change within native healthcare during this time frame began in 1955 when the I.H.S. was created and subsequently moved from the Department of the Interior to the Department of Health, Education, and Welfare. Here, the I.H.S. eventually became one of the nine agencies of the U.S. Department of Public Health and Human Services.¹²⁶ With this shift in departments came an immediate increase in funds: Congress doubled appropriations for the I.H.S. from \$18 million to \$36 million.¹²⁷ Along with this increase in funds, came the appointment of a new director for the department, Dr. James Ray Shaw. Dr. Shaw is noted as one of the key figures in spearheading the increased involvement of native voices in decision making, planning, and programming of Indian Health Service programs.¹²⁸ Specifically his leadership led to training programs for I.H.S. staff that focused on cross-cultural medicine, involving both western practices and tribal practices. This training was extended not only to I.H.S. staff members but also to traditional healers of tribes. Shaw wanted tribal members serviced by the I.H.S. to be able to obtain care from both western medicine and traditional medicine.¹²⁹ This was a dramatic shift in respect for traditional native medicine as compared to the prior mentality of the United States government; throughout the time of the Bureau of Indian Affairs, several programs were designed in order to eliminate all cultural practices of federally recognized tribes, and these programs were followed by laws that prohibited

¹²⁶ Rhoades and Rhoades, "The Public Health Foundation of Health Services for American Indians & Alaska Natives."

¹²⁷ Ibid.

¹²⁸ Everett R. Rhoades, "The Indian Health Service and Traditional Indian Medicine," *Virtual Mentor* 11, no. 10 (October 1, 2009), doi:10.1001/virtualmentor.2009.11.10.mhst1-0910.

¹²⁹ Ibid.

traditional healers from treating their patients.¹³⁰ Furthermore, the implementation of traditional medicine became a new foundation for the principles of the I.H.S., and this appreciation became even more official in 1992 when the I.H.S. established the Traditional Medicine Program, which was designed to formally increase the interface between western medicine and traditional tribal healing.¹³¹

Additionally, when Shaw took office in 1955, the department conducted a series of surveys regarding the state of health among tribal members receiving care from I.H.S. facilities. These reports showed horrible health trends, illustrating how the prior 50 - 100 years, had been ineffective in their attempts to provide healthcare. Of these reports, Shaw and colleagues published the *Health Services for American Indians*, in 1957; this report became known as the Goldbook. The Goldbook reported on the current clinics and facilities available for natives living on reservations while simultaneously highlighting how underfunded, run-down, and inadequate these facilities were. The Goldbook was a modern-day version of the 1928 Meriam Report. Although it would be best to include health data from various sources regarding native health, such reports do not exist; the I.H.S. was the sole producer of health data reports on native populations from the 1950s to the early 2000s.^{132,133} This causes a stream of issues regarding interpretation of these reports as well as the depth to which they accurately reflect health trends among natives. Because of this, the following discussion of changing health trends should be assessed

¹³⁰ Ibid.

¹³¹ Ibid.

¹³² T. Kue Young, "Recent Health Trends in the Native American Population," *Population Research and Policy Review* 16, no. 1/2 (1997): 147-67.

¹³³ T. Kue Young, *The Health of Native Americans: Toward a Biocultural Epidemiology* (Oxford University Press, 1994).

with a critical lens, yet also valued as they attempt to provide a picture of the conditions natives faced during the latter half of the 20th century.

The 1955 I.H.S. health trends report showed that the average life expectancy of natives was 10 years less than that of the average non-native American. It showed that native children and infants were the most sick and most likely to perish from communicable diseases than any other race, and due to the high infant mortality rate and child mortality rate, the average age of death for natives in 1955 was 37.7 years as compared to the average age of death for non-natives was 61.4 years.¹³⁴ Additionally, the report showed that the infant mortality rate for natives, 80.3 per 1,000 live births, was more than double that of the national average, 28.4 deaths per 1,000 live births.¹³⁵ These rates show that 27% of the total registered deaths that occurred among natives were within the infant population. In the non-native population, only 7% of all registered deaths represented infant deaths. Additionally, the report highlighted that diseases such as tuberculosis, trachoma, and gastroenteritis were rampant on reservations. Trachoma, although had decreased in prevalence since the 1930s, was still at an incidence rate of 2,000 per 100,000 individuals compared to its non-existence in the non-native population. The death rate for tuberculosis among natives was still five times that of the rest of the country despite the fact that the number of tuberculosis deaths among natives had been declining since 1940.¹³⁶ These trends are just a few of the many reported within this document, and they accurately demonstrate the inadequate nature of government-funded health services during the 19th and 20th centuries.

¹³⁴ The Indian Health Service, *The IHS Goldbook: The First 50 Years of the Indian Health Service: Caring & Curing* (The Indian Health Service, 2005).

¹³⁵ Ibid.

¹³⁶ James P. Rife and Alan J. Dellapenna, *Caring and Curing: A History of the Indian Health Service* (PHS COF, 2009).

Despite the tremendous task ahead, during Shaw's 10 year period as director, and during the leadership of his successors, the I.H.S. was able to make various achievements in health outcomes among natives. Dr. Shaw's direction focused on bridging the gap between tribal medicine and western medicine and this included bettering clinical care facilities and finding more experienced and culturally educated physicians for I.H.S. clinics.¹³⁷ In order to not only increase the number of physicians, but also increase the number of well-trained physicians, Shaw recruited physicians through the infamous "Doctor Draft" that was enacted in 1950 at the start of the Korean War. The draft required physicians to fulfill a two-year service obligation in the United States Armed Forces; this requirement however could be fulfilled by joining the Public Health Service, and thus Dr. Shaw was able to pool together young, well-trained physicians that would fulfill their service obligations by providing care at reservation clinics.¹³⁸ Due to Shaw's leadership however, many of these physicians chose to spend the remainder of their careers working at I.H.S. reservation hospitals.

Furthermore, during Shaw's initial years as director, he conducted another series of surveys regarding the status of healthcare facilities present on reservations. These surveys led to a detailed report in which Shaw highlighted the lack of basic sanitation facilities, lack of clean water, lack of hygienic clinic spaces, and lack of adequate facilities.¹³⁹ In an effort to combat these conditions, the I.H.S. secured the passage of the Sanitation Facilities Construction Act in 1959, which restored authority for construction of sanitation facilities that had not been included in the Transfer Act of 1954. This act highlighted the importance of access to safe water and proper waste disposal, thus

¹³⁷ Bergman et al., "A Political History of the Indian Health Service."

¹³⁸ Ibid.

¹³⁹ Rife and Dellapenna, *Caring and Curing*.

facilitating the creation of proper plumbing systems, water well and pump systems, as well as educational resources on how to implement such systems.¹⁴⁰ Establishing such systems helped significantly reduce the spread of infectious diseases, especially disease such as gastroenteritis and cholera. Additionally, integration of proper sanitation was coupled with improved clinical care that included the use of antimicrobials, proper antibiotics, and fluid and electrolyte management protocols. Collectively with these changes led to the reduction of mortality caused by gastrointestinal diseases.¹⁴¹ These diseases were particularly significant among children and infants, and thus there was a significant reduction in the infant and child mortality rates.¹⁴²

Conducting these health status surveys were crucial in the process of improving health trends. These reports provided direction regarding the specific needs of native communities serviced by the I.H.S. The importance of these surveys can be seen in the fact that in just 10 years under Dr. Shaw's direction, there was a reduction in all-cause mortality rates among natives, an increase in life expectancy, reduction in infant mortality, a reduction in tuberculosis rates and trachoma rates, and better control of infectious diseases on reservations.¹⁴³ Specifically, infant deaths were reduced by 36%, deaths from gastro-enteric diseases were reduced by 60%, deaths from influenza and pneumonia were reduced by 30%, and the greatest threat to the adult population, tuberculosis, fell by 54%.¹⁴⁴ In addition to reducing mortality rates, the use of I.H.S. facilities by tribal members increased during this period as well as the number of native

¹⁴⁰ Rhoades and Rhoades, "The Public Health Foundation of Health Services for American Indians & Alaska Natives."

¹⁴¹ Ibid.

¹⁴² Ibid.

¹⁴³ Ibid.

¹⁴⁴ Ibid.

babies born in I.H.S. hospitals. These improvements were due to the increase in available physicians, better healthcare facilities, standardized healthcare protocols, implementation of tribal practices, and better sanitation facilities. The changes in health trends due to a shift in more adequate healthcare illustrate how poorly led government healthcare programs successfully marginalized native communities and prohibited their abilities to achieve stability and express sovereignty.

In addition, to changing healthcare methods, these efforts were enhanced by the seven new hospitals that were built and the 42 new health centers and field clinics that were constructed. These new facilities increased the number of overall I.H.S. clinics to 49 hospitals, 46 large-based health centers, and several hundred-field clinics. These new facilities were accompanied by increases in staff members as well: 275 new physicians, 60 new dentists, and 860 new nurses.¹⁴⁵ These initial changes were primarily due to the use of cross-cultural medicine, increased funding, Shaw's leadership, and the push for certain federal laws that established funding, better trained physicians, sanitation systems, access to clean water, and construction of facilities. Shaw's leadership created the beginning of an era that valued the importance of tribal involvement, integration of traditional systems, and organizations run by tribal members. Both during and after Shaw's direction there was a proliferation of tribal and community health advisory boards, which helped emphasize the health of native communities as well as the individuals.¹⁴⁶ These advisory boards began collaborating with the I.H.S., other tribal health boards, and federal agencies like the Centers for Disease Control and Prevention and the National Institutes of Health, and voluntary organizations like the American

¹⁴⁵ The Indian Health Service, *The IHS Goldbook: The First 50 Years of the Indian Health Service: Caring & Curing*.

¹⁴⁶ Ibid.

Heart Association. These new collaborations, along with continued leadership from Dr. Shaw to Dr. Carruth Wagner (served 1962-65) to Dr. Erwin Rabeau (served 1966-69) and to Dr. Emery Johnson (served 1969-1981) kick-started the shift to increase tribal representation at the governmental level. These changes coupled with the tide of native movements calling for tribal sovereignty resulted in the push for the enactment of two crucial laws: the 1975 Indian Self-Determination and Education Assistance Act (ISDEAA) and the 1976 Indian Health Care Improvement Act (IHCIA).¹⁴⁷

It is essential to note that during the time period from when Shaw's tenure as director of I.H.S. ended to the establishment of both the ISDEAA and IHCIA, I.H.S. leadership continued to value the importance of tribal representation and autonomy in healthcare decisions. To illustrate this, the following paragraph will briefly discuss some key moments of Dr. Shaw's successors. After Dr. Shaw's resignation, Dr. Carruth Wagner became director. Serving just three short years from 1962 to 1965, Wagner was able to establish management training programs and medical and dental residency programs as well as training programs for nursing, nutrition, and environmental health. Following Dr. Wagner came Dr. Erwin Rabeau; Rabeau also served a short term from 1965 to 1969. During Rabeau's leadership an innovative training center, the Community Health Representatives (CHR) program was established in Desert Willow, Arizona. This program was built in order to bridge the gap between the needs of the patients and the care provided by the health clinics and hospitals. Additionally during Rabeau's time as director he oversaw the formation of the Health Services Research Systems Center in Tucson (1967), which was designed to increase the efficacy of the I.H.S. health clinics

¹⁴⁷ The Indian Health Service, *The IHS Goldbook: The First 50 Years of the Indian Health Service: Caring & Curing*.

and expand participation of tribal members. Assuming leadership after Rabeau was Dr. Emery Johnson. Serving from 1969 to 1981, Johnson oversaw some of the most progressive changes of the I.H.S. A leader during the most revolutionary period in history for native health and rights, Johnson ensured that President Nixon's progressive "Indian Policy" came to fruition. This policy, heavily influenced by the American Indian Movement and Indian Sovereignty Movement, brought forth the era of self-determination, which proposed the idea that federal programs for tribes, such as the I.H.S. health programs, be taken over and managed by the tribes themselves.^{148,149} This ideology led to the passing of the 1975 Indian Self-Determination and Education Assistance Act (ISDEAA) and the 1976 Indian Health Care Improvement Act (IHCIA). These two acts helped build upon the momentum of increasing tribal involvement and representation; they fostered community involvement, local initiatives, and program management by the tribes themselves, inherently contributing to tribal sovereignty.¹⁵⁰

More specifically, the Indian Self-Determination and Education Assistance Act of 1975 (ISDEAA) established that Congress would now recognize the importance of tribal involvement and autonomy in the decision-making processes regarding tribal affairs. This act encouraged tribal involvement at the government level and is perhaps the most significant law affecting how health services are provided to native tribes today.¹⁵¹ Subsequent amendments to this act, specifically in 1992, have authorized a Tribal Self-Governance Demonstration Project within the I.H.S., which gives federally recognized tribes the option of entering into self-governance compacts, Title V, or self-determination

¹⁴⁸ Ibid.

