

Making Amends: Recommended Strategies and Actions to Improve the Health and Safety of American Indian and Alaska Native Mothers and Infants

Preface:

Words and Language Matter

Around the world, various terms are used in speaking about the original inhabitants of places before colonization and conquest: Aboriginal, Indigenous, First People, First Nations, Native, and Autochthonous, among others. And within broad categorizations used to describe specific populations are a diversity of smaller non-homogeneous groups, with unique names that highlight their distinct cultures and traditions. Preferred terms vary by country and sometimes within countries, limiting consensus about which terms are most appropriate, accurate, or acceptable.

Language is important. Words used to represent and describe groups of people can show respect or disparage the populations and communities to which they refer. Selected terms can support or malign the world view, history, culture, activities, and practices of these groups. Population descriptive words play a major role in whether a group of people gains a sense of belonging to or being alienated from the broader society in which it exists and functions. This sense of belonging or alienation has significant health implications. Words matter.

"I share with you some terminology concerns ... from the Tribal perspective. I've heard talk about serving indigenous populations, but there is a correction that the Tribes would like to see, and that is the American Indian and Alaskan Native term. Those are legal terms. They portend a legal status of our people in the United States. These are the correct terms to use when discussing federal policy as it pertains to the sovereign nations and their citizens. This is found in the United States Constitution and because of treaties and our special relationship, again codified in law Supreme Court cases and the constitution, the United States government has a special trust and treaty obligation to the Tribes it attaches to the 574 federally-recognized Tribal nations. Yes, we are indigenous to these lands, but when working on policy and discussing American Indian/Alaskan Native in any kind of a policy-making environment, those are the correct terms to use, because they are the legal terms of art and expressions of our people, and they respect our political status that our people have in this country."

Stacy Bohlen (Sault Ste. Marie Chippewa Tribe)
CEO, National Indian Health Board

After broad consultation with members of populations who are the focus of these recommendations, and with due respect for the diversity of preferences and opinions, when discussing people, programs and policies, the Advisory Committee on Infant and Maternal Mortality (ACIMM) will use the term 'American Indian and Alaska Native' (AI/AN) in our report ***Making Amends: Recommended Strategies and Actions to Improve the Health and Safety of AI/AN Mothers and Infants***. We do so with utmost respect and honor.

ACIMM also appreciates that language used to recognize and describe gender identity is in transition and that no clear consensus has been reached on gender-inclusive and non-binary terminology. ACIMM acknowledges that transgender and gender non-binary individuals also birth and support infants. For this report ACIMM will use terminology consistent with the language in our Charter, which states that ACIMM “*advises the Secretary of the Department of Health and Human Services (HHS) on department activities, partnerships, policies, and programs directed at reducing infant mortality, maternal mortality and severe maternal morbidity, and improving the health status of infants and women before, during, and after pregnancy.*”¹

¹ United States Department of Health and Human Services. (2021). Health Services and Resource Administration. *Charter: Advisory Committee on Infant and Maternal Mortality (Formerly Advisory Committee on Infant Mortality)*. <https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/infant-mortality/2021-2023-charter.pdf>

Executive Summary

“Making Amends: Recommended Strategies to Improve the Health and Safety of American Indians and Alaska Native Mothers and Infants” marks the first time that the Secretary of Health and Human Services Advisory Committee on Infant and Maternal Mortality (ACIMM) has made safeguarding and promoting the health and well-being of American Indian and Alaska Native (AI/AN) women, infants, and families a priority. This report offers a strategic set of recommended actions that could be among the many steps the Federal government must take, both to reconcile past actions and step up to the obligations to American Indians and Alaska Natives that it has abrogated since the founding of our nation.

This report offers a compelling analysis of the historic issues and current conditions facing American Indian and Alaska Native women and infants in the United States, through the lens of persistently poor birth outcomes for AI/AN mothers and babies. It highlights a toxic legacy of genocide and trauma and acknowledges centuries of detrimental policies and programs that have disadvantaged and destroyed AI/AN populations. It recognizes that the adversities AI/AN mothers and infants face are of such magnitude and complexity that no single report or committee can comprehensively or adequately do them justice.

In developing this report, the ACIMM spent 24 months reviewing the literature on AI/AN birth outcomes and the impact of genocide and historical trauma, and social, economic, political, and environmental factors on the health status of AI/AN populations. At five separate meetings, ACIMM members heard testimony from representatives of federal, state, local, and Tribal agencies, non-governmental organization, and academic institutions who are working on AI/AN maternal and child health issues. The work culminated in an ACIMM meeting on the Tribal land of the Shakopee Mdewakanton Sioux Community (SMSC) in Minnesota in September 2022.

The meeting at the Shakopee Mdewakanton Sioux Community was unprecedented in that it was the first ACIMM meeting ever held outside of Rockville, MD and the first held, by invitation, on Tribal land. ACIMM meeting participants (on site and live streamed) heard the firsthand stories and experiences of Tribal leaders, elders, and members, along with organizations serving urban and Tribal AI/AN individuals from across the country. Some of that powerful testimony is included in Appendix B of this report, which ACIMM encourages readers to review, to better appreciate the magnitude, severity, and persistence of the problems facing AI/AN mothers and infants in our country.

ACIMM focused its work on the birth outcomes of AI/AN mothers and infants because AI/AN populations are often overlooked in programmatic and policy discussions and investments even though their birth outcomes are among the worst in the country. Reasons for this oversight are numerous, including: small population size, dispersed populations, lack of representation in decision-making spaces, and Tribes being non-state entities. The ACIMM believes that this oversight and related excuses can no longer be tolerated. The plight of AI/AN mothers and infants in the United States is a human rights issue that must be urgently addressed.

Report submitted by ACIMM, December 2022, to Health and Human Services Secretary Xavier Becerra

Based on the findings of previous reports on the health of AI/AN people, populations, and communities, ACIMM's analysis of maternal health and birth outcome-related data, presentations by representatives of federal health programs, and the testimony and input of over 88 individuals with relevant lived and professional experience, ACIMM framed its recommended strategies and actions around four premises:

1. The health of AI/AN women, parents, and infants has never been a priority for our country, which has led to living conditions and a healthcare system that are not supportive of optimal health and good birth outcomes in these populations.
2. Like every other population group, a healthy social and physical environment and access to high-quality care are essential to good birth outcomes. However, social, economic, geographic, and environmental conditions, along with certain policy and political choices have negatively affected the living conditions of AI/AN populations and inhibited them from accessing essential high-quality healthcare.
3. Because of racism and the devaluing of AI/AN women, some issues disproportionately affect this population, which negatively impact maternal and infant health outcomes and mortality. Prominent among these are incarceration, Missing and Murdered Indigenous Women and Girls, substance use, mental health concerns, and violence.
4. AI/AN people have inherently protective practices embedded in their culture that contribute to their ongoing resilience.

