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INDIGENOUS CHWS AND PUBLIC HEALTH WORKING TOGETHER TO IMPROVE EQUITABLE DATA COLLECTION & REPRESENTATION IN SOUTH CAROLINA

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Failure to document Indigenous People is “paper genocide”, and failing to publish existing Indigenous health data is akin to pseudo-erasing an entire population. “Invisible No More” is a national Indigenous movement in many areas. Pine Hill Indian Tribe, through its nonprofit business aims, has developed training opportunities and pathways to launch Indigenous Public Health awareness, bridge gaps, and created a culturally significant Indigenous Community Health Worker model to meet the unique needs of the Indigenous and non-Indigenous people. Our goal, specifically in rural Indian communities, is to meet health needs and bring to light Indigenous health data.

Importance and Background on Data Collection

Indigenous People have continued to participate in American politics for the purpose of building and rebuilding Indigenous communities. However, quoting Philippe Kruchten, “If it is not written down, it does not exist.” The same holds true for the existence of Tribes, tribal communities, and the Indigenous Population as a whole. Indigenous data proves the existence of the Indigenous population and proving our existence is essential to rebuilding our communities.

**"Our ancestors fought for our freedom, and it is our duty to
continue their struggle." — Dennis Banks**

The Indigenous population is tentatively settled on reservations held by the United States in trust. However, history has shown, what the United States grants, the United States can take back. Currently, it is not land but identity that is being taken. The United States is currently an active participant of “rescinded” recognition. This was historically called “termination” of federal recognition. It means those once recognized as part of the tribal community found themselves immediately and irrevocably designated to the status of an “urban Indian.” This moniker is an outright denial of their birthright and blood and leaves the Indigenous person psychologically without a home.

Due to inequity on reservations, “reservation Indians” from tribal lands moved for better economic stability, education, employment and several other mainstream social incentives. “Urban Indians,” who are tribal people that do not live on “federally defined” tribal lands but in urban areas (rural and non-rural), are often an overlooked population. However, Pine Hill

asserts that regardless of political status, Indigenous Data proves an Indigenous Population exists. The Indigenous are a protected Population based on Sovereignty Rights, Treaty Rights and laws created by the United States.

It is critical to recognize and identify the health needs of Native Americans in the United States. On a national scale, it is widely known that Indigenous health data shows high rates in chronic disease, premature deaths, and suicide. However, South Carolina has historically failed to show, indeed (i.e., fiscally), their commitment to the “least of these.”

In June 1924, under the Indian Citizenship Act, Pine Hill Indian Tribe’s citizens born in the United States after 1924 became United States citizens. Over the next forty years, Native Americans would eventually be allowed to vote in federal elections.

“The civilization that is my heritage did not have orphanages, did not have old homes, did not have prisons, did not have judges and juries, did not have locks or keys.” — Russell Means

The Tribe follows the 1924 Self Determination Act, operating the Pine Hill Indian Community Development Initiative as an umbrella of several affiliate organizations. Pine Hill Health Network is one of these organizations. Pine Hill Health Network has historically provided services to multiple tribal entities and communities and the “SC entity” unaffiliated Indigenous population in South Carolina. The PHHN staff includes an experienced team of CHWs providing case management, health services, substance use prevention, mental health, and emergency services.

Chief Michelle Mitchum, the PHHN Executive Director and Johns Hopkins Awardee¹, recognized in the early 2000’s that there was a lack of Indigenous data, and this gap was a barrier to policy change, and consequently socioeconomic and health outcomes.

“My people are destroyed through a lack of knowledge.” — Hosea 4:6

For a while, Indigenous prison inmate data was the only Indigenous data maintained and published in South Carolina. Then, when comparing the small number of self-identified “Indians” in the voter registration to the high number of Native American students, it was apparent that either each Native American adult had 15 or more children or there were not enough adults counted to justify the number of children.