¹⁴⁹ Steinman, "Settler Colonial Power and the American Indian Sovereignty Movement."

¹⁵⁰ The Indian Health Service, *The IHS Goldbook: The First 50 Years of the Indian Health Service: Caring & Curing*.

¹⁵¹ Rhoades, D'Angelo, and Hurlburt, "The Indian Health Service Record of Achievement."

contracts, Title I, which allow tribes to request a block budget from the I.H.S. so that they can reprogram and organize healthcare facilities and services.¹⁵² Both a Title V compact and Title I contract transfer the responsibility of managing healthcare services and funds that serve natives from current I.H.S. service providers to the tribes. It is important to note that a Title V compact is a step beyond Title I contract in that it is a form of self-governance, meaning it is founded on the government-to-government relationship between the federal government and a tribe, ultimately making a compact more flexible for a tribe than a contract; it is the epitome of reclaiming tribal sovereignty.¹⁵³

These compacts and contracts allow tribes to assume responsibility for organizing and implementing health care programs while still using funds appropriated by Congress to the I.H.S. This form of autonomy provides an avenue for tribes to exhibit sovereignty that is not undermined by the trust-responsibility. In other words, improving healthcare has been a goal of the I.H.S. as well as the tribes for a century now, and in creating PL-93-638, tribal nations are able to be autonomous in providing healthcare, thereby enhancing health status, providing the ultimate symbol of governing competency. By 1994, 14 tribes exercised their right to enter into self-governance compacts, and by 2016 over 350 of the 567 federally recognized tribes have either self-governance compacts or self-determination contracts with the I.H.S. Furthermore, the ISDEAA received another amendment in 2000 in which Congress passed the Tribal Self-Governance Amendments authorizing the Tribal Self-Governance Program and making the “Tribal Self-Determination Act”, the ISDEAA, a permanent authority.¹⁵⁴ Ultimately the ISDEAA has

¹⁵² Indian Health Service, “Tribal Self-Governance,” accessed January 16, 2017, <https://www.ihs.gov/newsroom/index.cfm/factsheets/tribalselfgovernance/>.

¹⁵³ PDF file on PL-93-638

¹⁵⁴ Indian Health Service, “Tribal Self-Governance.”

allowed hundreds of tribes to create effective healthcare programs that are geared towards their tribal members, thus resulting in increased tribal participation and better health outcomes among those served.¹⁵⁵ These changing health trends accompanied by the compacting and contracting programs further indicate the benefits of this reclaimed form of tribal sovereignty.

In addition to the ISDEAA, the 1976 Indian Health Care Improvement Act (IHCIA) was instrumental in establishing federal policy to improve the health of native peoples. It reaffirmed the Snyder Act of 1921, and further established the federal-trust responsibility between the U.S. government and federally recognized tribes. This act also highlighted the importance of obtaining modern healthcare technology for tribal healthcare facilities as well as expanding services for tribal members. Also, the IHCIA specifically called for securing funds from Congress, providing health professional scholarships for native students, permission for the I.H.S. to secure funds from Medicare, Medicaid, and other private insurance companies, and for construction of new facilities.¹⁵⁶ These specific changes enhance tribal sovereignty as they inherently indicate tribal competency, something lacking within the restricting nature of the federal trust responsibility.

Additionally, Title V of the IHCIA established the Urban Indian Health Programs. The Urban Indian Health Programs are health services available for tribal members that are a part of a federally recognized tribe living off of their designated reservation. The Urban Indian Health Programs, UIHP, are an extension of the federal-

¹⁵⁵ Stephen Cornell and Joseph Kalt, "American Indian Self-Determination: The Political Economy of a Successful Policy" (Native Nations Institute and The Harvard Project, November 2010), http://nni.arizona.edu/pubs/jopna-wp1_cornell&kalt.pdf.

¹⁵⁶ Bergman et al., "A Political History of the Indian Health Service."

trust responsibility and are designed to ensure that all tribal members of federally recognized tribes receive the care they are entitled to. Today, there are 33 UIH programs across the United States, spreading across 59 different locations.¹⁵⁷ These programs are designed to combat the unmet needs of urban natives through culturally appropriate services. The Urban Indian Health Programs have become part of a three tier healthcare system designed by the I.H.S. and tribes. Accompanying the Urban Health Programs, designated a “U”, are the services provided directly by the I.H.S., designated “I”, and the Tribal Health Services, designated “T”, which are the services designed by tribal members and implemented via the compacting and contracting services. Collectively the three-tier system, “I/T/U”, creates a comprehensive healthcare service that aims to reach all tribal members of federally recognized tribes in order to advance their health and prevent diseases.

Despite the successes of the compacting/contracting services outlined by the ISDEAA, as well as the provisions of the IHCA, many tribal leaders have expressed concerns over contracting and compacting. These concerns are due to the drastic increase in healthcare prices coupled with the stagnant funding from Congress. Furthermore, because Congress is the acting authority in releasing and appropriating funds to the I.H.S. there is a level of variability in the level of funding as members of Congress can drastically sway funding from the I.H.S. Thus, there is a limit in the stability and security of 638 compacts and contracts. This conundrum however has forced certain tribes to start allocating their own funding sources towards healthcare programs that would normally be

¹⁵⁷ Indian Health Service, “Urban Indian Health Program - Indian Health Service (IHS),” accessed January 17, 2017, <https://www.ihs.gov/newsroom/factsheets/uihp/>.

covered by I.H.S. funds, illustrating further independency.¹⁵⁸ To further combat the rising costs of healthcare, the Centers for Medicare and Medicaid Services and the Children's Health Insurance Program (CHIP) have become increasingly involved in native healthcare; providing service coverage for the disadvantaged, elderly, and tribal members living in poverty. More tribal members are seeking care, have access to care, and feel comfortable receiving care as it is now culturally driven and those providing the care are often natives. Furthermore, tribes participating in the self-governance program have been able to create programs that both better address the local needs and are more responsive to the needs of their communities. With this program, federal funds are utilized more effectively as they actually address the needs of tribal members, and because of this, the health of participating tribes has improved significantly since the beginning of this program.¹⁵⁹

Ultimately, the success of these programs during the '70s was followed by another era of great I.H.S. leadership that allowed for effective tribal collaboration with the I.H.S. Following the progressive era of Dr. Emery Johnson's leadership in the 1970s came the appointment of the first native I.H.S. director in 1981, Dr. Everett R. Rhoades. Dr. Rhoades, an enrolled member of the Kiowa Nation, Oklahoma, was the first member of his tribe to receive a medical degree and one of the first natives across the country to receive an M.D.¹⁶⁰ Rhoades' appointment to director of the I.H.S. further illustrates the continuing progressive era of the I.H.S. He served as director from 1981 to 1993, and during this time Rhoades oversaw the continuation of the ISDEAA and IHCA.

¹⁵⁸ Warne and Frizzell, "American Indian Health Policy," June 2014.

¹⁵⁹ Berry et al., "Broken Promises: Evaluating the Native American Health Care System."

¹⁶⁰ Jane Westberg, "Everett Rhoades: The First American Indian Director of the I.H.S.," *Winds of Change*, 2006, <http://aianhealthcareers.org/page1/page12/page13/page13.html>.

Furthermore, he established the first formal consultation between the I.H.S. and the tribes it serviced. This consultation was the first time in which Tribal governments were involved in establishing and designing allocation methodologies to be used in annual appropriations. Now tribes were not only designing their own healthcare services at the community level, they were also integrated at the federal level, another key to the continuing success of combating health disparities and reclaiming sovereignty.

During his tenure, Rhoades also published a series of articles regarding the status of health among natives, the achievements of the I.H.S. regarding health outcomes, and the importance that tribal involvement has had on improving native health. In these publications, Rhoades reported that infant mortality, maternal mortality, and infectious disease related deaths were all reduced significantly to rates comparable to the non-native population. Specifically, in a 1987 publication, Rhoades states that from 1940 to 1982, 20 years of longevity were added to the native lifespan, increasing from 51.0 years to 71.1 years. Also, the rate of birth was 79% higher than that of the U.S. population in 1982 and the rate of infant mortality fell by 82% from 1955 to 1982. Furthermore, the maternal mortality rate for natives, which was twice the rate of the U.S. population in the 1950's, had dropped 89% and was approximately the same as the U.S. all races maternal mortality rate by 1982. Continuing with these positive trends, the incidence rate of tuberculosis dropped significantly, as did the likelihood that contracting the disease would result in death: the death rate in 1955 was 57.9 per 100,000 individuals and by 1983 it had dropped to 3.3 per 100,000 individuals. In addition to this improvement, mortality from other infectious diseases like gastrointestinal diseases dropped significantly from 15.4 per 100,000 individuals to 4.2 per 100,000 individuals from 1955

to 1983. This specific drop was largely due to the addition and proper installation of sanitation facilities and clean water sources.¹⁶¹ Collectively, these improvements in health outcomes are due to the various changes in healthcare services: the sudden tribal representation and autonomy in implementing healthcare programs along with the integration of traditional practices allowed for increased tribal participation, better outreach, and more effective services.

As Rhoades highlighted the vast improvements that were made, he also noted that as the rate of communicable diseases decreased, and the rate of neonatal and maternal mortality dropped, native communities began experiencing an epidemiological shift in which the burden of disease stemmed from non-communicable diseases such as diabetes heart disease, and cancers.¹⁶² In order to combat these changing health trends, as well as continue the line of improving health conditions, Rhoades saw that the I.H.S. budget grew from \$617 million to \$1.87 billion, seven new hospitals were built in: Tahlequah, Oklahoma, Browning, Montana, Kanakanak, Alaska, Crown Point, New Mexico, Chinle, Arizona, Rosebud, South Dakota, and Sacaton, Arizona. In addition to increasing funding and the number of hospitals, Rhoades ensured an upgrade in research regarding local epidemiology. He refined resource allocation, developed programs that emphasized health promotion and disease prevention, and helped design women's health programs, and establish a chronic diseases center. He also established a national adolescent alcohol and substance abuse prevention and treatment program and created the country's leading fetal alcohol syndrome program.¹⁶³ These programs have created a foundation for further

¹⁶¹ Rhoades, D'Angelo, and Hurlburt, "The Indian Health Service Record of Achievement."

¹⁶² E R Rhoades et al., "The Indian Burden of Illness and Future Health Interventions.," *Public Health Reports* 102, no. 4 (1987): 361–68.

¹⁶³ Westberg, "Everett Rhoades: The First American Indian Director of the I.H.S."

projects and organizations to take fruition among various tribes across the country. Collectively these actions illustrate that Rhoades' leadership not only led to continual achievements in the realm of native health but also led to the continuation of native leadership and involvement within the I.H.S. Following his term, each subsequent I.H.S. leader has represented a tribe from across the United States and the department has become increasingly diverse.

