

“American Indian 101”: Understanding the history and contemporary experiences of Native people in a United States health policy context

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AUTHOR’S NOTE ON THIS BRIEF

As a two-spirit, Native person who is tribally affiliated with the Oneida Nation, I wanted to write a piece about American Indian / Alaska Native (AI/AN) people’s history and identity in the context of health policy in my role as SHADAC’s inaugural Health Equity Fellow. While completing my master’s degree in public health over the past two years, I observed little attention to Indigenous health and health care systems in my program’s curriculum, and Native people going often overlooked in terms of data collection. My work at SHADAC has focused on understanding and conceptualizing root causes of health inequities in the Medicaid program, which provided me an opportunity to have illuminating discussions with experts across the country on structural racism. From these conversations, I learned the importance of providing historical context, filling in the blanks of what both the general public and field of public health don’t understand, and uplifting moments when health and racial equity are centered successfully. Having personally faced many of the struggles highlighted in this brief – being 1/16th short in blood quantum of being a full member of my tribe, experiencing ‘lateral violence’ as a mixed Native person, and the exhausting process of navigating health care, this brief has been a passion project in illuminating the structural issues that AI/AN people face generally, including those of mixed Native people like myself.

NOTES ON LANGUAGE USED IN THIS BRIEF

There are many terms to identify AI/AN people and their communities.

American Indian / Alaska Native (AI/AN for short) is used throughout this piece for consistency with presented statistics and is the standardized racial/ethnic label imposed by the U.S. government. American Indian and Native American are both generally acceptable terms.

Native and **Indigenous** are both acceptable terms that are also more inclusive. These terms include those who identify as AI/AN, but are not enrolled in their affiliated tribe or a federally recognized tribe (for reasons discussed in Section 2 in this brief). This term is also used internationally to identify people whose ancestry is Indigenous to the lands they were born.

Note that these are **general guidelines** – and it is always best to ask Native people in your life, workplace, or research how they should be referred to.

ACKNOWLEDGEMENTS

Thank you to Dr. Katy Kozhimannil for providing invaluable contributions with a second set of Native health policy oriented eyes on this work. Additional thanks to Christina Worrall for asking important clarifying questions while developing the content of this piece, which refined this report into its concise format. Lastly, thank you to Elliot Walsh and Jessica Ngoboka for their efforts in polishing this piece to be easy to read with accessible visuals that strengthen this report further.

See the Appendix for this brief for miscellaneous notes.

This report has four sections that are organized and grounded in the indigenous ways of knowing – we outline the present, reflect upon the past, which then helps us chart the path for the future. With a focus on health care and insurance access among American Indian and Alaska Native people, this report has three aims: Section 1 provides the **present context** of American Indian / Alaska Native within the United States and the health care system by providing demographic data, a brief explanation on contemporary data collection issues, and breaks down the unique care delivery structure of the Indian Health Service. Section 2 of this brief provides an overview of specific early US history and AI/AN social policies and legal cases, where Section 3 contextualizes how this history constructed a unique identity for AI/AN people in comparison to other racial groups that impacts not only their access to care, but to their “dedicated” health services. Section 4 concludes with an overview of recent progress in AI/AN health and social policy, highlights potential future directions, and the limitations of focusing on access without consideration for issues of mistrust and utilization of care.

Jump to:

Section 1: Introduction to AI/AN Demographic Data and Health Outcomes

Section 2: The Federal Government and Early American Indian Policies

Section 3: Who Counts as AI/AN is (Federally) Complicated

Section 4: Recent Progress, the ACA, and the Future of Health for Native People

Appendix

References

SECTION 1: INTRODUCTION TO AI/AN DEMOGRAPHIC DATA AND HEALTH OUTCOMES

Overview of the American Indian and Alaska Native Population Today

American Indian and Alaska Native (AI/AN) is a racial/ethnic category that describes people with ancestry indigenous to North America prior to colonization in 1492. As of the 2020 U.S. Census, there were around 9.7 million Americans who identified as Native American alone, or Native American in combination with another race in total.¹ Despite AI/AN’s racialization, AI/AN is a political and kinship identity rather than a racial identity – and AI/AN people exist across many other racial categories.²

There are 574 federally recognized sovereign AI/AN nations, with 16 states having additional state recognized nations that are not recognized at the federal level, and other tribal nations that are not recognized by US government entities.^{3,4} Approximately 13% of AI/AN people live on reservation lands, and AI/AN people also have the least representation of any racial/ethnic groups in metropolitan areas with only 60% of the population living in urban settings.⁵ This highlights the diversity among Native people and the wide geographic differences between the Native population and other groups, with many people living in rural or smaller towns.