Even more incredulous, these Native American students, despite self-identifying as Native American in the SC school system, were not being acknowledged in state reports. Reporting racial identification is required by the No Child Left Behind Act. By law, when there are 40 children in the same grade, in the same school district, with the same racial identification, that qualifies as a ‘gradable group’. However, Indigenous data racial profiles submitted were not consistent with those identifying as Native American, indicating possible absorption of Native American identity into other racial profiles. As a result of being invisible to the

¹ Johns Hopkins University. “Indigenous Stories of Strength (video).” Available at <https://www.youtube.com/watch?v=2SVgd4g9Avc>.

government in the No Child Left Behind Act, no resources were developed in South Carolina to support Indigenous health or identify health gaps in the Indigenous Population. There is no doubt that this disacknowledgement has led to missed opportunities to support Indigenous youth.

And they said, 'Thou Shalt Not Kill,' and our young people have ten times the suicide rate of the rest of the nation." — Russell Means (1973)

It is the duty and responsibility of an Indian Tribe to represent the best interests of its citizens to protect life, property, and environmental threat by natural or man-made disasters. For Pine Hill Indian Tribe, this includes our original tribal land (Cofitachequi, later called the Wateree and Congaree Indians - Richland County, South Carolina), our current settlement in Pine Hill (western Orangeburg County, South Carolina), surrounding areas where our tribal citizens reside, and the people who live on that land. Therefore, to fill the gap and protect the health and interest of the Indigenous population, Pine Hill Health Network is committed to identifying and supporting the needs of the community.

Background on CHW/Tribal CHW Infrastructure in the State

Community Health Workers, as is understood in society today and utilized by Pine Hill, has existed within tribal systems for centuries. Through the tradition of caring for others, Tribal entities have survived genocide, plague, integration, and relocation. Trusted tribal community people are called "Chief", "Medicine Man", "Fire Talker", "Medicine Woman", "Healer", "Seer", "Mother", "Aunt", "Auntie", "Grandfather", "Uncle", and so many other names.

**"When you have a spiritual foundation, you look at poverty different then."
— Dennis Banks**

Pine Hill Indian Tribe meets the legal definition of an Indian Tribe as defined in 25 U.S.C. §1603 through its acknowledgement by Fort Jackson, controlled by the US Department of Defense. However, Pine Hill Indians have long memories, and we understand that our original tribal lands were taken by the United States and turned into an Army Reservation (Fort Jackson), we know that we are denied our Ancestors human remains, and we know we were forcefully removed and resettled in western Orangeburg County in what is now known as Pine Hill Indian Community.

This is in part because the Pine Hill Tribe, the First People of Fort Jackson, has never entertained filing a petition for "state recognition". In South Carolina, to obtain state recognition, a Tribe must relinquish tribal sovereignty, land, and tribal and/or treaty rights. Historical trauma is continuously felt to be knocking on our door, as other state systems subsequently do not recognize Pine Hill. For example, South Carolina researching archaeologists rarely include Pine Hill Indian Tribe in research studies, despite repeated offers to volunteer. Therefore, we continue to be denied existence, even in research for events

that took place hundreds of years ago.

In addition, the University of South Carolina (USC)-Lancaster Native American Studies Center, another state agency, currently holds Pine Hill historical artifacts and refuses to return them. USC-Lancaster, while proclaiming our Tribe is a “state recognized group” quietly removed our Tribal Seal flag from its halls.

South Carolina led Native Americans to the Commission for Minority Affairs (CMA) to become CMA’s “Native American Initiative” in the early 2000s, the agency wasted years alienating and abusing this population. Several requests were made in 2002-2003 to the Administration for Native Americans (ANA), a granting agency, to stop funding alleged “tribal entities” in South Carolina after over \$500,000 was granted to six South Carolina groups in 2002 (nearly \$240,000 to Orangeburg County groups²) to stop Indigenous appropriation and identity issues. This level of gratuity, with the best intentions desired, only oppressed Native Americans and no Indigenous data was collected under ANA grants. CMA legislation changed in 2003 to include creating a State Recognition process that has proven to be faulty. Alienation and abuse of Native Americans by the state agency led to an investigation in 2015 by the South Carolina Office of the Inspector General (IOG). The OIG report validated complaints of Native Americans about CMA and found many problems within the agency.³ The OIG report led to the South Carolina House Legislative Oversight Committee investigation launched in 2018 with considerable presence and testimony from Native Americans (e.g., Chief Michelle Mitchum, Pine Hill Indian Tribe, provided testimony⁴). After a 429-day investigation, the House Legislative Oversight Committee issued a letter dated July 17, 2018, conveying its historic “first” conclusion in the history of the State that the Committee found “no confidence” in the CMA agency to the Governor Henry McMaster.⁵

² U.S. Administration for Native Americans. “Grants Archive FY2002.” Available at: <https://www.acf.hhs.gov/ana/grant-funding/grants-archive-fy-2002>.