The I.H.S. in the 21st Century has taken on more challenges and has continued to expand to better address the needs of its user population. The I.H.S. services natives who are enlisted members of one of the 567 federally recognized tribes. Today, this corresponds to approximately 2.2 million natives of the 5.2 million whom self-identify as "AI/AN".¹⁶⁴ A federally recognized tribe is defined by the B.I.A., as a tribal entity that is recognized as having a special government-to-government relationship with the United States with responsibilities, powers, limitations, and obligations of that of a sovereign nation.¹⁶⁵ Federal recognition has been a topic of debate for many years, as it requires tribes to prove their legitimacy and origins via official historical documents or government documents, which for certain tribes simply do not exist.¹⁶⁶ Because of this, the number of natives serviced by the I.H.S. is much smaller than that of the actual population of natives in the United States.¹⁶⁷ Federal recognition is not to be confused with a racial classification; it is strictly political distinction that allows the federal government to determine which tribes are "eligible" for the federal trust responsibility.¹⁶⁸

¹⁶⁴ "About IHS | Indian Health Service (IHS)."

¹⁶⁵ "Indian Affairs | FAQs," accessed February 4, 2017, <https://www.bia.gov/FAQs/>.

¹⁶⁶ David E. Wilkins, "Breaking into the Intergovernmental Matrix: The Lumbee Tribe's Efforts to Secure Federal Acknowledgment," *Publius* 23, no. 4 (1993): 123–42, doi:10.2307/3330879.

¹⁶⁷ "Indian Affairs | FAQs."

¹⁶⁸ Sneed, EBCI relationship with I.H.S. and tribal compacting.

Despite the complex topic of federal recognition, the I.H.S. continues to work to provide care, and the many changes within the I.H.S., coupled with native participation over the past 60 years, are responsible for the decrease in many health issues. Although achievements have been made, it is important to note that there is still much that needs to change in order for the health gap to diminish and the fight for sovereignty to persevere. The most striking barrier here is the issue of funding; the I.H.S. 2010 funding level of \$4.05 billion represented only 57% of the funding that was deemed necessary to adequately treat all native patients; it constitutes an annual per patient spending of \$3,348, far below the average annual per patient spending of the larger country: \$9,086.¹⁶⁹ This accurately illustrates the present dilemma within healthcare across the world. Without adequate funding, health disparities will prevail, and although tribal autonomy of healthcare has significantly reduced health issues, funding continues to remain a barrier in continuing the success.

Although there are many challenges today regarding health disparities among native communities, they do not diminish the health achievements made and the significance of tribal-led healthcare systems. The changes within the I.H.S., as well as the push for 638-compacts and contracts, illustrates the resiliency of native communities in their fight to regain sovereignty. This resiliency can be seen throughout the positive health changes discussed in this chapter, as well as the increase in tribal representation in the I.H.S., the new organizational structure of the I.H.S., and the changing health trends among native communities. These trends are further supported by the changing demographics of the I.H.S. In 2005, natives predominated in the I.H.S. workforce: 88%

¹⁶⁹ Thomas D. Sequist, Theresa Cullen, and Kelly J. Acton, "Indian Health Service Innovations Have Helped Reduce Health Disparities Affecting American Indian And Alaska Native People," *Health Affairs* 30, no. 10 (October 1, 2011): 1965–73, doi:10.1377/hlthaff.2011.0630.

of administrative I.H.S. personnel were native, 94% of the technical/ clerical staff were native, and 50% were professional staff, ie: physicians, nurses, physician assistants and nurse assistants etc.¹⁷⁰ Furthermore, 15% of I.H.S. physicians self-identify as being American Indian/ Alaska Native.¹⁷¹ Additionally, today, all I.H.S. decisions are made in consultation with tribal leaders, something that began under the leadership of Dr. Everett Rhoades. These changes have resulted in an I.H.S. of today, as compared to its 1955 counterpart, that is largely decentralized, as half of the native health care systems are now managed by tribal health departments under 638-compacts. In 2010, of the \$1.98 billion the I.H.S. was granted from Congress, \$780 million were appropriated for contracting tribes.¹⁷² These contracting services have resulted in a proliferation of healthcare centers run by certain federally recognized tribes. In Arizona alone there are 48 health care service stations operated under 638 programs.¹⁷³ Currently, there are about 350 federally recognized tribes that have 638-compacts and contracts, and among these, the Eastern Band of Cherokee Indians in Cherokee, North Carolina have been particularly successful in their control over their healthcare system. The specific public health system of the EBCI will be discussed in depth in the following chapter, serving as model demonstrating the impact of tribal-led healthcare systems.

Researchers have analyzed the efficacy of the compacting and contracting services and have found that tribes engaged in 638-compacts or 638-contracts are better able to address the healthcare needs of their communities, which not only results in

¹⁷⁰ The Indian Health Service, *The IHS Goldbook: The First 50 Years of the Indian Health Service: Caring & Curing*.

¹⁷¹ Sequist, Cullen, and Acton, "Indian Health Service Innovations Have Helped Reduce Health Disparities Affecting American Indian And Alaska Native People."

¹⁷² Ibid.

¹⁷³ "ITUs List - Indian Health Service (IHS), Tribally-Operated 638 Programs, and Urban Indian Health Programs in Arizona," accessed February 4, 2017, <https://www.azahcccs.gov/AmericanIndians/AmericanIndianHealthFacilities/ITUsList.html>.

improved health conditions, but also results in more satisfied patients.¹⁷⁴ This process of 638-compacting and contracting is not only essential to improving and maintaining health among tribal communities, but also to creating new avenues for exercising tribal sovereignty. Through the analysis of the past 50 years of the I.H.S., as well as government funded healthcare, it is clear that persistent health disparities have prevailed due to negligence from the federal government, lack of resources, as well as the many exacerbating social determinants of health. However, as discussed throughout the chapter, changes in leadership and legal policies in the past half-century have been instrumental in making positive strides towards closing the health gap. It is clear that Public-Law 93-638, The Indian Self-Determination and Education Assistance Act, a product of the fight for tribal sovereignty movement of the 1970s, has played a crucial role in reshaping healthcare services for native communities. Tribal autonomy in healthcare has created a path to reclaim tribal sovereignty and to better health outcomes among tribal members. In order to further investigate the efficacy of this law and illustrate the power and influence of tribal autonomy in healthcare services, the following two chapters will discuss an in-depth case study of the Eastern Band of Cherokee Indians (Cherokee, NC) healthcare system as well as their path to assuming responsibility of their healthcare services.

¹⁷⁴ Cornell and Kalt, “American Indian Self-Determination: The Political Economy of a Successful Policy.”

Chapter IV. Case study of the Eastern Band of Cherokee Indians Healthcare System: From the Indian Health Service to Tribal Self-Governance

The contemporary Eastern Band of Cherokee Indian healthcare system provides an excellent model to illustrate the power of self-governance and determination facilitated through Public Law 93-638. In order to highlight these points, this chapter will first give some background regarding the Eastern Band and then dive into the information provided by the key-informant interviews regarding this transition to tribal-led healthcare. The case study will include specifics regarding the transition to a tribal-led healthcare system, the changes that occurred, as well as the intricacies of this particular healthcare system. Ultimately, the case study provides solid evidence supporting the efficacy and importance of tribal-autonomy of healthcare services; this successful healthcare system exemplifies tribal competency and the ways in which healthcare autonomy escapes the paradoxical nature of the trust responsibility.

The Eastern Band of Cherokee Indians, from here referred to as EBCI, is the only federally recognized tribe in the state of North Carolina.¹⁷⁵ The Eastern Band has roughly 15,000 enrolled tribal members whose home is on the 56,000-acre Qualla Boundary in Western North Carolina. The Qualla Boundary is adjacent to the Great Smoky Mountains National Park and spans over 5 counties in Western North Carolina. Of these five counties, the majority of the boundary is located in the Swain and Jackson counties, with smaller discontinuous acres located in the Graham, Cherokee, and Haywood counties.¹⁷⁶ Unlike other tribes in the United States, the EBCI do not reside on a reservation, rather their lands were bought by the tribe, in fee simple during the late 1800's and then later

¹⁷⁵ Vickie Bradley et al., "Eastern Band of Cherokee Indians Tribal Health Assessment" (Cherokee, North Carolina, July 1, 2013).

¹⁷⁶ Ibid.

put into trust by the United States government.¹⁷⁷ It is because of this that the EBCI lands are referred to as the Qualla Boundary and not a reservation. This purchasing of land was a later result of President Jackson's infamous Indian Removal Act of 1830. This act resulted in the forcible removal and relocation of five major southern tribes: the Seminole, Creek, Choctaw, Chickasaw, and Cherokee. However, during this period of negotiation and forced removal, a group of Cherokees resisted the forced removal of their tribe to Oklahoma in the "Trail of Tears" of 1838.¹⁷⁸ The EBCI members today are the direct descendants of those who avoided and resisted the removal. Through this resistance, the EBCI members eventually bought what is the Qualla Boundary, a mere fragment of the extensive original homeland of the Cherokee Nation, and later put the land in trust with the United States. The EBCI today are just one of two of the 567 federally recognized tribes that live on a portion of the original lands of their ancestors.¹⁷⁹ This land history is crucial illustrates the complexities of the trust responsibility as it relates to the EBCI while simultaneously demonstrating the history of resiliency and strength of the EBCI tribe.

Today, the EBCI are considered one of the more economically prosperous and thriving tribes in the country. This is largely due to great leadership, community based programing, casino revenues, and its strong tribal government. The tribal government of the EBCI provides services to its citizens that are typical of most municipal governments. Police, fire, public safety, EMS and sanitation services, as well as water and sewer services, road construction and maintenance, and environmental planning are all provided

¹⁷⁷ Sneed, EBCI relationship with I.H.S. and tribal compacting.

¹⁷⁸ Cave, "Abuse of Power."

¹⁷⁹ Sneed, EBCI relationship with I.H.S. and tribal compacting.

for tribal members.¹⁸⁰ Furthermore, the tribe is actively engaged in economic development on the reservation. Currently, the majority of the economy on the boundary is based on tourism; due to the close proximity to the Great Smoky Mountains National Park, which is the nation's most visited park, the tribe has a continual influx of tourists throughout the summer months.¹⁸¹ Additionally, a primary economic engine, not only for the tribe but also for all of Western North Carolina, is the Harrah's Cherokee Casino and Hotel. The casino opened in 1997 and since then has created both a booming economy for the tribe as well as a stable financial resource for tribal programs. Half of the gaming revenue goes towards the tribal council, which allocates funds for tribal operations and infrastructure, while the other half is allocated equally to its 15,000 enrolled members. These per-capita payments are sent out every six-months and most recently have climbed towards \$9,000/year.¹⁸² The continuing stability of the tribal government as well as the success of Harrah's Casino have played, and still do, a large role in the tribe's efficacy in assuming responsibility of its healthcare system. These factors will be further explored in relationship to the EBCI healthcare system throughout the chapter. Collectively these relationships display the ways in which tribal healthcare autonomy is supported by other autonomous actions such as economy regulation and government organization.

The information and evidence regarding the current EBCI healthcare system along with the transition to tribal autonomy of health care services were obtained through key informant interviews. Interviews with various members of the tribal health care system were conducted on site March 2017 (Cherokee Nation, NC). Among those

¹⁸⁰ Bradley et al., "Eastern Band of Cherokee Indians Tribal Health Assessment."

¹⁸¹ Ibid.

¹⁸² "Gambling Wagers Pay Community-Health Dividends for Eastern Band of Cherokee – Daily Yonder," accessed March 22, 2017, <http://www.dailyyonder.com/gambling-wagers-pay-community-health-dividends-for-eastern-band-of-chokeee/2015/10/05/8848/>.

interviewed were Vickie Bradley, Deputy Health Officer, Aneva Turtle Hagberg, Operations Director of Public Health and Human Services (PHHS), Martha Salyers, Public Health Consultant for PHHS, Sarah Sneed, Tribal Contracting Officer for Cherokee Indian Hospital and Carmalita Monteith, chair of the Cherokee Indian Hospital Authority. More information regarding the process of conducting the interviews, as well as how and why these individuals were contacted, can be found in the methodologies section: appendix ii. These interviews, accompanied by the Tribal Health Assessment (THA) and the Tribal Health Improvement Plan (THIP), will be discussed throughout this chapter and the following chapter in order to demonstrate the success of the EBCI healthcare system and the significance of 638-compacting services facilitated by Public Law 93-638.