These premises are reflected in ACIMM's three recommended areas for strategic action. Cross-cutting is the acknowledgment of Tribal sovereignty, the value and benefits of Indigenous knowledge and birthing and childcare practices, and the need to improve the collection and analysis of data related to the factors influencing AI/AN birth outcomes. Cultural strength and resilience, collective and intergenerational,^{2 3} are inherent in each area:

- I. MAKE THE HEALTH AND SAFETY OF AI/AN MOTHERS AND INFANTS A PRIORITY FOR ACTION.
- II. IMPROVE THE LIVING CONDITIONS OF AI/AN MOTHERS AND INFANTS AND ASSURE UNIVERSAL ACCESS TO HIGH QUALITY HEALTHCARE
- III. ADDRESS URGENT AND IMMEDIATE CHALLENGES THAT DISPROPORTIONATLY AFFECT AI/AN WOMEN BEFORE, DURING, AND AFTER PREGNANCY.

² Oré, C. E., Teufel-Shone, N. I., & Chico-Jarillo, T. M. (2016). American Indian and Alaska Native resilience along the life course and across generations: A literature review. *American Indian and Alaska native mental health research (Online)*, 23(3), 134–157. <https://doi.org/10.5820/aian.2303.2016.134>

³ California Department of Public Health, Maternal, Child and Adolescent Health Division. (2018). *California American Indian/Alaska Native Maternal and Infant Health Status Report*. Accessed on December 5, 2022 online at: <https://www.cdph.ca.gov/Programs/CFH/DMCAH/MIHA/CDPH%20Document%20Library/AIAN-MIH-Status-Report-2019.pdf>

Within these areas, the report outlines 59 interrelated strategies that will help change the character and course of programs, policies, and systems that have been detrimental to the health, safety, and well-being of AI/AN mothers and infants. Given the current gravity of AI/AN maternal and infant birth outcomes, and following consultation with Tribal and other stakeholders, the report contains an expansive package of opportunities for action. The following is a summary of “*Recommended Strategies to Improve the Health and Safety of American Indians and Alaska Native Mothers and Infants.*” (See also Appendix C for a summation.)

RECOMMENDED STRATEGIC ACTIONS:

I. MAKE THE HEALTH AND SAFETY OF AI/AN MOTHERS AND INFANTS A PRIORITY FOR ACTION.

The collection, appropriate analysis, and use of a broad range of high-quality data is a prerequisite step in prioritizing the health of AI/AN mothers and infants. Similarly, the inclusion of representatives from AI/AN communities in venues and situations where policy and programmatic decisions are being crafted is essential in making AI/AN mothers and infants a priority.

ACIMM believes that the health of AI/AN mothers and infants can be made a priority now by:

- **Engaging and centering AI/AN communities as active, empowered leaders and decision makers in working towards solutions to the challenges facing AI/AN mothers and infants in Tribal and urban settings.** This will require assuring meaningful AI/AN leadership and decision making on how to collect, analyze, use, and disseminate data – including the establishment of AI/AN Fetal and Infant Mortality Reviews (FIMR), Child Death Reviews (CDR), and Maternal Mortality Review Committees (MMRC). Assuring representation of Tribal and urban AI/AN on ACIMM is also essential.
- **Mobilizing federal and state agencies to end data invisibility and erasure by accurately identifying AI/AN people and including them in data policy development processes.** Because of their relatively small numbers and geographic dispersion, AI/AN people too often are ignored, overlooked, and/or misclassified in data reports. In this report, ACIMM outlines solutions to help address this oversight.
- **Expanding and leveraging the programs and funding of the Health Resources Services Administration (HRSA) and the Maternal and Child Health Bureau (MCHB) to include a specific focus on and greater investment in AI/AN women and infants.** Title V of the Social Security Act; workforce development; Maternal, Infant, and Early Childhood Home Visiting (MIECHV), Healthy Start; and Sudden Infant Death Syndrome and Sudden Unexpected Infant Deaths (SIDS/SUID) are all MCHB-related programs within the

portfolio of HRSA. Each of these should be leveraged to advance the health and safety of AI/AN mothers and infants at the federal, Tribal, state, and local levels.

II. IMPROVE THE LIVING CONDITIONS OF AI/AN MOTHERS AND INFANTS AND ASSURE UNIVERSAL ACCESS TO HIGH QUALITY HEALTHCARE.

One of the most powerful and frequently expressed messages that ACIMM heard in its deliberations is that the Indian Health Service (IHS) is not meeting the essential needs of AI/AN women, children, and families. The failure of IHS to meet its obligations is fostered and magnified by a woefully inadequate workforce and lack of effective oversight. Chronically inadequate living conditions of AI/AN families was also highlighted as a major contributor to poor health and birth outcomes among AI/AN mothers and infants.

While larger structural and systems changes will be required to prevent AI/AN maternal and infant mortality and for lasting amends to be made, ACIMM urges that current shortcomings can and must be effectively addressed by:

- **Evaluating, sufficiently funding, and improving the Indian Health Service.** A comprehensive assessment of the quality of maternal and infant care by the IHS needs to be done. This evaluation should include the benefits and limitations of Compact and Contract relationships between the Tribes and IHS. An audit and evaluation of the contract between IHS and the American College of Obstetrics and Gynecology (ACOG) related to maternity care should be done and its finding reported to ACIMM. (The scope of these essential evaluations is beyond the current resources of ACIMM.).
- **Expanding and diversifying the workforce to include AI/AN practitioners.** The “medicalization” of birthing has created barriers to the use of midwives, doulas, and other traditional birth workers. Including these providers in the team caring for birthing individuals would help increase workforce diversity and advancement, facilitate incorporation of cultural practices, and improve birth outcomes. HRSA has levers to help make this happen.
- **Strengthening approaches to adapt and augment improvements in the social determinants of health.** Living conditions are the most significant determinants of health. These conditions are influenced by policies at all levels of government. The federal government plays a lead role in driving these policies. Collectively and collaboratively, all departments within the federal government (Health and Human Services, Housing and Urban Development, Transportation, Education, Justice, Interior, Agriculture, Commerce, Labor, Veterans Affairs, Homeland Security, Environmental Protection), should include an evaluation of the impact of their policies and programs on AI/AN populations.

Medicaid is also a major source of funding for the provision of medical care for the AI/AN population. It is a resource that is not being optimally used to maximize its benefits to AI/AN

populations. It is also not being used uniformly across the country. Even though there are provisions in federal law related to Medicaid that would benefit Tribes, states often interfere with receipt of those benefits. While ACIMM did not have the resources to adequately address issues related to Medicaid and AI/AN maternal and infant health, it recognizes that opportunities to better utilize Medicaid to support AI/AN populations should receive attention.