AI/AN Data Sovereignty

While the purpose of this section is to discuss the present context of AI/AN health, it is important to highlight significant issues with collecting, aggregating, and, especially, sharing data specific to AI/AN populations with tribal and Native health organizations. This problem with collecting comprehensive and statistically powerful data sets related to Native people is far from new, and many of these issues stem from the complex and historically violent relationship between the United States government and academia, and Native nations. For example, most of the statistics included in this very brief impose a deficit narrative on Native people as well as comparisons to White counterparts.⁶ Additionally, Western approaches to consolidating small sample sizes are inconsistent and often lead to misclassification of AI/AN people based on race, ethnicity, or nationality when linking datasets.⁷

At the same time, data collection is not a new concept to Native people, who collected and shared data with other Native nations prior to colonization. Data collection was grounded in values of reciprocity, meaningful relationships, responsibility to one another as people, and accountability.⁶ Re-implementing these practices into research today are a part of the movement toward **Indigenous data sovereignty**, which is defined as “the right of Indigenous Peoples and nations to govern data about their peoples, lands, and resources”⁸

These issues related to complete, accurate, and representative AI/AN data in Western research practices affect health policy development and public health efforts in Native communities, including barriers to accessing health care or obtaining insurance coverage.

AI/AN Health Outcomes

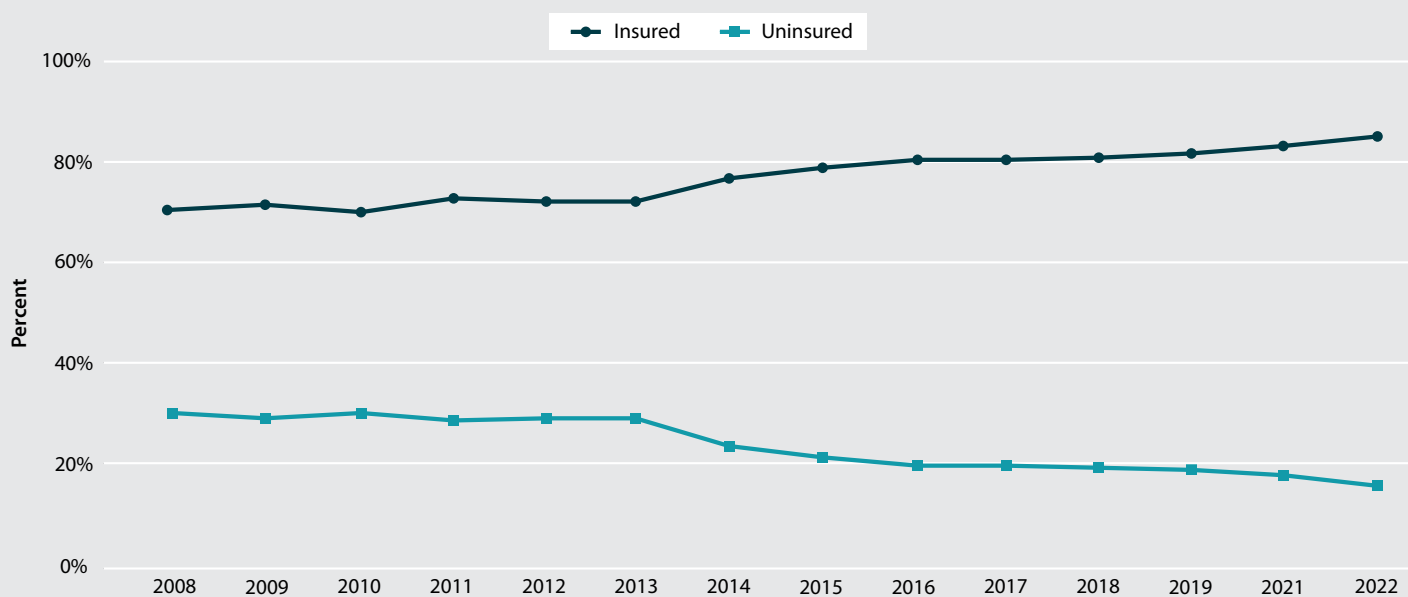
Despite issues with data collection, it is commonly understood in both the health policy and public health spheres that Native people experience some of the greatest health inequities compared to all other racial and ethnic groups in the United States, demonstrated by an overall life expectancy that is 12-13 years younger than White people in the U.S.⁹ The AI/AN population currently experiences the highest rate of premature deaths across all other racial/ethnic categories in the nation.¹⁰ Many of the leading causes of death among Native people (excluding COVID-19) are chronic diseases, including heart disease, cancer, and diabetes.⁴ Native people also experience high rates of unintentional injuries, obesity, substance use, severe mental health issues, and death by suicide among other health risks.⁶

AI/AN people suffered greatly from the COVID-19 pandemic with disproportionately more severe symptoms and more often fatal outcomes compared to other racial/ethnic groups. In fact, AI/AN racial identity was found to be the greatest risk factor for severe illness from COVID — The Center for Infectious Disease Research and Policy at the University of Minnesota found that 54% of AI/AN people became severely ill from COVID compared to around 36% of Hispanic and 31% of White patients, despite those groups having a greater prevalence of risk factors such as hyperthyroidism, hyperlipidemia, sleep apnea, history of smoking.¹¹