³ South Carolina Office of the Inspector General. “Performance Review of the Commission for Minority Affairs.” Available at: <https://www.scstatehouse.gov/CommitteeInfo/HouseLegislativeOversightCommittee/StateInspectorGeneralLettertoCommittee/Inspector%20General%20Letter%20to%20Committee%20and%20Review%20-%20Commission%20for%20Minority%20Affairs.pdf>.

⁴ South Carolina House Legislative Oversight Committee. Chief Mitchum Testimony available in Archive Video, October 16, 2017, at 1:50:09. Available at : <https://www.scstatehouse.gov/CommitteeInfo/HouseLegislativeOversightCommittee/AgencyPHPFiles/MinorityAffairs.php>

⁵ South Carolina House Legislative Oversight Committee. Letter to SC Governor, July 17, 2018. Available at : https://www.scstatehouse.gov/CommitteeInfo/HouseLegislativeOversightCommittee/AgencyWebpages/MinorityAffairs/Committee_Letter_to_Governor_re_CMA.pdf



Map 1: Native American Composition (Orangeburg County). A star identifies the Pine Hill Indian Community’s entire area boundaries in Orangeburg County. Pine Hill Indian Tribe resettled in western Orangeburg County, now known as Pine Hill Indian Community. This geographic area is a portion of the infamous “Corridor of Shame”⁶, illuminating social and community context and healthcare access and quality as those social determinants of health impact leading health indicators, priority chronic health conditions and negative health outcomes. The Native American communities map created by Commission for Minority Affairs (2019), above, identifies Native American communities in both eastern and western Orangeburg County.⁷

“Never underestimate the strength and resilience of a community.”
— Chief Wilma Mankiller

Improving Statewide Data Collection and Building a Relationship between Pine Hill and the South Carolina Department of Public Health

Due to the findings of the House Legislative Oversight Committee, CMA underwent construction and attempts to mend wounds between the agency and Native Americans “state recognized entities”. However, despite promises, CMA has collected minimal, if any, data from the Indigenous population in South Carolina and currently relies on the US Census Bureau website as a main source of “Indigenous data” in addition to sending data requests

⁶ Bowers, S. (April 2021) “South Carolina’s Corridor of Shame.” Available at: <https://storymaps.arcgis.com/stories/a57474f36c7144b3a42932a4e37abd6c>

⁷ Carter, C. (April 2019) “Spatial Dynamics of Socioeconomic Deprivation in Orangeburg County, South Carolina: A Geospatial Brief”. Published by South Carolina Commission for Minority Affairs. Available at: https://drive.google.com/file/d/1_g2iNPaDotwAhxiwNGITK-07bt1sTokF/view

to fellow state agencies where sufficient Indigenous data collection is not known to occur.

Pine Hill Indian Tribe, like many other Tribes, who pay taxes and vote, are denied state citizenship, and have long settled for “invisible citizenship”. Out of over 30 tribes, only the Catawba (since 1944) are considered citizens of South Carolina.⁸

In 2020, due to the COVID-19 pandemic and seeming refusal of South Carolina to provide “unrecognized” Indigenous communities with protective gear, Pine Hill Indian Tribe, through Pine Hill Health Network (PHHN) issued its Declaration of Tribal State of Emergency and Tribal Emergency Response and Recovery Plan. After the declaration, PHHN, an organization, as mentioned above, under the Pine Hill Indian Community Development Initiative (PHICDI), is the only community-based tribal organization operated by Community Health Workers, has been considered a leading voice in Indigenous health. Throughout the pandemic, PHHN was largely responsible for advocating and protecting tribal citizens and tribal communities statewide.