III. ADDRESS URGENT AND IMMEDIATE CHALLENGES THAT DISPROPORTIONATELY AFFECT AI/AN WOMEN BEFORE, DURING, AND AFTER PREGNANCY.

Because of racism and the devaluing of AI/AN women, this population is both disproportionately affected by and targeted for abduction, violence, sexual exploitation, and incarceration. The lack of effective data collection and surveillance systems around incarceration, Missing and Murdered Indigenous Women and Girls (MMIWG), and violence hides the magnitude and significance of these problems and hinders the development of appropriate programs and policies to address these issues.

ACIMM believes that these urgent and immediate challenges facing AI/AN women should be addressed by:

- **Expanding efforts to identify MMIWG and prevent its occurrence.** This will require the development of regional, state, and local offices on MMIWG, state-to-state and regional collaboration, development and use of standardized data collection and reporting protocols, and the ability of Tribal Nations to advocate for their community members living in urban areas when they are missing or killed.
- **Improving the care of incarcerated AI/AN pregnant and postpartum women as well as pregnant and postpartum women of all races/ethnicities.** There are evidence-based guidelines, interventions, and programs that support physical, emotional, mental, and spiritual health in a culturally appropriate manners that should be provided to all incarcerated women.
- **Expanding violence surveillance and universal screening for intimate partner violence (IPV) among AI/AN and all women.** Universal screening and referral for IPV are needed in the evaluation of pregnant and postpartum individuals. The Pregnancy Risk Assessment and Monitor System (PRAMS) survey should also include IPV modules. Maternal Mortality Review Committees should review all pregnancy-associated and pregnancy-related deaths, including homicide, IPV, suicide, and overdoses during pregnancy and one year postpartum. Including the pregnancy and interpersonal violence fields in surveillance should be required for all jurisdictions, using the CDCs National Violent Death Reporting System (NVDRS) database.

Substance use and mental health issues are a major concern in AI/AN communities. Adequately addressing these issues and developing actionable comprehensive recommendations require resources and time beyond the current capacities of ACIMM. In this report, ACIMM offers several recommendations as a starting point for a dedicated and concentrated focus on these issues that must occur in the near future.

Finally, the importance of holding an ACIMM meeting that is dedicated to AI/AN maternal and child health on Tribal land cannot be overstated. It allowed ACIMM to engage and listen directly to the voices of both urban and rural AI/AN from multiple Tribes, in a safe, welcoming, and supportive environment. It allowed Tribal advocates for maternal and child health from around the country to come together to collectively highlight the needs of their people. It demonstrated to Tribal leaders and advocates that the federal government, at least in one small way, was willing to do something different to engage with and accommodate the AI/AN population. **Based on its experience, ACIMM recommends that priority be given to having federal advisory committee meetings that focus on issues of specific communities, regardless of the topic, be held in those communities to assure greater engagement, understanding, representation, and accountability.**

Making Amends: Recommended Strategies and Actions to Improve the Health and Safety of American Indian and Alaska Native Mothers and Infants

History Matters: A Historical Context

History matters and historical context is essential for understanding the reasons why AI/AN women and infants persistently have among the worst maternal and child health outcomes in the country.⁴

Prior to 1492, Indigenous people of what is now called the Americas had complex civilizations with organized food systems, extensive trade and political systems, and robust health and cultural practices and beliefs. European settlers arrived on these continents with the overall intent to conquer land, obtain precious resources, and evangelize non-Christian populations. This colonization was guided by the “Doctrine of Discovery”⁵ which justified and allowed European nations and descendants to claim foreign lands they “discovered,” disenfranchising indigenous people from their land, and conquering and enslaving Indigenous people who resisted.⁶

The supremacy of Western language, culture, religion, ideology, and philosophy became the “gold standard” upon which all other racial and ethnic groups were measured. Following the American Revolution, the newly formed United States continued the practices inherited from British colonial rule, leading to special trust relationships, treaties, laws, and policies that shaped and defined the government-to-government relationship between the

“We need to talk about this in a historical context. We know that native people are the top of every disparity that exists in education, health. What we don't often talk about is that the that the root cause of these disparities is colonialism and white supremacy. This country built its wealth and status as a world superpower through stolen land and stolen people, and the industrial revolution would not have taken place without the extraction of our land and resources and the extraction of free labor. The lack of resources infused into our communities is a continuation of genocide. Hundreds of years of federal Indian policy has had a direct horrific effect on our health and well-being. We live a country of extreme wealth, and the hoarding of this wealth is both unethical and immoral when our people are literally dying. The hoarding of resources directly impacts our people's health, wellness, and the quality of life.”

Marisa Miakonda Cummings
(Umonhon/Omaha)
President and CEO, Minnesota Indian
Women's Resource Center

⁴ Palacios, J. F., & Portillo, C. J. (2009). Understanding Native women's health: historical legacies. *Journal of transcultural nursing* : official journal of the Transcultural Nursing Society, 20(1), 15–27. <https://doi.org/10.1177/1043659608325844>

⁵ Wikipedia. (2022, October 2). *Doctrine of Discovery*. Accessed October 18, 2022 online at: https://en.wikipedia.org/wiki/Discovery_doctrine

⁶ Dunbar-Ortiz, R. (2019). *An Indigenous Peoples' History of the United States*. Beacon Press, Boston.

Gordon, H. S. J., Around Him, D., & Jordan, E. (2022). Federal policies that contribute to racial and ethnic health inequities and potential solutions for Indigenous children, families, and communities. Comments to the National Academy of Sciences Ad Hoc Committee on Racial and Ethnic Health Inequities. *Child Trends*. <https://doi.org/10.56417/9136x1024u>

federal and Tribal governments, while also codifying structural racism leading to racial and ethnic health inequities for AI/AN people.⁷

During the late 19th century, in exchange for the forced removal of AI/AN people from ancestral lands and relocation onto reservations, the federal government entered into treaties and made promises to promote Tribal self-governance, provide medical services and education to American Indian people, and protect their lands and resources.^{8,9}

In addition to forced relocation and cessation of traditional lands, Tribes were coerced to surrender their children to boarding schools, where children were compelled to change their appearance, wear Western clothing, become Christian, speak English, learn a trade skill, and embrace Western cultural practices that did not always serve them upon return to their communities.¹⁰ Extensive physical, psychological, sexual, emotional, and spiritual abuse were forced upon children by adults in charge of their