The EBCI assumed responsibility of their healthcare system in September of 2002.¹⁸³ Yet prior to achieving a self-governance 638-compact, the tribe went through a century-plus of inadequate and negligent healthcare “sponsored” by the U.S. government.¹⁸⁴ Prior to compacting, the tribal healthcare system was maintained and operated by the Indian Health Service, and prior to the I.H.S., healthcare was provisioned by the Bureau of Indian Affairs, under first the Department of War and then later the Department of the Interior.¹⁸⁵ Just as the hundreds of other tribes across the nation, health care services provided for the EBCI were done so through military operations in the early 1800s. Yet, unlike most tribes, for the EBCI, post the Indian Removal Act 1830, neighboring Quakers brought the first physician to the boundary in 1894. Years following

¹⁸³ Cherokee Indian Hospital Authority, “Cherokee Indian Hospital,” accessed March 23, 2017, <http://cherokeehospital.org/page?title=Core-Purpose>.

¹⁸⁴ Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting

¹⁸⁵ Ibid.

this act by the Quakers, in the 1920s, during the height of the boarding school era, a field nurse was stationed in the basement of the primary school on the boundary. It was not until the 1930s that the U.S. government authorized funding to build a hospital on the Qualla Boundary. From the 1930's to the mid-1970s, there were some improvements made to facilities, yet technology was set at the bare minimum, and in addition, the Indian Health Service determined the number of physicians, nurses, and qualified health professionals present at these field sites.¹⁸⁶ Health data specific to the EBCI from this period are, unfortunately, non-existent, however it can be speculated that conditions for the EBCI were similar to those experienced by tribal members across the nation: life-expectancies were 10-years below the national average, infectious diseases such as tuberculosis and trachoma wreaked havoc, and an infant mortality rate that was more than twice the national average.¹⁸⁷

In this brief discussion regarding the early stages of healthcare for the EBCI it seems most appropriate to mention that this authorized funding of healthcare is specific to tribal nations as determined by the federal trust responsibility. In the words of Deputy Health Officer, Vickie Bradley, MPH, RN:

It was the cessation of the lands that codified treaties: we have your land, we're going to always give you health care, so its not free health care. There was a penance to pay, and I think that's important because native people are often accused of getting free health care, it's not free at all, there was a price that we paid...¹⁸⁸

This is a perfect explanation of the conundrum that exists within the federal trust responsibility, and how it relates to healthcare specifically: care was only given in return

¹⁸⁶ Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting.

¹⁸⁷ Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

¹⁸⁸ Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting.

for tribal lands. For almost 200 hundred years, under the federal trust responsibility, federally recognized tribal nations received what was deemed “healthcare”, yet in reality was anything but healthcare. Inexperienced physicians, inadequate resources, lack of funding, coercive, and culturally inappropriate medical treatment does not constitute as healthcare. This broken system, as illustrated through chapters I, II, and III, did anything but improve the health of native peoples. This longstanding history dramatically shifted with the transitioning of healthcare responsibilities back to tribal nations themselves. Tribal-led healthcare via PL-93-638 escapes the paradox of the trust responsibility and sovereignty as this system in fact increases expression of sovereignty without forcing further cessation of tribal rights, and allows for the reclaiming of sovereignty by gaining back the abilities to dictate healthcare, and thereby health status.

When the EBCI compacted in 2002, after months of negotiations with the federal government, healthcare responsibilities were transitioned to tribal authority. In this process the tribe assumed responsibility of the Cherokee Indian Hospital that was previously built in 1985 and run by the I.H.S. With this transfer, the tribe created a separate health governing board, the Cherokee Indian Hospital Authority, CIHA, that would exist independently from the political governing boards of the tribe.¹⁸⁹ As Carmaleta Monteith, current chair of the CIHA, explained to me, the CIHA is an independent board that is self-perpetuating and designed to make healthcare decisions without political influence. It currently consists of 11 tribal members who hold some form of higher educational degrees.¹⁹⁰ Under the direction of the CIHA, an investment was made to improve health care; part of this investment would be a new hospital,

¹⁸⁹ Carmaleta Monteith, EBCI relationship with I.H.S. and tribal compacting, March 8, 2017.

¹⁹⁰ Ibid.

designed, constructed, and funded by the Eastern Band of Cherokee Indians.¹⁹¹ The CIHA were crucial in rebuilding and re-organizing the tribal healthcare system. The CIHA recreated the mission of the Cherokee Indian Hospital: “to enhance the prosperity of the next seven generations of the Eastern Band of Cherokee Indians through relationship based quality healthcare.”¹⁹² With this shift to relationship based care, the CIHA held community forums and meetings to discuss the needs of their patient population. From these meetings it became evident that the “old” hospital (the previous I.H.S. hospital) was not effective in caring for the needs of the tribe. Furthermore, because the old hospital was previously I.H.S. built and run, many community members did not feel comfortable receiving care from the facility despite the recent transfer in authority.¹⁹³ Such conversations, coupled with the direction of the CIHA and support from the tribal government, initiated the plans to construct a brand new state of the art hospital.

However, prior to the opening of the new hospital, the CIHA, along with the Public Health and Human Service Division, set out to identify the best ways to deliver care beyond just new facilities. As Deputy Health Office Vickie Bradley explained to me, the CIHA, and in particular, Casey Cooper, the CEO of the Cherokee Indian Hospital, began investigating other tribal healthcare systems. In this process, a particular model of an integrated healthcare team, driven by the desires and motivations of the patient, seemed most appropriate as a model for the EBCI. This model, known as the Nuka System of Care, designed by the Alaska Native population at South-central Foundation in Anchorage, Alaska, has been incredibly effective in addressing the health needs of the

¹⁹¹ “Eastern Band of Cherokees Unveil Their New Hospital,” *North Carolina Health News*, October 19, 2015, <http://www.northcarolinahealthnews.org/2015/10/19/eastern-band-choerokees-unveil-their-new-hospital/>.

¹⁹² Cherokee Indian Hospital Authority, “Cherokee Indian Hospital.”

¹⁹³ Casey Cooper – introduction to CIH June 2016 via NRN

Alaskan Native population.¹⁹⁴ This system, now adapted by the EBCI, emphasizes physician-patient relationships and provides patients with an integrated healthcare team that consists of a primary care physician, a mid-level practitioner, a nutritionist, a pharmacist, a mental health provider, and sometimes a certain specialist if necessary. With this, system patients come in for just one visit and are able to address all of their healthcare needs at once, and most importantly the team is directed based on what the patient wants. The level of personalized care is a direct result of a tribal-led healthcare system, and as will be discussed in chapter V, this system has allowed for drastic changes in community attitudes towards health as well as improved health trends. Furthermore, this integrated system has become even more effective in recent years with the opening of the new Cherokee Indian Hospital.

In November of 2015, the EBCI unveiled their brand new hospital. The hospital was designed by and for the tribe. As Carmaleta Monteith explained, as the CIHA navigated the best approach to addressing the healthcare needs of the community, it became obvious that the new hospital must incorporate Cherokee tradition and legend through artwork and architectural design, see figures 1 and 2. The new hospital has Cherokee culture ingrained in every aspect, and each piece of artwork and signage were intentionally chosen to support Cherokee tradition. Furthermore, this \$80 million project was completely funded by tribal assets. As Ms. Sarah Sneed, the hospital's Tribal Contracting Officer, put it, "the new hospital embodies the power of self-governance".¹⁹⁵

¹⁹⁴ Katherine Gottlieb, "The Nuka System of Care: Improving Health through Ownership and Relationships," *International Journal of Circumpolar Health* 72 (August 5, 2013), doi:10.3402/ijch.v72i0.21118.

¹⁹⁵ Sneed, EBCI relationship with I.H.S. and tribal compacting.

The new hospital houses numerous healthcare programs including 20-bed inpatient rooms with windows overlooking the Great Smoky Mountains, integrated care outpatient services, a lab, pharmacy, emergency room services, complimentary services including physical therapy and acupuncture, behavioral health services, a dental clinic, and an eye clinic to name a few. The hospital focuses on primary care for the 13,000-plus tribal members. However, when a patient is in need of a specialty medical service not provided by the hospital, such as a surgical operation, Purchased and Referred Care, PRC, ensures that the patient can receive the medical treatment at a tertiary level-hospital in the surrounding area. PRC is a complicated system that consists of a \$20 million “safety net” to cover medical costs for patients referred to outside hospitals or specialty clinics. This service is comprised of a committee of physicians, nurses, and pharmacists who review referrals made in-house at the Cherokee Indian Hospital. The PRC committee determines whether or not the referral is medically necessary or if alternative care is an option. If the referral is deemed medically necessary, then the PRC committee approves the purchasing of that service that is provided by an alternative hospital, or in some instances, a private sector clinic. This system becomes complicated as the non-native hospital providing care for the native can also qualify for 100% FMAP, Federal Medical Assistance Percentage; meaning that if the services provided can be covered by the state’s Medicaid system, the costs of the service are instead reimbursed by federal dollars rather than the Medicaid system, thus the state does not “lose” money when treating the native patient.¹⁹⁶ With PRC, 100% FMAP, and the new CIHA hospital, tribal members are able to obtain high-quality and effective services. The system, while

¹⁹⁶ Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting.

complex, is multifaceted and ensures medical treatment that was previously not present under I.H.S. control.

In addition to the new hospital, the EBCI Public Health and Human Services, PHHS, supervises a variety of outpatient clinics that were previously not present under I.H.S. These clinics work in conjunction with the CIHA. As mentioned, the CIHA is a separate governing authority that works independently of the tribal government. PHHS however, works as a sub-division of the tribal government and thus is subject to different authorities than the hospital. Despite the differing governing circles, the CIHA and PHHS work together to enhance the health of the individual as well as the community. PHHS specifically supervises a wide range of health and community services, (see figure 3 for a diagram of services). As illustrated from the diagram in figure 3, these services range from environmental safety and conservation, to human services, to health programs. Many of these services were either created with compacting in 2002 or have changed and improved since the take over. These services were created under the re-designed PHHS, originally the Health and Medical Division. In fact, the tribe originally created the Health and Medical Division in order to provide services that the federal government would not fund. The funding from these services came from gaming revenue; about 8% of gaming was, and still is, appropriated for healthcare directives in the community.^{197,198} Tribal revenue coupled with a new public health directive paved the way for an extensive field of outpatient clinics. Among the services outlined in figure 3, a few will be discussed in more detail here.

¹⁹⁷ Martha Salyers, EBCI relationship with I.H.S. and tribal compacting, March 7, 2017.

¹⁹⁸ Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting.

To begin, the Cherokee Choices Diabetes Prevention and Awareness Program helps educate tribal members about type II diabetes, provides nutrition education, as well as basic education regarding prevention. Additionally, there is the Nurse-Family Partnership, NFP, which serves pregnant mothers of the EBCI tribe, pairing a pregnant EBCI mother with a registered nurse who visits the mother early in her pregnancy and receives ongoing nurse home visits that continue through the child's second birthday. This program began as a result of a lack of OB/GYN physicians at the hospital, both during I.H.S. control and currently under tribal-control. There is also the Women, Infant, and Children, WIC, program, which is run by the PHHS division, supplemented by tribal gaming dollars. There is also the Tsali Care Center, which is a 60-bed assisted living facility that is equipped to deliver quality-nursing care to the elderly. As Dr. Martha Salyers described to me, every day the Tsali center has about 80-100 elders for free lunch.¹⁹⁹

In addition to these services, the tribe has identified the dangers of its food-desert status. In order to combat this the PHHS runs a Tribal Food Distribution Program that is dedicated to distributing nutritious foods to eligible households living within four of the county-areas of the Qualla-Boundary (Jackson, Swain, Graham, and Cherokee). It is clear that the many services provided by the PHHS are far-reaching and truly designed to improve the health and awareness of their community. The efficacy of this division, as Deputy Health Officer Vickie Bradley puts it, is due to increased competency within the division,²⁰⁰ and in combination with self-governance, the tribe is truly able to address the needs of the community.

¹⁹⁹ Salyers, EBCI relationship with I.H.S. and tribal compacting.