To further support tribal survival, PHHN submitted an emergency CDC-RFA-OT20-2004 Supporting Tribal Public Health Capacity in Coronavirus Preparedness and Response – 2020 grant. The grant was filed five (5) days after a fatal tornado in Pine Hill. This grant would have greatly aided protecting Native Americans lives and would have established the collection and analysis of Indigenous data during the recent pandemic. Immediately, the CDC refused the grant stating PHICDI was not a “federally recognized” tribe or tribal organization, even though PHICDI’s grant was selected to be awarded.⁹

PHICDI pursued the CDC based on the Plain English Act holding the agency accountable to the language of its grant instructions. Pine Hill Indian Tribe and PHICDI Board was in total disbelief that during a pandemic any agency in the United States would ignore Native Americans “unless” those individuals are or were affiliated somehow with federally recognized Tribes. The decision to seek the assistance of Senator Tim Scott lay entirely on the implication that a new pathway had surfaced to block services to Native Americans during the pandemic, denying equitable access to pandemic relief and forcing Native Americans to claim a different ethnic/racial identity. CDC allowed Pine Hill three (3) days to become the “bona fide agent” of a federally recognized Tribe. Pine Hill Indian Tribe reached out to Chief Bill Harris of the Catawba Indian Nation.¹⁰ Chief Harris spoke to the CDC and was given three (3) days to make Pine Hill Indian Tribe (or PHICDI) the bona fide agent for the Catawba Indian Nation. In the end, federal laws dictated that Pine Hill’s grant, grant funds and critical services would only benefit the “recognized” Catawba Indian Nation. Consequently, countless and undoubtedly unrecognized South Carolinian Native American lives were lost to COVID-19 because of a commitment to punish defiance towards tethered legitimacy.

⁸ South Carolina Code of Laws, Section 7-1-70. “Catawba Indians, otherwise qualified, are citizens. All Catawba Indians, otherwise qualified, are hereby declared to be citizens of the State of South Carolina and shall enjoy and have all the rights and privileges belonging to other citizens of the State.” Available at: <https://www.scstatehouse.gov/code/t07c001.php#:~:text=SECTION%207%2D1%2D70,other%20citizens%20of%20the%20State>. Information on the 30 tribes can be found at <https://www.sciway.net/hist/indians/geo.html>.

⁹ See Attachment 1

¹⁰ Catawba Indian Nation is the only federally recognized Tribe in South Carolina.

In addition to denial at the federal level, “unrecognized tribes” were denied at the state level. PHICDI applied for and was denied several small grants to purchase PPE to distribute. It was startling to see that there was a concentrated effort to force Native Americans, in a very vulnerable time, to submit or die. It became apparent that at the state level, the thought of legitimizing “unrecognized tribes” through providing face masks was a greater threat than spreading an unprecedented pandemic.

“COVID-19 brought a new Trail of Tears, and they forced the blood of my People lost to the pandemic on my hands.” — Chief Michelle Mitchum

Confronted with the reality that history was repeating itself, Chief Mitchum finally asked if COVID-19 had become a “political genocide” tool against Pine Hill Indian Tribe and all Native Americans. Once the words “political genocide” was spoken, funds were immediately made available to allow PHICDI to purchase PPE for Pine Hill Health Network to distribute in addition, food boxes were provided, funded by emergency COVID grants from Urban Indian Health Institute, NDN Collective and No Kid Hungry. However, data on SC Native Americans impacted by COVID-19 remained invisible and/or uncollected. Except for three to five sentences combined on an online infographic and a separate webpage, the impact of COVID-19 on SC Indigenous people is largely undocumented.

**“According to John Hopkins University, even before COVID-19, Native American Indians were more impacted by infectious disease than any other population in the U.S. ... The John Hopkins Center for American Indian Health has some good materials based on information from the CDC.”¹¹
–South Carolina Department of Public Health (formerly SC Department of Health and Environmental Control)**

Launch of the South Carolina Native American Health Board and Partnership with Public Health

Due to the historical absence of consistent, valuable data on SC Indigenous people, Chief Mitchum approached the Pine Hill Indian Tribe’s Council to create a South Carolina Native American Health Board under PHICDI through Pine Hill Health Network. The Tribal Council approved.