So I'm half Native American and half black, but I grew up on the reservation. So I can say that as an indigenous woman, we are angry. Like, we don't even have voices. It's not fair. Like, you have people just shutting us up just because they don't want us to have a voice. And that's what's hard about it.
Lenice Antel-White
Incarceration Survivor

care, and similar behaviors were encouraged by older students.¹¹ Indian boarding schools often were subsidized by the Federal government and became a generational venue for targeted assimilation policies aimed at de-indigenizing children and purposely dismantling familial structures.¹² Modern day assimilation and cultural disruption which sustains cultural disenfranchisement continues when AI/AN children are taken from families and communities and placed into foster care or adoption,¹³ where they are overrepresented.¹⁴

⁷ Gordon, H. S. J., Around Him, D., & Jordan, E. (2022). Federal policies that contribute to racial and ethnic health inequities and potential solutions for Indigenous children, families, and communities. Comments to the National Academy of Sciences Ad Hoc Committee on Racial and Ethnic Health Inequities. *Child Trends*. <https://doi.org/10.56417/9136x1024u>

⁸ National Congress of American Indians. (2022, October 1). *Tribal Governance*. <https://ncai.org/policy-issues/tribal-governance>

⁹ Indian Health Service. (2015, January). *Basis for Health Services*. Accessed October 18, 2022 online at: <https://www.ihs.gov/newsroom/factsheets/basisforhealthservices/>
<https://www.ihs.gov/newsroom/factsheets/basisforhealthservices/>

¹⁰ Newland, B. United States Department of the Interior. (2022, May). Office of the Secretary. *Federal Indian Boarding School Initiative Investigative Report*. Online at: https://www.bia.gov/sites/default/files/dup/inline-files/bsi_investigative_report_may_2022_508.pdf

¹¹ Ibid.

¹² Ibid.

¹³ Udall, M. Committee on Interior and Insular Affairs. (1978). United States House of Representatives. 95th Congress, 2nd Session. *Establishing Standards for the Placement of Indian Children in Foster or Adoptive Homes, to Prevent the Breakup of Indian Families, and for Other Purposes*. 95th Congress, 2nd Session. Online at: <https://www.narf.org/nill/documents/icwa/federal/lh/hr1386.pdf>

¹⁴ LaPlante, K. (2017). *The Indian Child Welfare Act and Fostering Youth Cultural Identity: A New Model to Provide Culturally Competent Services to American Indian Children, Families and Tribes*. Online at: <https://www.apa.org/pi/families/resources/newsletter/2017/12/indian-child-welfare>

"51 years ago, in 1971, Representative Julia Butler Hansen of Washington, who ran the Appropriations Committee serving Indian health, said, 'The problem arises when Indians leave a reservation on their own and are clustered in cities such as Minneapolis-Saint Paul.' She also stated that 'Improving the health of mothers and children has always had the highest priority in the Indian Health Service.' Here we are today, hearing the exact same issues over and over and over again. The language of the colonizer is apparent here when it says that Indians left the reservation on their own, (knowing the reality of)... how people were relocated, displaced, and terminated."

Meredith Raimondi

Vice President of Public Policy, National Council on Urban Indian Health

The federal government's efforts to assimilate AI/ANs into Western culture can be seen throughout the 20th century. In the 1950s, Congress established a new policy towards erasing Tribes and Tribal lands, which resulted in the relocation of AI/AN families to urban settings - often referred to as the 'termination era.' This federal program frequently failed to provide jobs and resources that were promised to those moving to urban areas, leaving entire families stranded. It also led to the termination of some Federally recognized Tribes and contributed to today's vast population of urban Indians.¹⁵

Another example of annihilation efforts: a mass sterilization campaign enacted throughout Indian Health Service facilities, reimbursed by the Federal government,¹⁶ targeted AI/AN women without informed consent.¹⁷ While true rates of forced or

coerced sterilization are presently unknown, a recent study found that AI/AN women were 2.5 times more likely to experience sterilization than any other racial group of women,¹⁸ and an estimated 25% of the AI/AN childbearing population was lost.¹⁹ Today, long-acting chemical contraception (depo Provera, Norplant, Nexplanon and Mirena intrauterine devices) is encouraged and used more frequently upon AI/AN women than any other group of women.^{20,21}

"I hear stories around the rights as indigenous people, native women not being honored in their birthing experience, people still getting episiotomies that they don't need and did not ask for. Un-consented procedures is still an issue. I don't see an apology from Indian Health Services for their forced sterilizations (of) our people in the 1970s."

Nicolle Gonzalez (Dine')

Nurse Midwife, Navajo Nation

¹⁵ Dunbar-Ortiz, R. (2109). *An Indigenous Peoples' History of the United States*. Beacon Press, Boston.

¹⁶ Comptroller General of the United States. (1976). General Accounting Office. *Investigation of Allegations Concerning Indian Health Service*. HRD-77-3, 18 (Nov. 4, 1976). Accessed October 2, 2022 online at: <https://www.gao.gov/assets/hrd-77-3.pdf>

¹⁷ Lawrence J. The Indian Health Service and the sterilization of Native American women. *Am Indian Q.* 2000;24(3):400-19. doi: 10.1353/aiq.2000.0008.

¹⁸ Cackler, C. J., Shapiro, V. B., & Lahiff, M. (2016). Female Sterilization and Poor Mental Health: Rates and Relatedness among American Indian and Alaska Native Women. *Women's health issues: official publication of the Jacobs Institute of Women's Health*, 26(2), 168–175. <https://doi.org/10.1016/j.whi.2015.10.002>

¹⁹ Lawrence J. The Indian Health Service and the sterilization of Native American women. *Am Indian Q.* 2000;24(3):400-19. doi: 10.1353/aiq.2000.0008.

²⁰ Rutman, S., Taulii, M., Ned, D., & Tetrack, C. (2012). Reproductive health and sexual violence among urban American Indian and Alaska Native young women: select findings from the National Survey of Family Growth (2002). *Maternal and child health journal*, 16 Suppl 2, 347–352. <https://doi.org/10.1007/s10995-012-1100-1>

²¹ Use of the Drug, Depo Provera, by the Indian Health Service, Oversight Hearing Before the H. Subcomm. on General Oversight and Investigations of the Committee on Interior and Insular Aff., 100th Cong. 1 (Aug. 6, 1987).