AI/AN Insurance Coverage

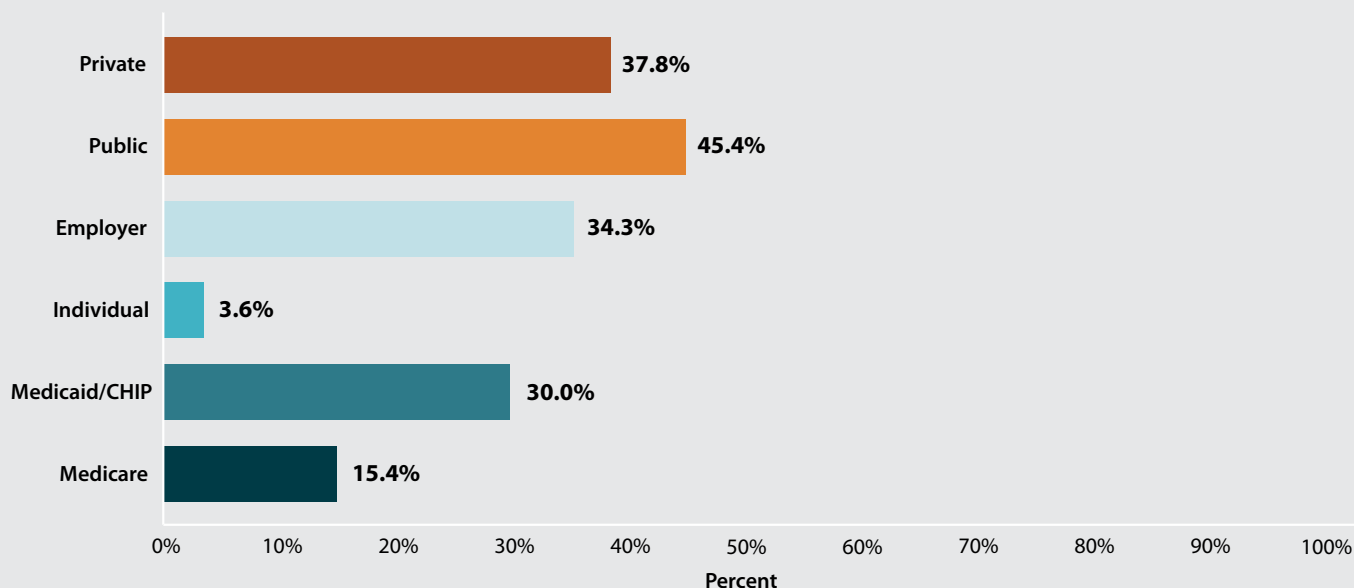
AI/AN insurance coverage has improved greatly over the past decade, with coverage increasing from 70.4% to 83.2% across the population from 2008 to the most recent data from 2022.¹² Important to note is that Native people are the only racial/ethnic group in the United States whose primary sources of insurance are public options, with 45.4% of the population having public insurance coverage through Medicaid/CHIP and Medicare combined versus 37.8% covered through private options.¹²

Figure 1: Breakdown of Insured vs. Uninsured among AI/AN, 2008-2022



Source: SHADAC analysis of the American Community Survey (ACS) Public Use Microdata Sample (PUMS) files, State Health Compare, SHADAC, University of Minnesota, statehealthcompare.shadac.org. Accessed 14 August 2024.

Figure 2: Breakdown of AI/AN Insurance Coverage Type, 2022



Source: SHADAC analysis of the American Community Survey (ACS) Public Use Microdata Sample (PUMS) files, State Health Compare, SHADAC, University of Minnesota, statehealthcompare.shadac.org. Accessed 14 August 2024.

Despite these recent improvements, the AI/AN population still has the highest uninsurance rate of all racial/ethnic groups in the United States, with 15.2% of AI/AN people being uninsured across all age groups.¹³ Being uninsured is a major risk factor for lacking access to care. However, even many insured AI/AN people face geographical, administrative, and cultural challenges that limit their ability to seek care beyond lack of coverage.⁹