²⁰⁰ Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting.

The EBCI self-governance compact has allowed for the expansion of medical services available for enrolled tribal members. This expansion has also allowed for increased healthcare competency as well as a sense of cultural integrity that was non-existent during I.H.S. control. Although the 638-compact has greatly enhanced healthcare services as well as healthcare accessibility for the EBCI tribe, the initial movement towards this form of self-governance was met with hesitation and skepticism. Many tribal members worried that the financial burdens of healthcare would be too great for the tribe to handle. Furthermore, there was skepticism regarding whether or not organizationally the tribe would be able to re-design a healthcare program that was free of the lingering effects of federal oversight. Despite these hesitations, as Deputy Health Officer Vickie Bradley informed me, the EBCI had experienced “rationed health care for so long, that the tribe was ready to do something different.”²⁰¹ This rationed healthcare is simply what it sounds like: patient procedures and needs were prioritized based on a classification system: P1A and P1B priority lists. A P1A priority was an immediate and life-threatening condition that if care was not received within thirty days the patient would lose their life. In contrast, P1B priorities were procedures listed as “life-altering” if treatment was not received within thirty days. Ultimately P1B priorities would then be put on hold indefinitely as the federal government could not afford, and some in stances would not be willing to pay for, such procedures:

...And so we had hundreds of people on the P1B list, and so when the tribe took over, the tribe could purchase that [service] at a much better rate, and so that list went away because the tribe chose to purchase those services for their people and appropriate those dollars. And so as a result, purchase, what we call purchase and referred care, is about \$20 million dollars into the region that we purchase from specialty services.²⁰²

²⁰¹ 5/15/17 10:17 AM

²⁰² Ibid.

As Ms. Bradley explained, although there were many hesitations regarding compacting, the tribe felt that in order to improve health trends among the community, compacting was necessary. As illustrated through the quote above, with compacting the tribe was able to clear both P1A and P1B health priorities, freeing hundreds of tribal members of their ailments. Thus, the compacting system proved incredibly effective in its initial stages. Furthermore, the CIHA is a separate entity of the tribal government; this separated system helps to ensure that tribal politics do not influence healthcare decisions, again illustrating the efficacy of the healthcare design.²⁰³

Ultimately, EBCI tribal compacting of healthcare services resulted in a complete redesign of healthcare services that has positively impacted the tribe. This tribal-led healthcare system is culturally appropriate and effective in addressing the many health needs of the community. Furthermore, although compacting for the EBCI, as for all other federally recognized tribes, comes from the sacrifice of land as well as many other lingering impacts of colonialism, healthcare autonomy allows for the reclaiming of sovereignty and successfully combats the undermining nature of the federal trust responsibility. Successful tribal healthcare autonomy, as illustrated with the EBCI healthcare system, provides undeniable evidence regarding the competency of tribal governments thereby defying the condescending nature of the trust responsibility. In defying these connotations, tribal healthcare autonomy successfully reclaims tribal sovereignty in a way that allows for both enhanced self-governance and far-reaching effective medical care that was previously unavailable through the healthcare services of the Indian Health Service. In order to further support the efficacy of tribal compacting,

²⁰³ Monteith, EBCI relationship with I.H.S. and tribal compacting.

PL 93-638, and the significance of health and tribal sovereignty, the following chapter will provide statistical data as well as qualitative data regarding health trends of the Eastern Band of Cherokee Indians since they assumed responsibility of healthcare in 2002.



Figure 1: image of the entrance of the Cherokee Indian Hospital. The Rotunda entrance is supposed to mimic a traditional Cherokee woven basket.



Figure 2 image of Rotunda entrance: the artwork on the tile is of the famous Cherokee water spider that brought fire to the Cherokee people in a basket on her back. The tile artwork then feeds into a river-way that outlines the walking path throughout the first floor of the hospital.



Eastern Band of Cherokee Indians
Public Health & Human Services 2016

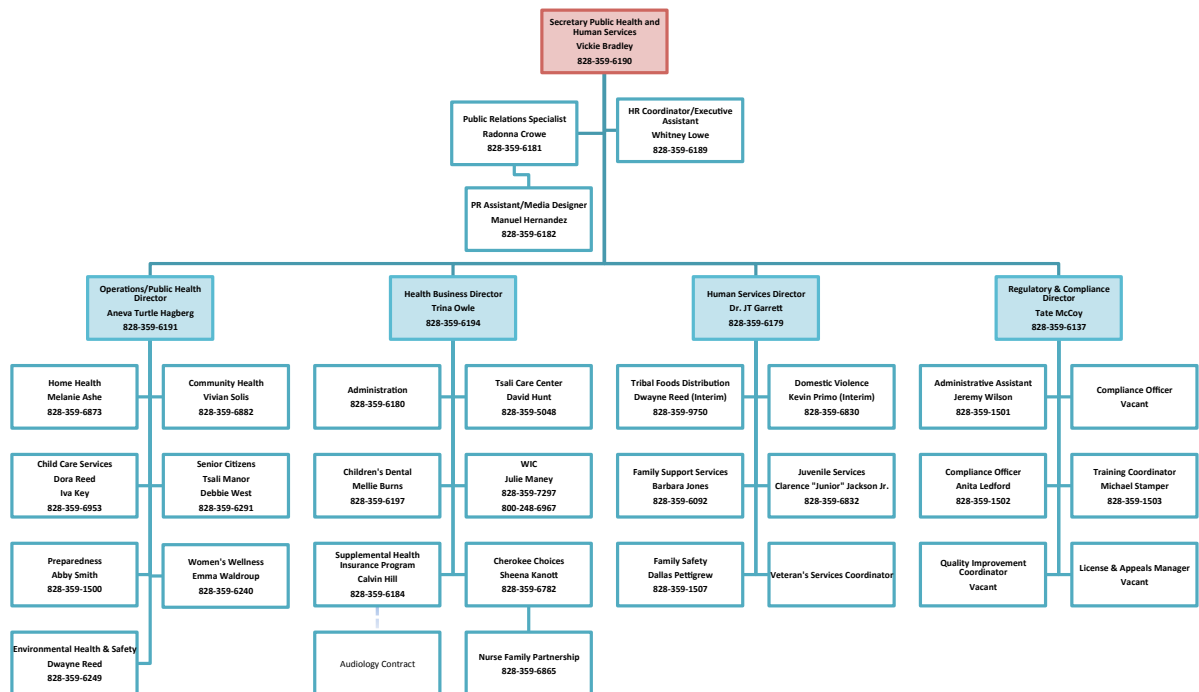


Figure 3: Branching diagram of all of the services provided and supervised by the Public Health and Human Services Division.²⁰⁴

²⁰⁴ Images were collected from the EBCI Cherokee Indian Hospital Authority and Public Health & Human Services Facebook pages

Chapter V. Health Trends of the EBCI Tribe: The Efficacy of a Tribal-Led Healthcare System

Tribal-led healthcare, as demonstrated in chapter IV, effectively reaches community members due to its cultural sensitivity as well as its directed healthcare programs. This chapter will specifically illustrate the association between tribal-led healthcare and changing health trends and improving health status among the EBCI. This chapter will illuminate how the EBCI healthcare system both effectively addresses the health-needs and issues of the community while simultaneously supporting tribal sovereignty. Collectively, the efficacy of tribal-led healthcare systems further supports the notion that healthcare autonomy enhances tribal sovereignty as it provides concrete evidence of tribal competency, the crux of the trust-responsibility paradox.

When the EBCI assumed responsibility of their healthcare system in 2002 there were many changes made to the structure and services offered to tribal members. Yet, as both Vickie Bradley and Aneva Turtle Hagberg explained to me, at the time, there was no quantitative data regarding the health issues affecting tribal members. The Cherokee Indian Health Authority, CIHA, and the Public Health and Human Services, PHHS, had an understanding of what the most salient health issues were, however no formal data were available to support those speculations. As discussed in the previous chapters, health data regarding natives has been very scarce, and historically, quite inaccurate due to misclassification of race and under-reporting.²⁰⁵ Thus, in order to understand what health issues were most prevalent among EBCI tribal members, the PHHS conducted the first ever-tribal health assessment report. This chapter will discuss some of the crucial

²⁰⁵ Jim et al., “Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area.”

findings of this health assessment, as well as discuss various comments from EBCI health professionals regarding health status among the EBCI today.

The push for the tribal health assessment came from the PHHS. During 2011-2013, the division was going through various structural changes in order to become more public health oriented.²⁰⁶ These changes resulted in the realization that in order to effectively promote health and prevent chronic disease, PHHS needed to know what exactly tribal members were suffering from. Throughout the following year the division put together a team to gather health data about the tribe. In the summer of 2013, PHHS released a 210-page report, the Tribal Health Assessment, THA, regarding the health status of their hospital user-population (about 8,000 tribal members) living within the Qualla Boundary. The report was compiled by a team of seven public health specialists working in the tribal health care system along with a group of sixteen other individuals involved in EBCI healthcare. Collectively the CDC, the National Indian Health Board (NIHB), the National Association of County and City Health Officials (NACCHO), and the EBCI Tribal Council & Tribal Health Board financially supported this report. Although this report contains statistics regarding a broad range of morbidity and mortality data, this chapter will focus on the data regarding the more prevalent health issues: diabetes mellitus, cardiovascular health, maternal and infant health, and substance use and abuse.

To begin, the Tribal Health Assessment Board, THAB, created the assessment with continual input from community members. Throughout the report are notes and comments, as well as a key-informant interview section containing valuable information

²⁰⁶ Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting.

regarding the significance of this report as well as the efficacy of the current healthcare system. The THAB also noted that among the many health indicators and trends reported, the community noted that the most important health issues to them were: rising diabetes mellitus incidence, obesity and its relationship to overall poor health, concerns regarding food accessibility and affordability, concerns regarding substance use, in particular alcohol, and a concern for receiving respectful clinical care with cultural competence.²⁰⁷

As Deputy Health Officer Vickie Bradley put it:

...It identified – it confirmed what our suspicions were. We suspected that are problems were diabetes, substance abuse, and obesity, and what it did [THA], was it confirmed those things and it gave validity to those thoughts.²⁰⁸

This point of validity is crucial, as with the quantitative data, PHHS would be able to argue for the importance of certain public health projects and then support those arguments with health data specific to the tribe. Furthermore, the THA not only highlighted health issues, but also incorporated the ways in which poverty, education, and access to nutritional foods and healthcare impact community health. As Aneva Hagberg stated:

It really tied back in to the poverty issue, in people being hungry and not getting enough food – some of those things we thought we knew, but we didn't know for sure, concretely to voice, and that came out [with THA] and I think that really helped in tribal leadership, and just our community as a whole, to be able to see that.²⁰⁹

Ultimately the results of THA have had far-reaching effects in terms of the direction of healthcare programs supervised by PHHS. The report also illustrates both the health issues present, and highlights the ways in which health issues have changed since the tribe compacted in 2002. Many of these statistics show that certain health issues

²⁰⁷ Bradley et al., “Eastern Band of Cherokee Indians Tribal Health Assessment.”

²⁰⁸ Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting.

²⁰⁹ Aneva Turtle Hagberg, EBCI relationship with I.H.S. and tribal compacting, March 7, 2017.

improved dramatically within a short time frame. These changing health trends will be discussed in the following paragraphs.

To begin, it is important to note who the sample population was and whom they reflect. At the time of the report, THA states that there are discrepancies between the U.S. Census Bureau population data regarding the EBCI and the EBCI Tribal enrollment data. Specifically, the U.S. Census population data of 2010 lists the number of EBCI tribal members as 2,861 individuals less than counted by the EBCI Enrollment Office. The tribe, at the time of this report, had listed about 10,965 enrolled members. This number is also an underestimation as every individual interviewed in PHHS department or the Cherokee Indian Hospital referenced tribal enrollment at 15,000. These discrepancies also exist within the county-level figures. Specifically, THA notes that the majority of EBCI members live in the Jackson and Swain Counties approximately 4,300 EBCI members in each county. They also note that EBCI members live in Cherokee, Graham, and Haywood counties, about 2,160 collectively. Despite this large number of enrolled members, the THA specifically reports on individuals who utilized the Cherokee Indian Health Departments and they were classified as either the active clinical population: individuals who are AI/AN, live within the 5-counties listed above, and have had two or more visits in the last three years; or the “user population”: individuals who are alive at the end of this report period, they are AI/AN and live within the 5 counties listed above, and have had one visit in the last three years. Of these individuals, approximately 96.75% of the AI/AN hospital users are enrolled members of the EBCI.²¹⁰ Thus, this report is highly indicative of the Eastern Band of Cherokee Indians health status.