Efforts to disenfranchise and marginalize AI/AN people from their ancestral Tribes, land, and culture and terminate their legal rights to land possession was further enhanced by colonial views and policies on land ownership and the establishment of arbitrary criteria for determining who was a tribal member. “Blood quantum” and lineage rules along with misclassification of race data makes identification of AI/AN people difficult. This leads to an undercounting of the AI/AN population. A thorough understanding of how the integration of colonial policies, AI/AN history, and cultural designation of identity interplay in locating and identifying this population for research as well as differential access to resources based on this history is essential.²²

Compounding this is an erosion of trust of the U.S. government by the AI/AN population, fostered by lack of oversight and inaction when detrimental and damaging misconduct by IHS personnel have been identified and documented.²³ Despite numerous pleas to establish effective oversight of staff, IHS has resisted both development of a standard format for documenting patient complaints and a consistent process to review regional trainings and policies concerning provider misconduct or performance.²⁴

The federal government’s trust responsibility to AI/AN citizens requires that the government provide services and resources to improve the health of AI/AN citizens. Furthermore, a “*major national goal of the United States is to provide the quantity and quality of health services which will permit the health status of Indians to be raised to the highest possible level and to encourage the maximum participation of Indians in the planning and management of those services.*”²⁵ In fulfillment of its trust responsibility and national goal, it is the policy of the United States “*to ensure the highest possible health status for Indians and urban Indians and to provide all resources necessary to effect that policy.*”²⁶ That federal trust responsibility for healthcare extends to all AI/ANs regardless of where they are located.

Unfortunately, the federal government has fallen short of this responsibility to AI/ANs, and they have failed to provide adequate assistance to support American Indian infrastructure, self-governance, housing, education, health, or economic development needs, which in turn has

²² Haozous, E. A., Strickland, C. J., Palacios, J. F., & Solomon, T. G. (2014). Blood politics, ethnic identity, and racial misclassification among American Indians and Alaska Natives. *Journal of environmental and public health*, 2014, 321604. <https://doi.org/10.1155/2014/321604>

²³ Weaver, C and Frosh, D. (2021). *Indian Health Service Managers Protected a Pedophile in Their Midst. Now the U.S. Agency is Protecting Them.* Frontline. <https://www.pbs.org/wgbh/frontline/article/indian-health-service-protects-managers-who-protected-pedophile-doctor-stanley-weber/>

²⁴ United States Government Accountability Office. (2020) *Indian Health Service: Actions Needed to Improve Oversight of Provider Misconduct and Substandard Performance.* GAO-21-97. <https://www.gao.gov/assets/gao-21-97.pdf>

²⁵ GovInfo. *Congressional Findings.* 25 U.S.C. § 1601(3) Online at: <https://www.govinfo.gov/content/pkg/USCODE-2020-title25/pdf/USCODE-2020-title25-chap18-other-sec1601.pdf>

²⁶ Ibid.

gravely impacted AI/AN people.²⁷ The results of this are manifested in myriad negative results including:

- AI/AN maternal mortality rates ranging from 2 to 4.5 times the rate of non-Hispanic White women^{28, 29, 30} with regional rates elevated to 7 times the rate of non-Hispanic White women,^{31, 32} and an estimated 93% of AI/AN deaths being preventable,
- consistently high infant mortality rates, a measure that gauges overall community health,^{33 34}
- high rates of substance use,³⁵
- inadequate prenatal care,³⁶
- increased risk for preterm birth and low birth weights,³⁷
- mental health complications,³⁸

²⁷ United States Commission on Civil Rights. (2018). *Broken Promises: Continuing Federal Funding Shortfall For Native Americans*. (Report No. GA00-21-97) Accessed October 2, 2022 online at: <https://www.usccr.gov/files/pubs/2018/12-20-Broken-Promises.pdf>

²⁸ Ely, D. M., & Driscoll, A. K. (2021). Infant Mortality in the United States, 2019: Data From the Period Linked Birth/Infant Death File. *National vital statistics reports: from the Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System*, 70(14), 1–18.

²⁹ Urban Indian Health Institute, Seattle Indian Health Board, *Community Health Profile: National Aggregate of Urban Indian Health Program Service Areas* (2016), 37, http://www.uihi.org/wp-content/uploads/2017/08/UIHI_CHP_2016_Electronic_20170825.pdf

³⁰ Heck, J. L., Jones, E. J., Bohn, D., McCage, S., Parker, J. G., Parker, M., Pierce, S. L., & Campbell, J. (2021). Maternal Mortality Among American Indian/Alaska Native Women: A Scoping Review. *Journal of women's health* (2002), 30(2), 220–229. <https://doi.org/10.1089/jwh.2020.8890>

³¹ South Dakota Advisory Committee to the US Commission on Civil Rights. (2021). *Report on Maternal Mortality and Health Disparities of American Indian Women in South Dakota*. US Commission on Civil Rights; Online at: <https://www.usccr.gov/files/2021/07-14-Maternal-Mortality-and-Health-Disparities-of-American-Indian-Women-in-South-Dakota.pdf>

³² Lewandowski KS, Baer CE, Schoustra R, Indatwa A, Celaya MF, Tarango P. (2020). SB 1040 *Annual Report on Maternal Fatalities and Morbidities in Arizona*. Phoenix, AZ: Arizona Department of Health Services. Online at: <https://www.azdhs.gov/documents/director/agency-reports/sb-1040-report-on-mmm-in-az.pdf>

³³ Ely, D. M., & Driscoll, A. K. (2021). Infant Mortality in the United States, 2019: Data From the Period Linked Birth/Infant Death File. *National vital statistics reports: from the Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System*, 70(14), 1–18.

³⁴ California Department of Public Health, Maternal, Child and Adolescent Health Division. (2018). *California American Indian/Alaska Native Maternal and Infant Health Status Report*. Accessed on December 5, 2022 online at: <https://www.cdph.ca.gov/Programs/CFH/DMCAH/MIHA/CDPH%20Document%20Library/AIAN-MIH-Status-Report-2019.pdf>

³⁵ Dickerson, D. L., Spear, S., Marinelli-Casey, P., Rawson, R., Li, L., & Hser, Y. I. (2011). American Indians/Alaska Natives and substance abuse treatment outcomes: positive signs and continuing challenges. *Journal of addictive diseases*, 30(1), 63–74. <https://doi.org/10.1080/10550887.2010.531665>

³⁶ Johnson M. B. (2020). Prenatal Care for American Indian Women. *MCN. The American journal of maternal child nursing*, 45(4), 221–227. <https://doi.org/10.1097/NMC.0000000000000633>

³⁷ Raglan, G. B., Lannon, S. M., Jones, K. M., & Schulkin, J. (2016). Racial and Ethnic Disparities in Preterm Birth Among American Indian and Alaska Native Women. *Maternal and child health journal*, 20(1), 16–24. <https://doi.org/10.1007/s10995-015-1803-1>

³⁸ United States Department of Health and Human Services. Office of Minority Health. (Last Updated on: May 5, 2021). *Mental and Behavioral Health- American Indians/Alaska Natives*. Accessed October 2, 2022 online at: <https://www.minorityhealth.hhs.gov/omh/browse.aspx?vl=4&vlid=39>

- comorbidities (e.g., hypertension and diabetes),
- exposure to excessive community violence including a longstanding and ongoing epidemic of MMIWG,³⁹ and evidence demonstrating AI/AN people are disproportionately killed by police than other races, with AI/AN police related deaths likely undercounted or miscategorized,^{40 41} and
- perpetuation of the stereotype that the inequities AI/AN communities face are the result of their own shortcomings, rather than the result of system-based root causes including racism, data erasure, and funding inadequacies for AI/AN people.^{42,43,44,45,46}