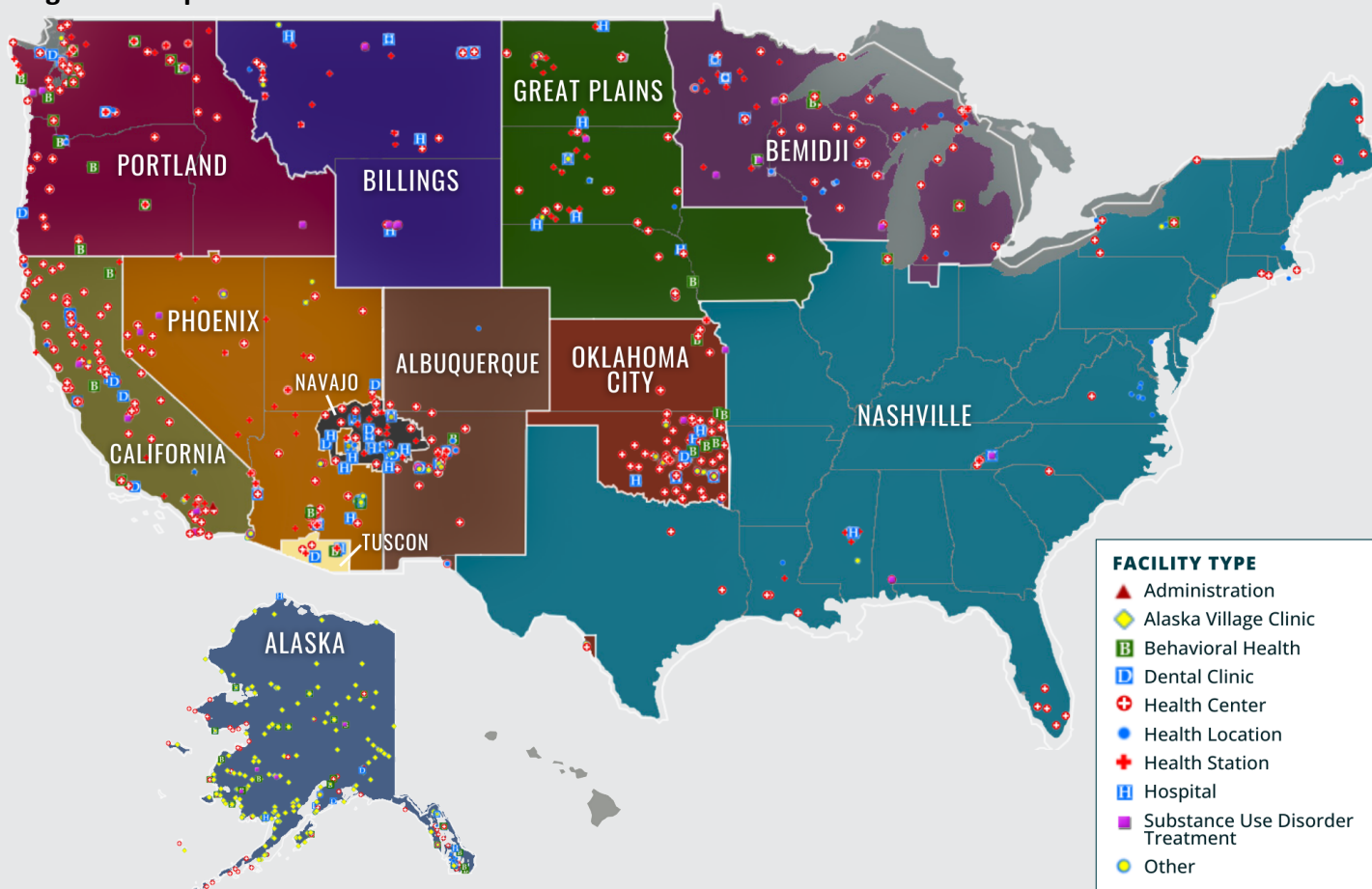
The Indian Health Service, Tribal Organizations, and Urban Indian Health Centers: The I/T/U Delivery System

The unique circumstances of AI/AN people, both in their history with the government and the vastly different conditions they live in across the country, has resulted in the formation of a dedicated health care delivery system for American Indian and Alaska Native people.

There are three segments of AI/AN health care, which together are known as the I/T/U delivery system: I for the Indian Health Service, T for tribal programs, and U for urban Indian health centers.¹⁴ Due to these three types of health organizations, the I/T/U is an expansive, but fragmented, system due to these three types of health organizations.

The Indian Health Service (IHS, or I in the I/T/U system) is the dedicated health system for Native people in the United States and is currently housed in the U.S. Department of Health and Human Services. In 2024, the IHS directly oversees 27 hospitals, 59 health centers, 9 school health centers and 32 health stations across 12 “service areas” in the United States, with the majority of these service areas located in the western part of the country.^{14,15} IHS has a unique health care delivery structure that provides care to around 2.8 million people in the U.S. every year.¹⁶ This is only around 30% of the people who identify as AI/AN.

Figure 3: Map of IHS Service Areas and Facilities



Source: Indian Health Service, U.S. Census Bureau

The **tribal health organizations** (T in the I/T/U system) were expanded after The Indian Self-Determination and Education Assistance Act passed in 1975, which directly provided Native tribes with *over half of the IHS budget* to facilitate their own health care systems through their respective tribal organizations.¹⁷ These independent health care programs include 18 hospitals, 284 health centers, 8 school health centers, and 79 health stations, which includes 163 Alaska Native village clinics, and 12 regional youth substance abuse treatment centers.¹⁷

Lastly, IHS provides direct funding for the **urban Indian health centers** (U in the I/T/U system) located in 34 different areas.¹⁷ The I/T/U system, while fragmented, attempts to accommodate for the wide range of life circumstances and lived environments that Native people experience across the country. While important to attempt to serve the large variety of people and situations in the AI/AN community, the fragmentation of the I/T/U model may contribute to the difficulties in navigating the AI/AN health care system in addition to other general systemic health care issues.