²¹⁰ Bradley et al., “Eastern Band of Cherokee Indians Tribal Health Assessment.”

First off, the report shows that the life expectancy at birth for AI/AN in the five-county area between the years of 2003-2010 is 78.39 years, which is slightly higher than the life expectancy at birth in North Carolina, 78 years. Furthermore the report indicates that from 2003 to 2010 the five major leading causes of death have all decreased in number of deaths per 100,000 individuals. Specifically the five leading causes of death in order were: circulatory-heart disease, malignant neoplasms, unintentional injuries, diabetes mellitus, and chronic liver disease and cirrhosis:

Condition	2003	2010
Heart Disease	201.29	97.15
Malignant Neoplasms	128.93	97.01
Unintentional Injuries	72.42	56.01
Diabetes Mellitus	68.89	44.49
Chronic Liver Disease	35.61	26.65

Table 1. Top 5 mortality rates, as # of deaths per 100,000 people, from 2003 to 2010 period.²¹¹

Additionally, the report showed that the percentage of AI/AN adults living in Jackson and Swain counties with cardiovascular disease dropped from 14.1% in 2002 to 10.8% in 2012. These numbers clearly indicate which health issues were most salient at the time of the THA in 2013, but they also indicate how these issues improved during the initial years of tribal-led healthcare.

In terms of alcohol use, the THA report shows data regarding alcohol consumption in 16 counties in Western North Carolina broken down by race. Here it shows that the percent of current drinkers and binge drinkers is lower than that of whites and the whole of the United States. Specifically, in the category of “current drinkers” whites came in at 44.5%, AI/AN at 29.3%, and U.S. population at 58.8%. This data is from 2012 and shows an improvement in alcohol consumption among AI/AN individuals

²¹¹ Ibid.

within this region. However when discussing salient health issues with various members of PHHS, substance use was noted multiple times; this substance use was in terms of opioid use. This data will be discussed later in the chapter in conjunction with the Tribal Health Improvement Plan.

In terms of maternal health and infant health, the report outlines data regarding pregnancy risk factors. This includes data on maternal tobacco use, maternal age, maternal obesity, maternal diabetes, maternal depression, and breastfeeding. The report shows that maternal smoking among active EBCI clinical patients has been higher than mothers in the state of North Carolina, the Nashville Area, and for all races in the United States. Specifically the report shows that from 2007-2009 maternal smoking has hovered around 33%, dipped in 2010 to 27.8%, and rose again to 39.9%, in 2011. Additionally, maternal age since 2006 has been dropping from 29.4 years of age in 2006 to 25.3 years in 2010. Furthermore, maternal obesity in 2010 among EBCI women was 45.1% compared to the 2010 rate of maternal obesity for all of North Carolina was 25.9%. In addition to this data, the report shows that maternal diabetes, also known as gestational diabetes, was recorded as 13.7% among AI/AN women living in the 5-counties. In comparison, the North Carolina state prevalence was 10.8%. The risk factor of gestational diabetes has become an increasing concern for pregnant women as it increases the woman's risk of developing type II diabetes by 20-50%. It also increases distress for the baby. Specifically, the risks increased are: high birth weight, requiring caesarean section during labor, low blood sugar, jaundice, and respiratory distress syndrome. These concerning factors however have been more effectively addressed with the Women, Infant, and Children's, WIC, clinic and the Nurse-Family Partnership, NFP, programs.

Despite this worrying data regarding maternal health, the THA did report that in 2011, unlike statewide mothers, among EBCI mothers – either pregnant or had recently delivered—only 21% were experiencing maternal depression whereas 75.4% of statewide women reported having feelings associated with postpartum depression in 2010. Maternal health and infant health have historically been an incredibly large issue among the realm of native health. For centuries natives were experiencing maternal mortality and infant mortality rates far above the national average.²¹² These issues, as discussed in chapter I, are rooted in various historical traumas and created a large setback for natives in terms of improving maternal and infant health.

Ultimately this health data brings forth various health issues that the tribe was dealing with at the time of its release in 2013, thereby effectively directing PHHS. These numbers also illustrate that the tribal-led healthcare system has clearly been effective in addressing the needs of the community, as seen by decreasing rates of cardiovascular disease, diabetes, chronic liver disease, cancer, and unintentional injuries. It is important to note however, that there are limitations as well as potential confounding variables in this data set and thus the results indicating improved health trends must be assessed with a critical lens. These limitations are that the early health data regarding the tribe are not in fact specific to EBCI members, yet gathered from the North Carolina Public Health division, which does not classify natives based on tribal enrollment. This is important, as although the EBCI is the only federally recognized tribe in North Carolina, there are various state recognized tribes such as the Lumbee and Haliwa-Saponi Tribe, thus these data points may capture a large native population than simply the EBCI. The implications

²¹² Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

of this are discussed in depth in the THA report. Despite these limitations, as well as the presence of potential confounding variables such as time, age, and sex, the work of the THA and the THIP, are not diminished. These reports indicate the initiative of the tribe as well as the efforts in place to improve health status among their community members, and with future data reports, these limitations will be addressed as the tribe is now in control, and actively collecting health data on their user-population.

Additionally, when discussing changing health trends with Deputy Health Officer Vickie Bradley she noted that although progress has been made, the changes have been slow:

But are we moving the mark? Very slowly, but will we, yes, because of things like Indian communities implementing public health systems [THA and THIP]. So that the community is in coordination with their health care teams, defining what the priorities are and then we address those priorities based on what the community identifies them as – and I think that is the way we’ll move the mark, is over the next 20 years if communities remain in partnership we will begin to see [change], but its going to be a slow progression.

Yet despite the slow changes, as Ms. Bradley states, changes will continue, and health issues will improve as long as the community remains involved in the healthcare process. Additionally, Ms. Bradley stated that the slow improvements have been coupled with improvements in blood pressure control, greater blood glucose control, decreases in A1C (glycated hemoglobin levels), increased check-ups, and increased preventative care visits for things like mammograms. In addition to Ms. Bradley’s comments, Sarah Sneed, Cherokee Indian Hospital Contracting Officer, as well as Carmaleta Monteith, governing chair of CIHA, stated that community attitudes towards healthcare have changed dramatically. Specifically, the integration of Cherokee cultural in the hospital layout as

well as increased cultural competency among hospital staff resulted in positive community attitudes towards healthcare.²¹³

Furthermore, with the release of the THA, PHHS also released a follow-up Tribal Health Improvement Plan for 2015-2017, THIP. THIP was released in order to identify the most salient health issues as identified by the community and provide reasonable and effective goals in targeting and alleviating those health issues. The specific health issues and targets for these issues outlined in THIP are: diabetes mellitus, substance abuse, and depression. THIP first describes the disease burden of these three illnesses. In particular diabetes mellitus has been identified as one of the most salient health issues among all Native Americans across the nation. For the EBCI, type II diabetes is consistently one of the top five admitting diagnoses, and in 2014 CIHA saw an 11.1% increase in the admitting diagnosis of type II diabetes. Furthermore, type II diabetes is the fourth leading cause of death among EBCI, and therefore has become a top priority in healthcare. The second illness identified was substance abuse. THIP shows that specifically opioid dependence and drug withdrawal are the top two admitting diagnoses at the Cherokee Indian Hospital. The tribe has identified that there has been a 57% increase between 2001 and 2014 in drug-related diagnoses at the hospital. Lastly, depression was identified as the third most salient issue. Since 2006, the tribe has seen 875% increase in behavioral health visits. Many of these visits have been accompanied by type of mood disorder diagnosis.²¹⁴

For these three health issues, THIP has outlined the current issue for the tribe, the focus for each illness either prevention or awareness, and outlined a specific goal to

²¹³ Monteith, EBCI relationship with I.H.S. and tribal compacting.

²¹⁴ Vickie Bradley et al., “Eastern Band of Cherokee Indians Tribal Health Improvement Plan 2015-2017” (Cherokee, North Carolina, 2015).

achieve. Although THIP highlights the most pressing health issues for the EBCI community, it simultaneously illustrates how active the tribe is in finding methods to curb the presence of these illnesses. Furthermore, THIP has currently been implemented within the Cherokee Indian Hospital, serving as a platform to mesh and integrate the Public Health and Human Services with the Cherokee Indian Hospital Authority despite their separate governing authorities. This integration is crucial as the two divisions operate under different authorities and thereby have different obligations and motivations, which at some points can become problematic in terms of integrating new healthcare measures.²¹⁵

Ultimately both THA and THIP represent the power of self-governance within healthcare. These directives show the initiative the tribe is taking in order to truly change health trends beyond just implementing new facilities. Furthermore, THA and THIP, along with the key informant interviews, show that although many changes are being made, and healthcare has improved significantly since the tribe compacted in 2002, there are still very many health disparities. Among them diabetes mellitus, cardiovascular disease, substance abuse, and depression have been identified as the most salient, and in the words of Vickie Bradley, “Diabetes looks like a Tsunami coming at us...” The EBCI are making incredible strides towards changing health trends to ultimately close the gap in health disparities for their tribal members. Yet, this process, as mentioned, is a very slow one, and not only must target contemporary health issues, but it also target the historical trauma and violence inflicted on the tribe. For the EBCI, 638-compacting has

²¹⁵ Bradley, EBCI relationship with I.H.S. and the transition to tribal compacting.

been a form of self-governance that has enhanced their tribal sovereignty in a way that supports cultural growth, community stability, and economic growth.

It is important to note that although many tribes across the nation have either 638- compacts or contracts, some have become more successful than others and only time will allow these programs to come to fruition. Furthermore, among those tribes who do not have compacts/contracts, it has been identified that this decision is a form of expression of sovereignty as well.^{216,217} In making such decisions regarding healthcare, it is evident that the realm of health is clearly a new avenue in which tribes can exercise sovereignty that actually allows for self-governance and a reclaim of sovereignty that escapes the condescending and limiting nature of the trust responsibility.

²¹⁶ Donald Warne, “Considerations for Tribes Regarding Contracting or Compacting for Clinical Services from the Indian Health Service under PL93-638,” August 2013.

²¹⁷ Alyce Adams, “The Road Not Taken: How Tribes Choose between Tribal and Indian Health Service Management of Health Care Resources,” *American Indian Culture and Research Journal* 24, no. 3 (January 2000): 21–38, doi:10.17953/aicr.24.3.h052286t22314634.

Conclusion: Breaking the Paradox of the Trust Responsibility through Health Care Autonomy and Reclaimed Sovereignty

The fight for tribal sovereignty has been, and still is, a balancing act for tribes. Throughout history the U.S. to tribal government relationship has been described as a one between a landlord and a tenant.²¹⁸ This analogy clearly illustrates the condescending nature of federal “Indian” policy and the historically limited expressions of tribal sovereignty. As discussed throughout the thesis, the federal trust responsibility permanently established this paradoxical relationship, and in turn for tribal lands, tribes would receive government appropriations for healthcare, education, and various other protective programs.²¹⁹ The federal trust responsibility however was designed based on the belief that tribes were incompetent and incapable of acting as independent governing structures, despite their complete functionality and prosperity prior to colonial contact.²²⁰ This belief of incompetency fueled many of the abusive and genocidal acts committed against native tribes throughout history, both of which simultaneously restricted sovereignty and created tribal dependency on the federal government. It is through the lens of this complex double standard of the trust responsibility in which tribal sovereignty is regained through healthcare autonomy.