The 2018 U.S. Commission on Civil Rights report “*Broken Promises: Continuing Federal Funding Shortfall for Native Americans*”⁴⁷ revealed that despite the original 2003 “*A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country*” report,⁴⁸ the federal government continues to fail in adequately supporting the social and economic wellbeing of American Indians. The report highlighted 3 key findings:

1. Federally sponsored American Indian programs designed to support the social and economic wellbeing of AI/AN people remain chronically underfunded and at times inefficiently structured, thereby leaving many AI/AN people’s basic needs unmet,
2. Federal accountability in maintaining accurate, consistent, and comprehensive record keeping of federal spending on American Indian programs is lacking, making monitoring of federal spending to meet its trust responsibility difficult, and

³⁹ Lucchesi, A., Echo-Hawk, A. *Missing and Murdered Indigenous Women & Girls: A snapshot of data from 71 urban cities in the United States*. Urban Indian Health Institute. Online at <https://www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=39>

⁴⁰ Commission on Civil Rights. (2018). *Police Use of Force: An Examination of Modern Policing Practices*. Accessed on October 3, 2022 online at: <https://www.usccr.gov/pubs/2018/11-15-Police-Force.pdf>

⁴¹ Koerth- Baker, M. (2016). *Police Violence Against Native Americans Goes Far Beyond Standing Rock*. FiveThirtyEight. <https://fivethirtyeight.com/features/police-violence-against-native-americans-goes-far-beyond-standing-rock/>

⁴² Thomas E. Dobbs, State Health Officer of the Mississippi Department of Health, Et al., v. Jackson Women’s Health Organization, Et al. No. 19-1392 (2021). https://www.supremecourt.gov/DocketPDF/19/19-1392/192846/20210917173106773_NIWRC%20Main%20FILE%20Sep%2017%2021.pdf

⁴³ Edwards K, Patchell B. State of the science: a cultural view of Native Americans and diabetes prevention. *J Cult Divers*. 2009;16(1):32-35.

⁴⁴ Orr, R., Sharratt, K., Iqbal, M. (2019). American Indian erasure and the logic of elimination: an experimental study of depiction and support for resources and rights for Tribes, *Journal of Ethnic and Migration Studies*, 45:11, 2078-2099, DOI: [10.1080/1369183X.2017.1421061](https://doi.org/10.1080/1369183X.2017.1421061)

⁴⁵ Huyser, K.R., Yellow Horse, A.J., Kuhlmeier, A.A., Huyser, M.R. (2021). COVID-19 Pandemic and Indigenous Representation in Public Health Data, *American Journal of Public Health* 111, no. S3 (October 1, 2021): pp. S208-S214.

⁴⁶ Urban Indian Health Institute (2021). *Data Genocide of American Indians and Alaska Natives in COVID-19 Data*. Seattle, WA: Urban Indian Health Institute. <https://www.uihi.org/projects/data-genocide-of-american-indians-and-alaska-natives-in-covid-19-data/>

⁴⁷ United States Commission on Civil Rights. (2018). *Broken Promises: Continuing Federal Funding Shortfall For Native Americans*. (Report No. GAO-21-97) Accessed October 2, 2022 online at: <https://www.usccr.gov/files/pubs/2018/12-20-Broken-Promises.pdf>

⁴⁸ U.S. Commission on Civil Rights. (2003). *A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country*. <https://www.hsdl.org/c/view?docid=689103>

3. Permissive unequal treatment of Tribal governments and lack of full recognition of the sovereign status of Tribal governments by local, state, and federal governments' laws, and policies diminish Tribal self-determination and negatively impact health, housing, education, criminal justice, and economic outcomes for American Indians.

The Work of the Advisory Committee on Infant and Maternal Mortality

Since 2020, the HHS Secretary's Advisory Committee on Infant and Maternal Mortality (ACIMM) has focused much of its work on the birth outcomes of AI/AN mothers and infants. This focus was chosen because AI/AN populations are too often overlooked or omitted in programmatic and policy discussions, though their birth outcomes are among the worst in the country.⁴⁹ The reasons for this oversight are numerous and include:

- Small population size: In 2021, the AI/AN population was 1.3% of the total U.S. population compared to White (Non-Hispanic): 75.8%, Latino 18.9%, Black 16.6%, Asian 6.1%, and Native Hawaiian and Other Pacific Islander 0.3%, and two or more races 2.9%.⁵⁰ To some, 'small numbers' confers insignificance. Small numbers can make statistical calculations and comparisons unstable, which may deter closer examination.
- Dispersed population: There are 574 federally recognized Tribes in the United States, which are widely dispersed throughout the nation due to the 1956 Indian Relocation Act. Today, most AI/AN people identify themselves as living off reservation in urban settings. There are no major population centers of AI/AN people, which magnifies the challenge of small numbers. The issues and needs of dispersed AI/AN populations also vary greatly throughout the country.

⁴⁹ Singh, G. K., & Yu, S. M. (2019). Infant Mortality in the United States, 1915-2017: Large Social Inequalities have Persisted for Over a Century. *International journal of MCH and AIDS*, 8(1), 19–31. <https://doi.org/10.21106/ijma.271>

⁵⁰ United States Census Bureau. *Quick Facts United States*. (2021). Accessed on October 2, 2022 online at: <https://www.census.gov/quickfacts/fact/table/US/RHI725221#RHI725221>

- Lack of representation: There are relatively few AI/AN individuals who hold governmental elected office (excluding Tribal government). There is also low representation of AI/AN people in academic and appointed positions, professional organizations, advocacy organizations, and on advisory committees. This limits the ability to raise issues of concern to AI/AN populations in settings where action can occur.
- Non-state entities: Tribes have a sovereign nation-to-nation relationship with the United States government. This means there are 574 unique relationships between the U.S. and Tribal governments. It's difficult to address the needs of each Tribe. In addition, Tribes are located in 50 states with varied relationships between Tribes and the states. States are also favored with most of the attention of the U.S. government. It is difficult for AI/AN needs to gain priority.