Along with issues caused by the fragmented I/T/U system, IHS struggles with being chronically underfunded and understaffed, resulting in a lower quality of care compared to other health care systems in the United States – this lack of sufficient funding may also contribute to the greater mortality rates of Native people and the widest disparities from other racial and ethnic groups in the country.^{13,18}

IHS states that their mission is “to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level”.¹⁹ But this is clearly not being achieved through the I/T/U system when Native people are continually underserved and experience such wide health disparities. Ultimately, the United States has a **legal obligation** (also known as the federal trust obligation) established by treaty agreements with tribes to care for Native populations and reified in the Affordable Care Act – that obligation is clearly not being met under current conditions. Unfortunately, this injustice has been ongoing long before IHS was even established, beginning early on in the country’s history.

SECTION 2: THE FEDERAL GOVERNMENT AND EARLY AMERICAN INDIAN POLICIES

In order to understand the current health policy context and status of Native people, it is important to describe the historical processes and decisions that shaped access to and quality of health care for AI/AN people. Prior to Indian Health Services, which was not established in its modern form until 1955 through the Transfer Act, the early relationship between the U.S. and Native nations ‘sets the scene’ for how AI/AN people are handled by the government and American society today.²⁰ This relationship was established around 1784 through multiple treaty agreements with tribes, in which the United States agreed to respect and care for Native peoples in exchange for sharing their lands with the new country.¹³ These treaties were closely followed by the drafting of the U.S. Constitution in 1787.

Constitutional Basis for Sovereignty and AI/AN Treaty Rights

Two clauses in the Constitution are important for AI/AN policymaking today: the Supremacy Clause, and the Commerce Clause. These clauses established Native people, and the treaties made with them, as **federal concerns**. Let’s look at how each of these clauses more closely to understand how each can and has impacted AI/AN health policy.

The Supremacy Clause **included treaties** alongside the Constitution and federal statutes as “the supreme law of the land” – essentially making treaties made with Native people as powerful as the Constitution.²¹ Despite this, many federal and state treaties with Native nations have not been held to the same level of authority.

AI/AN Rights Clarified in Court Cases

The Commerce Clause in Article I, Section 8 empowers Congress to **regulate Indian trade**.^{16,21} Originally, this clause identified Native tribes as foreign entities that the United States would be trading goods with frequently – requiring federal regulation from Congress as “commerce”. This concept associated with the Commerce Clause is known as “plenary power”, where the federal government, or Congress in this case, is given the highest authority in the country over regulating commerce, both between states, and with Native tribes.²²

A pivotal court case in defining what commerce meant for AI/AN affairs was *Seminole Tribe of Florida v. Florida*, where the Supreme Court stated that the Commerce Clause’s purpose is to make “Indian relations the exclusive province of federal law”.²² The Court doubled down on this decision in *Cotton Petroleum Corp. v. New Mexico*, where they decided that “the central function of the Indian Commerce Clause is to provide Congress with plenary power to legislate in the **field of Indian affairs**”.²²

The two clauses and the court cases that further refined the Commerce Clause’s interpretation are highly relevant to AI/AN policymaking. Firstly, because they **limit states’ abilities in navigating their own relationships and agreements with Native tribes**, and secondly, they **empowered Congress to legislate AI/AN policy and internal tribal affairs beyond commerce** due to commerce being loosely interpreted in legal precedents. Essentially, major changes to Native health and social policy have to come from the federal level. This is much more difficult to achieve due to the more intensive legislative process, polarized politics, and difficulties with focused agenda setting in comparison to the states.

Implementation of Federal Trust Responsibilities

Originally, it was the Department of War who oversaw “American Indian matters” and was responsible for fulfilling treaty agreements. Assigning the Department of War to this responsibility remains an interesting, and likely purposeful, choice, signaling to both the government and to Native nations that they were considered a ‘foreign entity’, as that was generally the type of work the Department of War was responsible for. This remained true with the establishment of the Bureau of Indian Affairs (BIA) in 1824 as the first official federal agency dedicated to Native people, which was housed in the Department of War for over twenty years until it was moved to the Department of Interior in 1849.²⁰

Despite the Supremacy Clause that gave treaties equivalent status as “supreme law of the land” and the establishment of a dedicated federal agency, it was not until the passage of the Snyder Act that Native people became citizens of the United States.²⁰ The act also allocated consistent funding for Native health care – the first indication of Congress fulfilling treaty promises with Native tribes that were broken very early on in the country’s history.²⁰ While the Snyder Act was a step in the right direction, lack of health care funding was only one of many injustices dealt to Native people at the hands of the government.

SECTION 3: WHO COUNTS AS AI/AN IS (FEDERALLY) COMPLICATED

As noted earlier on in Section 1, according to the 2020 Census, over 9.7 million people identify as AI/AN alone or in combination with another race. ***So why does IHS serve only a small fraction of that number, with the majority of AI/AN identifying individuals not eligible for or not enrolled in services?*** This is because IHS primarily serves *enrolled members* of federally recognized nations.²³ Through a complicated application process, Native people need to meet what’s known as a ***blood quantum*** requirement to be considered American Indian in the eyes of tribal and federal governments.

This separates Native people into two different statuses: enrolled, and unenrolled Native people who may not be enrolled for various reasons: by choice, difficulty navigating the enrollment process, or due to the blood quantum requirements for their affiliated tribe or tribes.