This thesis specifically points to the role of health status and healthcare in the fight for sovereignty. The association between persistent health disparities and government-funded healthcare, epitomizes how the trust responsibility, allegedly designed to protect sovereignty, in fact robbed tribes of it.²²¹ Throughout the chapters of

²¹⁸ PRYGOSKI, “FROM MARSHALL TO MARSHALL.”

²¹⁹ Reid Peyton Chambers, “Judicial Enforcement of the Federal Trust Responsibility to Indians,” *Stanford Law Review* 27, no. 5 (1975): 1213–48, doi:10.2307/1228040.

²²⁰ Gover, “An Indian Trust for the Twenty-First Century,” Spring 2006.

²²¹ Ibid.

the thesis, this corrupt relationship has been exposed and the ways in which healthcare and health status impact sovereignty have been highlighted. Together these points illustrate how changing legislation such as the 1975 Indian Self-Determination and Education Assistance Act (ISDEAA), and the push for healthcare autonomy, increases sovereignty by demonstrating the competency of tribal nations. This effectively defies the patronizing nature of the federal trust responsibility and escapes the restrictive nature of the landlord to tenant relationship.

Healthcare plays a pivotal role in this convoluted relationship as healthcare services were secured upon the cessation of native lands, which was later codified through the federal trust responsibility.²²² This healthcare, as illustrated throughout chapter I, was corrupt, culturally insensitive, and served as an extension of destructive colonial behaviors.²²³ Furthermore, as discussed in chapters I and II, government funded healthcare largely contributed to the many health disparities experienced by natives, and this ill-health, exacerbated by the negligence of the U.S. government, successfully restricted and threatened tribal sovereignty. This association was further explored in the discussion of the development of the Indian Health Service, I.H.S., in 1955. Chapter III assessed the ways in which federal changes within the I.H.S., which called for increased tribal representation in the department as well as a newfound respect for traditional medicine, resulted in improved health status among native communities.²²⁴ With the acknowledgment that healthcare was most effectively administered when directed by tribes themselves, federal legislators, in conjunction with various native leaders designed

²²² Warne and Frizzell, "American Indian Health Policy," April 22, 2014.

²²³ Dejong, *If You Only Knew the Conditions: A Chronicle of the Indian Medical Service and American Indian Health Care, 1908-1955*.

²²⁴ Rhoades, "The Indian Health Service and Traditional Indian Medicine."

the 1975 ISDEAA. The ISDEAA solidified the push for tribal-led healthcare systems, ultimately creating a new wave of legislation focused on tribal self-determination and self-governance.²²⁵ This topic of self-governance was investigated further through the case study analysis of the Eastern Band of Cherokee Indians healthcare system in chapters IV and V. These chapters specifically addressed how the transition to tribal-led healthcare has enhanced tribal sovereignty and improved health status among EBCI community members. Collectively chapters I –V demonstrate the ways in which health and healthcare both impact a tribe’s ability to express sovereignty as well as provide a new avenue to exercise sovereignty.

It is important to note that although the cessation of lands are the basis of the federal trust responsibility, and the funding of healthcare programs today can be seen as an extension of the trust responsibility, and therefore an extension of the paradoxical effort to limit tribal sovereignty, it is in fact not. These appropriations are no different than other types of healthcare aid that the United States appropriates to foreign countries.²²⁶ Furthermore, these funds are used based on the sole discretion of tribal governments. The 638-compacting and contracting services, coupled with tribal competency, are therefore successful ways for tribes to express sovereignty. This sovereignty specifically aims at improving and maintaining the health of native populations, creating a self-perpetuating cycle of stability and independency. It is through this lens that it is evident that tribal-led healthcare systems, which are more effective at addressing the health needs of their communities, as illustrated through the EBCI

²²⁵ Sneed, EBCI relationship with I.H.S. and tribal compacting.

²²⁶ In 2014, a third of the U.S. foreign aid budget went towards health expenditures: \$5.3 billion to be exact. Poncie Rutsch, “Guess How Much Of Uncle Sam’s Money Goes To Foreign Aid. Guess Again!,” *NPR.org*, accessed April 17, 2017, <http://www.npr.org/sections/goatsandsoda/2015/02/10/383875581/guess-how-much-of-uncle-sams-money-goes-to-foreign-aid-guess-again>.

healthcare case study, are expressions of sovereignty that are indirectly, and directly, free of the paradoxical nature of the trust responsibility. In other words, effective 638-compact and contracts illustrate the competency of tribal nations, thereby directly defying the logical premise of the federal trust-responsibility and inherently help reclaim sovereignty.

Furthermore, tribal-led healthcare systems are successful in reclaiming sovereignty in ways that are novel from prior methods. For instance, throughout history native efforts to reclaim sovereignty through actions like controlling land, enhancing economic growth, changing education systems, and creating tribal laws, were instead sources of tension within the peculiar U.S. to tribal relationship.²²⁷ Efforts to exercise sovereignty through these mediums were met with stark resistance throughout history.²²⁸ Many scholars such as anthropologist Jessica Cattelino discuss this tension in terms of economic independence and tribal sovereignty. Specifically, Cattelino discusses the complexity of tribal sovereignty and economics in terms of the ‘double bind’: some tribes, specifically gaming tribes, are able to achieve economic prosperity via gaming, which is a special privilege granted through sovereignty, yet this act of sovereignty is then challenged by non-natives.²²⁹ This threatened sovereignty comes from the basis that tribal sovereignty was granted upon the cessation of lands, and thus exercising legal rights that other citizens are unable to express results in a tension that questions the legitimacy of tribal sovereignty. Here, the use of tribal sovereignty to engage in casino

²²⁷ Andrew G. Hill, “ANOTHER BLOW TO TRIBAL SOVEREIGNTY: A LOOK AT CROSS-JURISDICTIONAL LAW-ENFORCEMENT AGREEMENTS BETWEEN INDIAN TRIBES AND LOCAL COMMUNITIES,” *American Indian Law Review* 34, no. 2 (2009): 291–315.

²²⁸ Jessica R. Cattelino, “Tribal Gaming and Indigenous Sovereignty, with Notes from Seminole Country,” *American Studies* 46, no. 3/4 (2005): 187–204.

²²⁹ Jessica Cattelino, “The Double Bind of American Indian Need-Based Sovereignty,” *Cultural Anthropology* 25, no. 2 (November 2, 2012): 235–63.

gaming to ultimately enhance economic growth for a tribe results in a tension that both strains the double bind relationship between tribes and the U.S. government and threatens the premise of sovereignty and power. This example is important to include as it both highlights the contentious path in the fight for regaining tribal sovereignty and the ways in which healthcare autonomy seems to enhance tribal sovereignty without creating tensions similar to those created due to tribal gaming.

Although this thesis takes a historical lens as well as a contemporary case study in order to effectively support the argument that healthcare autonomy is a form of reclaimed sovereignty, breaking free from the patronizing federal trust responsibility, there are limitations to this research. Non-natives write many of the historical documents as well as scholarly papers regarding healthcare services in “Indian Country” and tribal sovereignty. This presents an issue, as the unique native perspective is lost in these sources. In attempting to combat this issue, in-person key-informant interviews with Eastern Cherokee tribal members were conducted in order to gain first-hand perspectives regarding the importance of health and healthcare in maintaining and regaining tribal sovereignty. Furthermore, as mentioned in chapter I, access to meaningful, quantitative, historical health data and statistics about natives are nearly impossible to obtain. The issues of underreporting, falsifying data, and misclassifying race and tribal affiliation serve as the primary barriers in finding accurate statistical health data.^{230,231} These limitations are very difficult to circumvent, yet are necessary to acknowledge in order to see the ways in which historical documents can provide skewed perspectives.

²³⁰ Jim et al., “Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area.”

²³¹ Anderson, Copeland, and Hayes, “Linkages to Improve Mortality Data for American Indians and Alaska Natives.”

The work of this thesis also points to various areas for future research. In particular, expanding on the case study of the EBCI healthcare system by interviewing non-healthcare related tribal members in order to gain insights regarding the impact of healthcare autonomy from a non-public health perspective. Also, assessing the work of other tribes in their push for healthcare autonomy will provide further evidence regarding the strong association between healthcare, health status, and tribal sovereignty. Specifically, conducting key-informant interviews with members from various tribes across the nation with 638-compacts or contracts as well as learning more about tribes who chose to keep their healthcare systems run by the Indian Health Service, will greatly broaden the scope of this field and the understandings regarding the significance of health as it relates to and impacts tribal independency and sovereignty. Furthermore, it is essential to unravel the role that casino revenues play in the efficacy and efficiency of tribal-led healthcare systems as this could be a key variable in the success of such systems. Identifying this would be essential in order to understand how to circumvent this variable when working with tribes who do not operate gaming centers. Additionally, the research of this thesis highlights the need for, and the importance of, accurate health data regarding both specific tribes and natives as a whole. As seen through the case study of the Eastern Band of Cherokee healthcare system, tribes are conducting such efforts on their own in order to better understand how to redesign their healthcare systems. Yet, efforts to work in conjunction with various tribes to conduct such large scale epidemiological studies would be beneficial in order to ensure that changing healthcare systems accurately address the needs of the communities they service.

Lastly, it is important to note that although this thesis presents the positive impacts of tribal-led healthcare systems as well as the positive significance of laws such as the 1975 ISDEAA and the 1976 Indian Healthcare Improvement Act, not all tribes have experienced these positive impacts.^{232,233} There is still much more that must be done in order to truly reach a sense of equitable care for native communities. This includes increased funding appropriations, effective collaboration between tribal healthcare systems and I.H.S. services, and federal acknowledgement of intergenerational trauma and social determinants of health. Furthermore, the ability to engage in healthcare autonomy is specific to federally recognized tribes: of the 5.2 million individuals who self-identify as American Indian/Alaska Native (AI/AN), only 2.2 million individuals are classified as American Indians/Alaska Natives of federally recognized tribes. Thus, these 2.2 million are the ones deemed eligible to either receive care from the I.H.S, or to engage in tribal-led healthcare systems.²³⁴ This system was designed to protect the legitimacy of being native in the United States, yet it is fundamentally flawed and inherently limits tribal sovereignty.^{235,236} In the words of Sarah Sneed, EBCI Tribal Contracting Officer, "...The U.S. Supreme Court said that to be a federally recognized Indian is not a racial distinction, it is a political distinction".²³⁷ Federal recognition, although fascinating, is a topic that lies beyond the scope of this thesis and serves as a

²³² Kathleen Thiede Call et al., "Barriers to Care among American Indians in Public Health Care Programs," *Medical Care* 44, no. 6 (2006): 595–600.

²³³ Jeffrey E. Holm et al., "Assessing Health Status, Behavioral Risks, and Health Disparities in American Indians Living on the Northern Plains of the U.S.," *Public Health Reports (1974-)* 125, no. 1 (2010): 68–78.

²³⁴ National Congress of American Indians, "Demographics" accessed November 29, 2016, <http://www.ncai.org/about-tribes/demographics>.

²³⁵ Lorinda Riley, "WHEN A TRIBAL ENTITY BECOMES A NATION: THE ROLE OF POLITICS IN THE SHIFTING FEDERAL RECOGNITION REGULATIONS," *American Indian Law Review* 39, no. 2 (2014): 451–505.

²³⁶ Wilkins, "Breaking into the Intergovernmental Matrix."

²³⁷ Sneed, EBCI relationship with I.H.S. and tribal compacting.

platform for future research in how it impacts healthcare and health disparities. Despite these limitations, the increase in tribal representation within the I.H.S. as well as the shift to tribal healthcare autonomy are key measures that have both improved native health and successfully work towards reclaiming tribal sovereignty.

The fight for reclaiming tribal sovereignty has been a long one, and although there have been strides in this fight as illustrated throughout this thesis, the fight will continue until inherent sovereignty is regained in all aspects of native life. In the words of Wilma Mankiller, former chief of Cherokee Nation, Oklahoma,²³⁸

When visionaries like Richard Oaks, Oren Lyons and Tom Porter spoke of sovereignty, they always reminded us that our ancestors had fought very hard for us to remain together as distinct tribal groups, as Indian Nations. Protecting tribal sovereignty then became a sacred trust of each generation...We have given up way too much...from this day forward we must pledge not to allow any more of our rights to be eroded, we must not be moved a single inch, not a single inch.²³⁹

Reclaiming sovereignty through healthcare autonomy supports this fight in regaining complete sovereignty. Ultimately, it works to both enhance sovereignty and push back against the condescending nature of the federal trust responsibility, successfully demonstrating the power and resiliency of native tribes. The fight for this sacred trust therefore will continue until all avenues have been reclaimed.