"American Indians are unique in United States because our Tribes have a government-to-government relationship with the federal government. It's not like other underserved minority populations because we have the separate political entities. We're nations within the nation. It's very clear in the U.S. Constitution, Article I, Section 8 in the Commerce Clause, that, "Congress shall regulate commerce with the foreign nations and the Indian Tribes." We are put on par with foreign nations so that's recognition of Tribal sovereignty

Donald Warne, MD (Oglala Dakota)
Co-Director, Center for Indigenous Health,
Johns Hopkins University

With these concerns in mind, ACIMM embarked on a two-year effort to identify and address the strengths, conditions, and unmet needs of AI/AN mothers and infants. Part of this effort was an extensive review of the literature on AI/AN birth outcomes and on the impact of genocide, historical trauma, and social, economic, and environmental factors on the health status of AI/AN populations. At five separate meetings, ACIMM heard testimony from representatives of federal, state, local, and Tribal and urban Indian agencies, as well as academic institutions who are working on AI/AN maternal and child health issues. On September 13, 14, and 15, 2022, ACIMM met, by invitation, on the Tribal land of the Shakopee Mdewakanton Sioux Community (SMSC) in Minnesota and heard first-hand stories and experiences from Tribal leaders, elders, and members, along with organizations serving urban and Tribal AI/AN families and communities from across the country. ACIMM also heard their recommendations on what should be done to improve the health and well-being of AI/AN mothers and infants. (A list of those who presented and testified is included in Appendix A.) This meeting also was significant in that it was the first ACIMM meeting ever held outside of Rockville, MD, and the first held on federally recognized Tribal land.

FINDINGS:

The ACIMM has verified the accuracy of the findings of the *“Broken Promises”* report. ACIMM continues to learn more about how key variables such as housing, education, transportation, food security, the physical environment, and economic status can support or hinder people from thriving. When combined with historical trauma, ongoing harmful policies, and stressful daily experiences, the negative intergenerational impact can have a profound impact on maternal and infant health status.⁵¹

Acknowledging the disparities in the health of AI/AN mothers and infants, our nation’s obligations to the AI/AN people, the contribution of living conditions on health,⁵² ACIMM developed and approved a set of strategies to optimize AI/AN maternal and infant health. These strategies center the infant and mother as a dyad within the context of their wider families and community, and their inherited history across the life course. ACIMM recognizes that the pressing needs of AI/AN mothers and infants go far beyond the scope of these recommended strategies. However, these recommendations are a starting point for the ongoing work that needs to be done to assure that all American Indian and Alaska Native mothers and infants have the opportunity to be healthy, safe, and thrive.

The findings of the 2018 *“Broken Promises: Continuing Federal Funding Shortfall for Native Americans”* report and the ACIMM’s own investigations led to the framing of these recommended strategies and actions around three premises:

1. The health of AI/AN women, parents, and infants has never been a priority for our country, which has led to living conditions and healthcare systems that are not supportive of optimal health and good birth outcomes.
2. Like every other population group, a healthy social and physical environment and access to high-quality care for AI/AN women and infants are essential to good birth outcomes.

“Systems are people and people are benefitting from almost all of the tragedies that we see driving these outcomes, the housing crisis, someone is benefitting, the prison crisis someone is benefitting, substance use, someone is benefitting, and even sexual exploitation, someone is benefitting. (These people) shouldn’t have the privilege of the comfort of ignorance about what’s happening, and they shouldn’t have the comfort of not knowing or hearing the stories, and at a minimum, we should know who is benefitting and, they should be accountable to knowing the information we have.”

Marisa Miakonda Cummings
(Umonhon/Omaha)
President and CEO, Minnesota Indian Women’s Resource Center

“We’ve heard about the federal government’s trust responsibility. This is a sacred promise that the United States made to American Indians and Alaska Natives to provide health care.”

Meredith Raimondi
Vice President of Public Policy, National Council on Urban Indian Health

⁵¹ Palacios, J. F., & Portillo, C. J. (2009). Understanding Native women's health: historical legacies. *Journal of transcultural nursing : official journal of the Transcultural Nursing Society*, 20(1), 15–27. <https://doi.org/10.1177/1043659608325844>

⁵² Ibid.

However, social, economic, geographic, and environmental conditions, along with certain policy and political choices, have negatively affected the living conditions of AI/AN populations and inhibited them from accessing essential high-quality healthcare.

3. Because of racism and the devaluing of AI/AN women, some issues disproportionately affect this population which negatively impact maternal and infant health outcomes and mortality. Prominent among those are incarceration, MMIWG, substance use, mental health concerns, and violence.

After hearing the first-hand testimony, stories, and experiences of Tribal leaders, elders, and members, along with organizations serving urban and Tribal AI/AN from across the country, ACIMM learned that much of what is now considered evidence-based practice in Western medicine has been woven into AI/AN cultures since time immemorial, including: “breast is best” messaging, separate but proximate co-sleeping, sleep hygiene, “back to sleep” SIDS risk reduction (e.g. traditional cradleboards), birth supporters (e.g. doulas and midwives), and the positive impact of family, social, and cultural connectedness on child health, etc.

“We’ve talked about other things like the cradle boards and back to sleep. There’s a lot of things that we have done throughout history that are consistent with what we’re calling evidence-based practices. It might even be worth pointing out that modern science is finally catching up to indigenous knowledge.”

Donald Warne, MD (Oglala Dakota)
Co-Director, Center for Indigenous Health,
Johns Hopkins University

ACIMM recognizes that efforts to address the disparities described in this report should draw upon the many strengths found in AI/AN communities including: traditional and cultural practices, Native language, strong social networks, and a connection to land and place. Cultural connectedness (e.g., involvement in traditional practices or identification with traditional culture) is a protective factor among AI/AN populations that has been shown to promote healthy behaviors. Federal policies should build upon these strengths and be modified to reflect Indigenous cultural knowledge, with asset-based approaches that draw upon cultural protective and preventive practices, and are determined and implemented by AI/AN people and communities.^{53 54 55} With this knowledge, ACIMM added a fourth, cross-cutting premise in its framing of recommended strategies:

⁵³ Gordon, H. S. J., Around Him, D., & Jordan, E. (2022). Federal policies that contribute to racial and ethnic health inequities and potential solutions for Indigenous children, families, and communities. Comments to the National Academy of Sciences Ad Hoc Committee on Racial and Ethnic Health Inequities. *Child Trends*. <https://doi.org/10.56417/9136x1024u>

⁵⁴ California Department of Public Health, Maternal, Child and Adolescent Health Division. (2018). *California American Indian/Alaska Native Maternal and Infant Health Status Report*. Accessed on December 5, 2022 online at: <https://www.cdph.ca.gov/Programs/CFH/DMCAH/MIHA/CDPH%20Document%20Library/AIAN-MIH-Status-Report-2019.pdf>

⁵⁵ Oré, C. E., Teufel-Shone, N. I., & Chico-Jarillo, T. M. (2016). American Indian and Alaska Native resilience along the life course and across generations: A literature review. *American Indian and Alaska native mental health research (Online)*, 23(3), 134–157. <https://doi.org/10.5820/aian.2303.2016.134>

4. AI/AN people have inherently protective practices embedded in their culture that contribute to their ongoing collective and intergenerational resilience.⁵⁶