The History of Blood Quantum

American Indian and Alaska Native people are the only racial group in the United States who are, in many cases, required to demonstrate a bloodline connection to their affiliated, federally recognized tribe as part of the enrollment process. This is how a Native person obtains a tribal ID card, which is seen today as a mark of Native ‘legitimacy’ – and being an official member of a tribe provides AI/AN people eligibility for federal trust services, such as IHS. Blood quantum requirements today are decided upon by the tribes themselves and not the federal government, but the history of how blood quantum policies came to be is very telling in their role in AI/AN identity and policy today.

The history of blood quantum dates back to the 1800s as a means of limiting American Indian rights and benefits in the eyes of the U.S. government. The most important legislation related to blood quantum is the Dawes Act. Passed by the Dawes Commission (established originally as the Commission to the Five Civilized Tribes) in 1887, this act was used to divide native lands of the Cherokee, Creek, Choctaw, Chickasaw and Seminole nations into smaller, individual “allotments” based on blood quantum.²¹

Following the act came the Dawes Rolls: the federal government’s ***official list of over 101,000 American Indian people who applied for and were approved for land allotments on native lands***. The passing of the Indian Reorganization Act in 1934 repurposed the Dawes Rolls for their current use, where individuals must prove their ancestry to someone on the Dawes Rolls, or the 1885-1940 Indian Census Rolls to be eligible for enrollment in a tribe.²¹ The act, while at face value offered agency to tribes in establishing their own written criteria for enrollment, obligated tribes to establish federally acceptable constitutions that included blood quantum policies in their enrollment criteria.²¹

Blood Quantum Policy and the Effects on Native People

The Native Governance Center, a Native-led non-profit focused on power building and sovereignty for Native nations, describes blood quantum as an inherently structurally racist policy. They define blood quantum as “a concept created by white settlers that refers to the amount of so-called ‘Indian blood’ that an individual possesses. Blood quantum appears as a fraction (i.e. ¼) and is ‘calculated’ based on an individual’s family tree. Rooted in eugenics, the concept lacks any scientific basis and is a stand-in device for lineage imposed by the U.S. federal government to disempower Indigenous people and separate them from their lands, resources, culture, identities, languages, and futures.”²⁴ The ultimate goal of the blood quantum policy was to phase out Native identity over time, which would relieve the U.S. government of their original treaty obligations.²⁵

Prior to colonization, Native nations did not decide membership this way – they instead used matrilineal or patrilineal descent (depending on the tribe), and even allowed outsiders and non-Natives to join if they established positive relationships with members and contributed to the community.²⁵ Once established, though, some Native people have come to view blood quantum requirements as a necessity to define who can become a citizen of sovereign Native nations.

But this idea is a common form of “lateral violence”, or internalized colonialism, among AI/AN people. Lateral violence can be defined as “infighting” within an oppressed group that stems from lasting effects of powerlessness and trauma, leading to further siloing within the group rather than gathering support to resist their oppressors.¹⁹ Think back to the distinct ‘statuses’ that have emerged as a result of blood quantum and IHS’ use of it: Native people become distinctly separated from one another in categories dictated by the federal government (enrolled, unenrolled), which leads to further siloing and gaps.

In Native communities, lateral violence often arises through accusations of someone being “not Indian enough”.²⁶ The current enrollment process is embedded in colonialism and a legitimized means of inciting lateral violence among Native people – these additional barriers were created to purposefully limit access to those who want to connect with their culture and indigenous heritage.²⁶

Proving AI/AN Identity and Connecting Access to Health Care

Proving one’s heritage through The Dawes Rolls may be **impossible** for some, as the list of approved applicants is both far from comprehensive of every Native person at the time, and approval was determined by white people who assumed blood quantum based on appearance and skin color regardless of evidence an applicant provided.²⁴ On top of these inconsistencies, a Dawes Rolls connection alone unfortunately may not prove that one’s blood quantum is “high enough” for someone to be enrolled. Many applications require a blood quantum of half native blood at the very least, if not half-blood of the specific nation to which one is applying.

This is becoming increasingly more problematic for Native families across the United States and Canada for a number of reasons.²⁷ One being that the process of acquiring birth certificates for one’s parents and especially of ancestors to make the full Dawes Rolls connection can be systemically difficult to navigate due to “snail mail” application processes and differentiating state policies on who is able to access birth certificates and records. Secondly, if an applicant does not have enough knowledge of their ancestors or even their parents in cases of closed adoptions (a long standing issue from the boarding school era), acquiring this documentation is practically impossible. Even if one manages to successfully navigate the system and acquire the necessary documentation, this process can take several months.

The history and current policies related to blood quantum **are inherently connected to access to health care services through IHS** – in the past, blood quantum requirements were embedded into tribal enrollment processes by the federal government which shifted the siloing of Native identity onto tribes. At face value, it appears as if tribes are doing this of their own accord, but this was not the case originally.

When tribes today hold responsibility of deciding who is and who is not worthy of receiving federal trust benefits, distancing the federal government’s role in imposing these policies on tribes becomes much easier. Native people who are not enrolled are cut off from utilizing services like IHS, and becoming enrolled is an arduous, time consuming barrier to overcome.