The South Carolina Native American Health Board (SCNAHB), developed in 2022 by Pine Hill Health Network, is a space for tribal leadership to build access to health data, discuss data development, and identify opportunities for policy changes relating to Indigenous health while utilizing and lifting voices of Indigenous Community Health Workers. Launched in June 2022, the SCNAHB has since held statewide virtual meetings and has grown to include representatives from South Carolina Department of Public Health (SCDPH, previously called the South Carolina Department of Health and Environmental Control), South Carolina

¹¹ South Carolina Department of Public Health. “Communities of Color and COVID-19.” Available at: <https://scdhec.gov/covid19/communities-color-covid-19>

Department of Mental Health and South Carolina Commission for Minority Affairs.

In 2023, SCDPH asked Pine Hill Health Network to review the *petit* cache of information collected for publication in the State Health Assessment. As Pine Hill Health Network (PHHN) had successfully collected data under grants awarded by Urban Indian Health Institute, NDN Collective, and other grantors, PHHN was able to share this data with SCDPH for possible inclusion in the State Health Assessment.

Following work on the State Health Assessment, Pine Hill Health Network invited SCDPH to join the SCNAHB. This is published in the State Health Assessment¹²:

“To address representation inequity exacerbated by the pandemic, in January 2023 DHEC appointed a representative to the SC Native American Health Board, which was established by Pine Hill Health Network through the Urban Indian Health Institute. This provides direct communication between DHEC and tribal communities on matters of public health and ensures that tribal communities have equitable access to public health data for informed decision-making about the health of their communities.”

- (State Health Assessment, pg. 91-92)

The SCNAHB is still in the beginning (forming) stages. Future goals (2024-2025) are to develop a strategic plan, objectives, workplan, and timeline to complete activities. In addition to state agencies, PNNH's SCNAHB has engaged SC state representatives, several local governments, and community organizations. All partners mentioned have expressed commitment to these goals. Pine Hill is hopeful that finally, after hundreds of years, the agencies in South Carolina will recognize the need to include Indigenous Public Health into the grand scheme of “...Improving quality of life for all South Carolinians.” If not, Pine Hill will keep fighting.

“We are not historical or invisible.” — Chief Michele Mitchum

¹² South Carolina Department of Public Health. “State Health Assessment.” Available at : <https://scdhec.gov/sites/default/files/media/document/SHA-Report-1.8.24.pdf>

Infographic 1: South Carolina Native Americans: Data Equity and Inclusion (2023)

South Carolina Native Americans: Data Equity and Inclusion
South Carolina Native American Health Board
Chief Michelle Mitchum, Pine Hill Indian Tribe, The First People of Fort Jackson
Pine Hill Indian Community Development Initiative, Pine Hill Health Network

TIMELINE

- 1790 South Carolina passed The Negro Act eliminating the Native American race entirely.
- 1844 South Carolina granted Catawba Indian Nation state citizenship.
- 2004 South Carolina passed the Recognition of Native American Tribes, Clans, and Special Interest Organizations in a process managed by South Carolina Commission for Minority Affairs.
- 2018 SC Law eliminated recognition for future Native American Groups through South Carolina Commission for Minority Affairs.

FLOATING 100 YEAR EXISTENCE

A SC State Recognized "Tribe" means "an assembly of Indian people comprising numerous families, clans, or generations together with their descendants, who have a common character, interest, and behavior denoting a separate ethnic and cultural heritage, and who have resided on a separate settlement, on a substantially continuous basis throughout the past 100 years."

There is no requirement to prove ethnic ancestry, and the 100 year start date is 100 years ago from today.

© Chief Michelle Mitchum, Pine Hill Indian Tribe

INTRODUCTION

South Carolina (SC) eliminated the Native American "race" and "ethnicity" in 1790 with "The Negro Act". In 2004, under the South Carolina Commission for Minority Affairs, SC revisited at the acknowledgement of the existence of Native American/Indian/Alaskan/Native and tribal entities in SC with passage of the "State Recognition of Indian Entities".¹⁻⁴ The law creates "state recognized" tribal entities on a floating "100 year" existence⁵⁻⁷ but confers no state citizenship to any SC born Native Americans (with exception of Catawba Indian Nation granted state citizenship by law in 1944) and fails to include any Native Americans outside of the alleged "state recognized" tribal entities.

STATE ALIENATION

How is a "tribal entity" "recognized" by a State but its "members" not be state citizens acknowledged as Native Americans who are actual SC taxpayers?