²³⁸ Oklahoma Cherokee Nation are the descendants of the Trail of Tears survivors.

²³⁹ Mankiller, "Tribal Sovereignty Is a Sacred Trust."

Appendix

i. A Note on Terminology: Native American vs. American Indian vs. Native

In the past twenty years there has been debate regarding the proper terminology of indigenous populations in North America. This particular appendix aims to provide some context regarding this debate while simultaneously discuss the rationale for the use of ‘native’ or specific tribal names in this thesis.

When sifting through the hundreds of published government documents regarding the various native tribes across the country, these documents consistently use the label “American Indian/ Alaska Native”, AI/AN for short, when identifying native populations. Yet, when reading documents written by anthropologists or professors within the humanities, the term Native American is consistently used. Among historians it seems split; in some cases we see Native American and in others we see American Indian. Although the cultural debate of which term is better has been ongoing for some 40 years, it seems now that the majority of American Indians/Native Americans state that both are acceptable terms. However, designation by tribe would be the best form of classification.²⁴⁰ Despite this, in an article published by Indian Country News, where several prominent natives were interviewed on their opinions regarding which term should be used, the responses came back entirely split.²⁴¹ Yet, regardless of the split between American Indian and Native American designation, all of the interviewees mentioned they would first identify themselves by their tribe, then as a “native”, and then either American Indian or Native American. As Borgna mentions in his review of these

²⁴⁰ Borgna, Brunner, “American Indian versus Native American: A Once-Heated Issue Has Sorted Itself out,” 2009,

²⁴¹ Amanda Blackhorse, “Blackhorse: Do You Prefer ‘Native American’ or ‘American Indian’? 6 Prominent Voices Respond,” *Indian Country Today Media Network.com*, May 21, 2015,

terms, it seems that today many natives find both terms acceptable, however some will argue one is more politically correct.²⁴² Yet despite this, most will agree that designation by tribe or reference as native is most preferred.

Interestingly, some natives have taken a much stronger stance on the issue, stating that one is more pejorative than the other. For example, Russell Means, a Lakota activist and founder of the American Indian Movement, has been quoted on multiple occasions stating that he prefers the term Indian and that any term other than that is disgraceful to his former leaders and ancestors.²⁴³ Ultimately both of these terms, AI/AN and Native American, are problematic as they are used in an attempt to classify an incredibly diverse group of peoples into one all encompassing identity-term. This is problematic as these tribes are diverse in culture, language, heritage, and spirituality, and the continual grouping of all native peoples together as one can be disgraceful in-it of itself.

But where did this debate of which term is better originate? In order to answer this, it is first necessary to identify the origins of the two terms. The first use of Indian to describe native peoples began in the 1490s when Christopher Columbus mistakenly believed he had landed in the “West Indies” and thus referred to the indigenous populations of the Bahamas as “Indians”.²⁴⁴ This term then stuck throughout the period of initial colonization of the “New World”. Furthermore, with the official Declaration of Independence, and the formation of the United States, all legal federal documents

²⁴² Borgna, Brunner, “American Indian versus Native American: A Once-Heated Issue Has Sorted Itself out.”

²⁴³ Dennis Gaffney, “‘American Indian’ or ‘Native American’? | Follow the Stories | Antiques Roadshow | PBS,” *PBS.org*, April 24, 2006.

²⁴⁴ Borgna, Brunner, “American Indian versus Native American: A Once-Heated Issue Has Sorted Itself out.”

referring to native peoples used the term American Indian.²⁴⁵ Thus, historically, throughout legal documents, and within various public statements made by the government, as well as in various programs designed by the government, natives are referenced as American Indians/Alaska Natives.

Despite its widespread use in the government as well as the public, in the 1960s many people, both non-natives and natives alike, argued that the use of “Indian” was pejorative and culturally inaccurate. It was a term utilized by oppressors, and coined by Christopher Columbus. Furthermore, many argued that the term “Indian” harbored a romanticized image of natives that was often used in the media and was founded in cultural appropriation. Thus, these critics suggested that the term Native American was more politically correct and historically accurate as the word native implies being the original inhabitant of a place by birth.²⁴⁶ Yet this classification created its own group of critics as then most Americans today could argue that they are “native” to the United States. The debate of American Indian versus Native American continued for another 40 years, however now in more recent years it seems that use of the more “politically correct” term is not what is important. As mentioned earlier, most natives have stated that they wish to be identified primarily by their tribal affiliations, yet for all encompassing purposes either American Indian or Native American has been deemed acceptable. For the purposes of this paper, in all instances where I can, I will use specific tribal names, and when no tribal name is referenced, then native will be used. Yet, when outlining and assessing the history of healthcare programs initiated by the government for various

²⁴⁵ Ibid.

²⁴⁶ Gaffney, “‘American Indian’ or ‘Native American’? | Follow the Stories | Antiques Roadshow | PBS.”

federally recognized tribes, the term American Indian will occasionally be used when necessary to remain consistent with what is found in that realm of literature.

ii. Methodologies:

In order to successfully explore the relationship of healthcare autonomy and tribal sovereignty, I thought that a particular case study regarding a tribe engaged in the Public-Law 93-638 process, granted under the 1975 Indian Self-Determination and Education Assistance Act, ISDEA, could provide key insights on the impact of such autonomy. Today, there are over 300 hundred tribes with a 638-compact or 638-contract, and although a comprehensive review of these systems would provide the most telling evidence regarding the impact of healthcare autonomy in regaining sovereignty, such a large-scale project was not feasible in the given time frame to conduct this thesis. Despite this limitation, focusing on the history and path to healthcare autonomy regarding a specific tribe allowed for an in depth understanding of the impacts of health status and healthcare, and how these two properties impact tribal sovereignty. Thus, I chose to focus in on the Eastern Band of Cherokee Indians, EBCI, of Cherokee, North Carolina healthcare system.

In June of 2016 I had the opportunity to travel to Cherokee, NC to attend the 26th Annual Native Research Network Conference. This trip was funded by the Colby College Department's of Biology and History. While at the conference I had the opportunity to learn about the healthcare system recently designed and implemented by the EBCI tribe. This initial exposure sparked my interest to learn more about changing healthcare systems and their impacts on health disparities and health trends among native communities. This area of focus felt most appropriate for my thesis work and thus during

the course of my research regarding healthcare systems among natives I learned about the divide between Indian Health Service healthcare and tribal compacting/contracting healthcare services. This difference in healthcare control seemed to have impacts beyond just the realm of health status and trends. Yet, as it became evident due to the lack of quantitative data regarding specific tribal health trends, I realized that key-informant interviews would be the best possible way to learn more about the impact of PL 93-638. Thus, due to my previous exposure to the EBCI healthcare system, I decided to focus on this system for my case study.

Prior to contacting EBCI tribal members for interviews, Institutional Review Board approval was obtained through both Colby College's Institutional Review Board as well as the EBCI Medical Institutional Review Board. Due to the history of unethical medical research conducted with native communities, IRB approval from both institutions was secured in order to avoid such potential for unethical research.²⁴⁷ Furthermore, in-person interviews were chosen in order to establish the most positive environments and relationships to learn about this healthcare system. As discussed in chapter 4, the EBCI healthcare system consists of a governing health authority, the Cherokee Indian Hospital Authority, and the Public Health and Human Services Department. These two organizations work together to increase the health of the EBCI tribe, yet they are simultaneously governed and operated under separate structures of the tribe. Because of this two-tier system, I contacted members from both systems in order to conduct interviews.

²⁴⁷ Felicia Schanche Hodge, "No Meaningful Apology for American Indian Unethical Research Abuses," *Ethics & Behavior* 22, no. 6 (November 1, 2012): 431–44, doi:10.1080/10508422.2012.730788.

The travel, lodging, and food costs were all covered through the receipt of the Sandy Maisel Research Fellow Grant as sponsored by the Colby College Goldfarb Center for Civic Engagement and Public Affairs. During the second week of March, 2017, I flew down to Cherokee Nation, NC. During the week, I had the opportunity to travel around the Qualla Boundary and meet very many kind and welcoming tribal members.

Furthermore, Dr. Martha Salyers kindly took me to some of the health clinics on the boundary; she showed me the brand new Women, Infant, and Children's Clinic, the Tsali Care Center, the Unity Substance Abuse & Use Rehabilitation Center, and the Analenisgi Behavioral Health Center. Dr. Salyers also showed me the Cherokee language revitalization school and the new Cherokee public school (pre-K to 12th grade), built and designed by the tribal government. These visits greatly enhanced my understanding of the efficacy and role of the tribal government in preserving Cherokee culture and tradition.

For my key-informant interviews, various members from both the Cherokee Indian Hospital Authority governing board as well as the Department of Public Health and Human Services were contacted, via email, to set up interview times. Among those contacted and later interviewed were Sarah Sneed, JD, Tribal Contracting Officer of the Cherokee Indian Hospital, Carmaleta Monteith, Chair of the Cherokee Indian Hospital Authority governing board, Vickie Bradley, RN, MPH, Secretary of Public Health, Aneva Turtle Hagberg, Operations & Public Health Director, and Martha Salyers, MD, MPH, CEM, Accreditation Coordinator and Public Health Advisor. Additionally, Casey Cooper, RN, current CEO of the Cherokee Indian Hospital, was scheduled for an interview, yet unfortunately had to cancel last minute. Furthermore, due to the kindness of Dr. Salyers, Ms. Bradley and Ms. Hagberg, I had the opportunity to meet and chat,

informally, with various other individuals of the Department of Public Health and Human Services. These interactions were beneficial in the course of my fieldwork in Cherokee Nation, yet the specifics of these interactions have not been documented in this thesis.

All interviews were semi-structured interviews with a particular set of guiding questions that were previously approved by both Colby College's IRB as well as the EBCI Medical IRB.²⁴⁸ All interviewees were given these questions prior to my arrival in Cherokee and were informed of the purpose of these interviews, their potential use, and were allowed to opt from answering any questions. Additionally, all interviewees were able to end the interview at any time. Furthermore, interviews were recorded, upon informed consent, for transcribing and personal records. All interviewees willingly agreed to the use of their name and title in the publication of this thesis. Additionally, at each field site visit and interview I took detailed field notes for personal reference. My field notes were modeled after the detailed approaches from Harvey Bernard's, *Research Methods in Anthropology: Qualitative and Quantitative Approaches*.²⁴⁹

iii. Interview Guide

- 1) How long have you been working in the realm of healthcare?
 - a) Can you tell me about your current position at (insert healthcare program)?
- 2) How did your specific program evolve to the system it is today?
- 3) In 2000 the tribe decided to move away from Indian Health Service led healthcare, could you give me your take on this switch?

²⁴⁸ Harvey Russell Bernard, *Research Methods in Anthropology: Qualitative and Quantitative Approaches* (Rowman Altamira, 2011). This source was used thoroughly in the design and examination of the interviews.

²⁴⁹ Ibid.

- a) What was the immediate transition like for tribal members, for healthcare professionals?
- b) Was there any backlash or resistance in making this switch? If not, were there hesitations in making such a switch?
- 4) Was this program present during the times of I.H.S. involvement? If so, in what ways is it different today?
- 5) How did the removal of federal oversight in healthcare affect your specific program/area of work? How did it affect healthcare as a whole/ attitudes towards healthcare?
- 6) Generally speaking, in what ways does tribal involvement in the healthcare systems impact tribal member participation in healthcare programs?
- 7) Have you seen an increase in the use of these programs since the restructuring?
- 8) How does the casino play a role in the lives of tribal members? How does it impact healthcare programs?
- 9) What does tribal led healthcare mean for tribal sovereignty?

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