With every generation, the enrollment process becomes more and more difficult. More children of both mixed race and mixed tribal heritage are not qualifying for tribal citizenship, and many Native nations are facing dwindling populations due to children not meeting blood quantum requirements for enrollment.^{25,27} The long-term desired effect of colonization policies in eradicating indigenous people and culture are happening in real time.

SECTION 4: RECENT PROGRESS, THE ACA, AND THE FUTURE OF HEALTH FOR NATIVE PEOPLE

Looking back helps chart the path forward. With the integration of blood quantum into the enrollment process for tribes and ongoing conversations about the effects of its continued use, significant progress in decolonizing AI/AN identity has been difficult to achieve. While some tribes, such as the Minnesota Chippewa Tribe, have voted to remove blood quantum requirements from their enrollment process in recent years, lineal descendency is still a common requirement.²⁸ While decolonization of Native identity is a deeply rooted issue, there has been some progress in addressing health inequities for AI/AN people in recent years. These efforts have focused on major barriers in seeking access to care, such as lack of affordable health insurance coverage options and the continual underfunding of IHS.

AI/AN and the Affordable Care Act

The passage of the Affordable Care Act (ACA) in 2010 was a major step in alleviating some of the core issues with IHS’s limited funding. Benefits of the ACA, such as expanding Medicaid eligibility criteria for low-income adults with incomes up to 138% of the federal poverty level, was important in alleviating the health insurance coverage gap across racial/ethnic minorities, including Native people.¹⁶ Even for those who did not qualify for Medicaid, the reduced cost sharing and premiums for ACA marketplace insurance plans for 139% up to 400% of the federal poverty level are major improvements.²⁹ These expansions reduced the insurance coverage gap in expanded states for AI/AN across all age groups by 2015, and even increased coverage for Native people **regardless of their tribal enrollment status or eligibility to receive services from IHS**.¹⁶

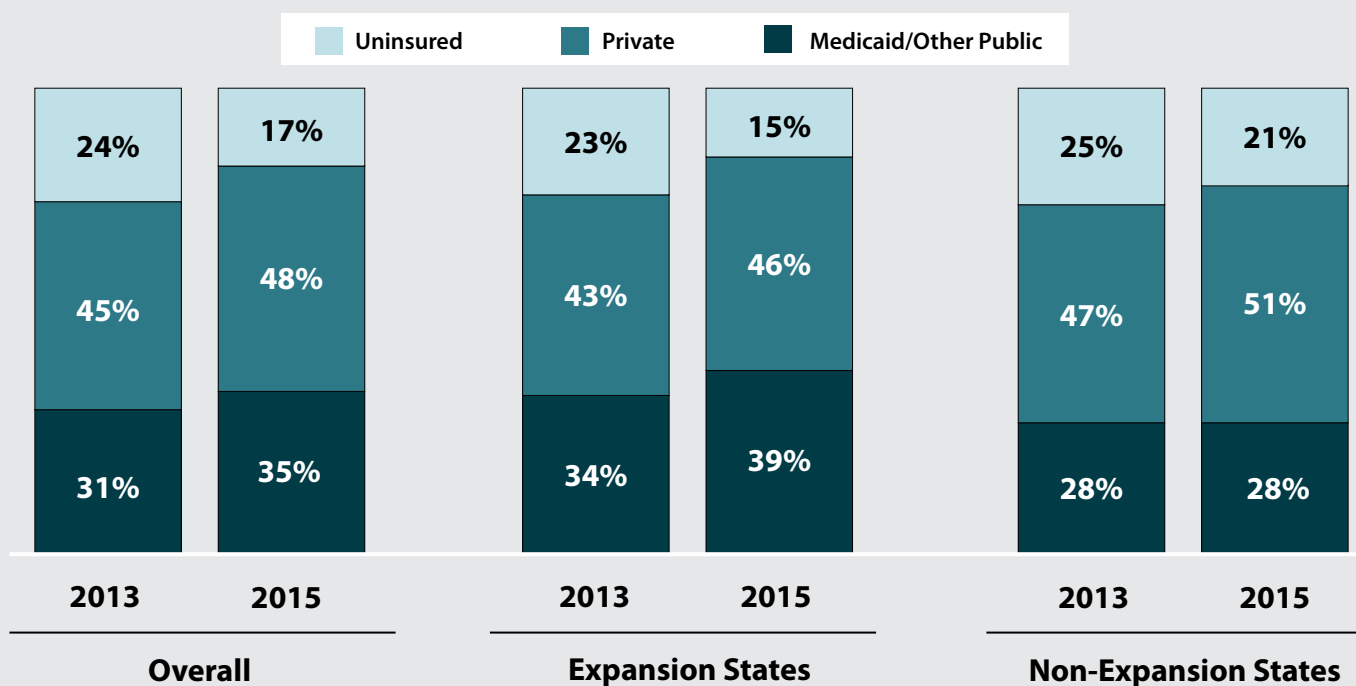
The Indian Health Care Improvement Act

The ACA also revitalized one of the most meaningful pieces of legislation for Native health care in the country’s history. Originally passed in 1976 as a revision to the Social Security Act, the Indian Health Care Improvement Act (IHCIA) allowed both directly funded IHS facilities and tribes facilitating their own health systems through IHS to bill Medicare and Medicaid for services.³⁰ President Barack Obama signed the IHCIA into law permanently as a part of the ACA, as the funding for the original IHCIA expired in 2000 – as a part of the ACA, the act no longer has a definitive expiration date.¹⁶