Why is the sovereignty of the historical entities that are not "state recognized" overlooked at a federal level?

What about Native Americans who move to SC? Are they still Native Americans?

Who is "Native American" in South Carolina?

FEDERAL ALIENATION

The federal level makes identification and inclusion even harder. Federally recognized Tribes largely ignore non-federally recognized Tribes and Native Americans unaffiliated with a tribal entity, whether legitimate or not. Because of these barriers, at least two definitive lists walk away. South Carolina and the Federal level. This is not unique to South Carolina. As a result, overall "Native American" data falls short at both the State and national levels in many areas.

HIDDEN FIGURES

South Carolina largely only documents "White", "Black" or "Other" in healthcare identifiers. Racial identification is usually by observation rather than self-identification. Historically, and legally, Native American data has not been collected or otherwise so low in number that the data is combined with another race. Usually on state records, Native Americans MUST identify as "Other".

"If you eliminate us in the data, we no longer exist"
Abigail Echo-Hawk,
Pawnee Nation of Oklahoma Citizen
Director, Urban Indian Health Institute

DATA EQUITY/INCLUSION FAILURE

Table 1. Excerpt from "Report Card on the Centers for Disease Control and Prevention (CDC) and their COVID-19 surveillance Data for American Indian/Alaska Natives, United States, January 2020-January 2022" (Source: Urban Indian Health Institute)⁸

State	State-Reported COVID-19 Information	AI/AN Population Included on State Dashboard? (on Dashboard)	Overall Grade
South Carolina	56,571	No	F (D)

DECOLONIZING DATA MOVEMENT

Since the 2019 pandemic, Pine Hill Health Network (PHHN)⁹ has advocated for South Carolina to establish health data and systematic healthcare data collection protocol changes to create Native American health data. South Carolina COVID-19 data failed to report Native American data, leaving tribal leadership blind in protecting their own People.

Funded by Urban Indian Health Institute, PHHN launched the SC Native American Health Board (SCNAHB) in June 2022 to continue this advocacy for policy change. "We didn't know there were Native Americans here" leads conversations into educating health providers of our existence. PHHN and the SCNAHB has engaged healthcare agencies to re-address their "cultural competence" and "cultural humility" towards the Native American presence in SC, allow self-identification at intake, and become aware that our health history information is vital to making informed medical diagnoses and treatment plans.

DECOLONIZED DATA

Table 2. Source: Pine Hill Health Network

Pine Hill Health Network Program	Native Americans Served in South Carolina in 2022
Total Native Americans Served	32,567

CONCLUSIONS

It is known that national health data is available for Native Americans, but national data largely excludes South Carolina. Thus...

- How is the "Tribal Health Data" conversation inclusive and equitable to SC Native Americans?
- Where does SC fit in the national discussion?
- Where is our voice in this national discussion?
- What is the defined population for "Tribal Health Data"?
- Should the definition of the defined population for "Tribal Health Data" change?

REFERENCES

1. S.C. Code § 5-1-15-40A(2)(B)
2. S.C. Code § 5-1-15-40
3. The "100 year" requirement from, e.g., 100 years ago from today. As time progresses, the first year of the 100 year progresses.
4. Pine Hill Health Network is a sub-organization of Pine Hill Indian Community Development Initiative, a "state recognized" tribal nonprofit organization of Pine Hill Indian Tribe, the First People of Fort Jackson.
5. Vukob M. Aray, Abigail Echo-Hawk, Susan B. Cochran, and Ronald J. Sims. 2022. Data Equity in American Indian/Alaska Native Populations: Respecting Sovereign Nations' Right to Meaningful and Stable COVID-19 Data. American Journal of Public Health 112(11), 1612-1616. <https://doi.org/10.2195/ajph.2022.301045>

* Poster presentation at a National Indian Health Board conference in August 2023.¹³

¹³ National Indian Health Board. "South Carolina Native Americans: Data Equity and Inclusion." Produced by the Pine Hill Indian Tribe, The First People of Fort Jackson. Available at: https://www.nihb.org/health-equity/resources/Mitchum_SouthCarolinaNativeAmericansDataEquityandInclusion.pdf