After a decade-long delay in reauthorizing the IHCIA, the act was improved upon greatly for its inclusion in the ACA and addressed issues with health care access and insurance coverage for AI/AN people. These improvements included providing stronger authority to the IHS director, and implemented long-term care, hospice, and assisted living as applicable services for Medicaid coverage. The IHCIA also modernized the reimbursement process for both Medicaid and Medicare for IHS health centers, establishing agreements with the Department of Veterans Affairs to share clinics to increase access to care, and integrated means for tribes and tribal organizations to provide employer-sponsored insurance through the Federal Employee Health Benefits (FEHB) program.²⁹ These are only a few of core benefits of the IHCIA relevant to AI/AN health care access and insurance coverage, where other components of the act focused on integrating Native values and practices of wellness and medicine into the IHS system.¹⁶

Since the reauthorization of the IHCIA as a part of the ACA, insurance coverage for Native people rose in states that expanded early. In 2013, Medicaid covered 34% of AI/AN adults in expanded states, which rose to 39% in 2015 – compared to no change in Medicaid coverage in non-expanded states.³¹ The coverage increase also had a positive impact on IHS funded and tribal run health care facilities – with more of their patients having insurance coverage to bring in more revenue, the health centers were able to expand their capacity to provide services.¹⁵

Figure 4: Health Insurance Coverage for Nonelderly AI/AN by Medicaid Expansion Status, 2013-2015



Notes: Includes nonelderly individuals age 0-64. Includes AI/AN alone and in combination with another race and those of Hispanic origin. Other public includes the Children’s Health Insurance Program, Medicare, and other public coverage.

Source: Kaiser Family Foundation analysis of the 2013 and 2015 American Community Survey (ACS), 1-Year Estimates.

The main caveat to these improvements is that all of these IHCIA benefits are only extended to states that choose to expand their Medicaid programs. These *currently optional* social safety nets created by the ACA are not as impactful to Native people in states that have not expanded Medicaid for their residents. That being said, deciding to not expand Medicaid disproportionately harms Native people among other groups, demonstrated by the positive impacts of expansion discussed in this brief.

Recent Progress in Sharing Data with AI/AN

While there were many improvements that came with the IHClA, there are many issues left unaddressed related to AI/AN health policy, especially related to the sharing of data with tribes. The IHClA bestowed “tribal epidemiology centers”, which are regional centers that serve multiple states and are independent of tribes themselves, with public health authority.³² This power should provide these centers with access to important protected health data, but there were no established processes for centers to request data which impeded the work of the centers across multiple disease outbreaks.³² Since these issues have been raised in 2022, new procedures and documentation have been developed in early 2024 through the U.S. Government Accountability Office – but these procedures were specific to tribal epidemiology centers, and not inclusive of tribes themselves.^{32,33}

Access and Coverage Issues Are Only Two Pieces of the AI/AN Health Inequity Puzzle

There are unfortunately limitations in what this report can highlight. The present context, historical background, and modern progress presented throughout this report mainly focus on **unique difficulties in accessing care and insurance coverage opportunities** for Native people, regardless of enrollment status. It is important to remember that coverage only alleviates one barrier in navigating the U.S. health care system: cost burden. While cost is a major deterrent to accessing care, having insurance does not necessarily mean that a person will remain able to access care or continue to utilize health care in the future. Access and utilization concerns among AI/AN people are entangled in similar, but separate pieces of history that understandably fuel mistrust in the U.S. government, health care systems, and research alike.

To better understand the specific barriers for AI/AN across the health care system, health policy researchers will need to engage directly with Native researchers, advocates and community members in candid conversations about their research and data collection values.⁹ Data should be shared not only with tribal epidemiology centers, but also with tribes themselves – and this requires establishing clear processes at the federal level so that states, tribal health organizations, and data centers can all work together in providing public health workers with the health data they need to serve AI/AN people properly.

APPENDIX NOTES

1. It is important to emphasize that **Native tribes are their own sovereign nations, separate from the United States**. While Native people are citizens of the U.S., Sections 1 and 2 of this brief discuss how Native people **were not** citizens of the U.S. from the beginning and are still fighting colonization efforts today.
2. While the majority of statistics included in this piece include Alaska Natives, the author focused on broader issues for AI/AN people, especially on the 48 mainland United States. Alaska Natives experience similar, but different issues specific to their culture, geographic location, as well as Alaska’s history with the United States. The social policy burdens discussed in this brief may include burdens that also impact Alaska Natives, but does not go in depth on their specific history and consequential systemic burdens.

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