Based on these premises, ACIMM has identified three categories of recommended strategies and actions:

- I. **MAKE THE HEALTH AND SAFETY OF AI/AN MOTHERS AND INFANTS A PRIORITY FOR ACTION.**
- II. **IMPROVE THE LIVING CONDITIONS OF AI/AN MOTHERS AND INFANTS AND ASSURE UNIVERSAL ACCESS TO HIGH QUALITY HEALTHCARE.**
- III. **ADDRESS URGENT AND IMMEDIATE HEALTH CHALLENGES THAT DISPROPORTIONATELY AFFECT AI/AN WOMEN BEFORE, DURING, AND AFTER PREGNANCY.**

ACIMM's Recommended Strategies and Actions to Improve the Health and Safety of American Indian and Alaska Native Mothers and Infants

- I. **MAKE THE HEALTH AND SAFETY OF AI/AN MOTHERS AND INFANTS A PRIORITY.**

The health, safety, and well-being of AI/AN women, mothers, and infants has never been a priority for the United States government, which has led to living conditions and healthcare systems that are not supportive of optimal maternal health and good birth outcomes. This has been manifested in chronically inadequate federal resources, including funding for the Indian

My mom was traumatized by her childhood as well as being in an abusive relationship. Yet she decided to raise five children by herself in an urban area without any family support. It was a real struggle. She had so many interactions with the system who pretty much told her, I don't care about you. I don't care if you survive or if you don't. She just had to fight her way through. And I think we do as Indian women, we just make the decision to fight the systems because every step of the way somebody's going to say, you don't matter. Then we shut down. We close up. And when there is a warm hand that reaches out, we don't trust it. We don't trust it because of what happened to my mom and how she instilled into us the message. 'You know, they just think we're dirty Indians.' When you're a child and you hear that, it just hits you, and you don't trust the system. There's no native person in this room that hasn't been told by the system you don't matter."

Jackie Dionne (Turtle Mountain Chippewa)

Director, American Indian Health, Minnesota Department of Health

⁵⁶ Ibid.

Health Service and physical Tribal infrastructure.^{57 58} Persistent lack of accountability across state and IHS in tracking AI/AN maternal and child health outcomes has helped perpetuate centuries of inhumane treatment of AI/AN populations. For maternal health and birth outcomes to be improved and persistent health inequities eliminated, prioritizing and meeting the needs of AI/AN populations must occur.

Assuring the conditions in which people can be healthy is not a zero-sum proposition. Prioritizing the health of AI/AN mothers and infants will not be at the expense of other population groups. In fact, it will benefit all mothers and babies as reflected in the 1912 vision of Julia Lathrop, the first director of the Children's Bureau: *"...the greatest service to the health and education of (all) children has been gained through efforts to aid those who were (disregarded)...Thus all service to the (disregarded) children of the community... also serves to aid in laying the foundations for the best service to all children of the Commonwealth."* This idea of prioritization expands the view of targeted universalism by recognizing that addressing the needs of a disadvantaged (often disregarded) population is essential to achieving the desired universal goal.⁵⁹

Context for making the health and safety of AI/AN mothers and infants a priority through Data Sovereignty, Inclusion, and Policy and Program Changes

Essential in prioritizing AI/AN women and infants is the inclusion of actions that will undo policies and systems of oppression and segregation, towards repair and reconciliation. Historically, Federal policies purposely have sought to disenfranchise AI/AN people from their land (forced removal and later relocation), resources, culture, and future (through sterilization and abducting children into boarding schools and/or foster care).

"Congress first established urban Indian health clinics in 1976, when only 40 percent of native people were residing in cities. 50 years later (when 75% of AI/AN live in urban areas), the budget for Indian health service for Urban Indian programs is 1 percent of all Indian health care. there is no dedicated funding for urban Indian health in the maternal area."

Meredith Raimondi
Vice President of Public Policy, National Council on Urban Indian Health

⁵⁷ United States Commission on Civil Rights. (2018). *Broken Promises: Continuing Federal Funding Shortfall For Native Americans*. (Report No. GA00-21-97) Accessed October 2, 2022 online at: <https://www.usccr.gov/files/pubs/2018/12-20-Broken-Promises.pdf>

⁵⁸ National Congress of American Indians. (2021). *Indian Country FY 2022 Budget Request: Restoring Promises*. Washington, DC. Accessed October, 2022 online at: https://www.ncai.org/resources/ncai-publications/NCAI_IndianCountry_FY2022_BudgetRequest.pdf

⁵⁹ Powell, J.A., Menendian, S., Ake, W. (2019). *Targeted Universalism: Policy & Practice*. Accessed October 4, 2022 online at: <https://belonging.berkeley.edu/targeted-universalism>

Policy makers must recognize that diverse AI/AN communities exist both in rural and urban areas. While more than 70% of AI/AN populations live in urban areas across the country, the “urban” designation is misleading and based upon US Census Bureau definitions that include towns composed of 2,500 people or more; it is more accurate to state that 54% of AI/AN people live in rural or small-town locations and 68% live on or nearby Tribal homelands⁶⁰. There is an urgent need to create and sustain pathways to better health for AI/AN women, infants, fathers, and families disenfranchised by relocation policies including those now living in urban settings. Urban Indian Organizations (UIOs) receive less than 1% of the IHS annual appropriation, with no funds directly set aside for urban AI/AN maternal and child health.⁶¹ Additionally, HHS does not currently have an agency-wide urban confer policy, and the only agency within HHS with a set urban confer policy is IHS. This often leaves UIOs out of direct communication with HHS agencies requiring UIOs to rely on IHS to convey UIO information and needs to other agencies.

“Many urban American Indian and Alaskan Native communities were established through federal termination and removal policies that began in the 1950s. This movement to cities directly led to socioeconomic disparities as the promise of a better life, opportunities like jobs, health care, education were not available when they got there. We have faced longstanding historical and cultural genocide that has led to the loss of many of our traditional birthing practices and the racial disparities that we see today.

Socia Love-Thurman, MD
(Cherokee/Yuchi/Delaware)
Chief Health Officer, Seattle Indian Health Board

The collection and appropriate analysis of a broad range of high-quality data related to AI/AN mothers and infants and using those data to support program and policy initiatives to correct longstanding disparities and inequities is also essential to prioritizing the health of this population.

It is by colonial design that the AI/AN population is small. Small populations, like AI/AN people, are often overlooked, underfunded, and left out of policy agendas, resulting in harm, despite having great health disparities.^{62 63} National reports and public data sets consistently fail to provide detailed information on AI/AN people, likely resulting from:

- cultural and/or linguistic barriers in question interpretation,

⁶⁰ Dewees, S., Marks, B. (2017). *Twice Invisible: Understanding Rural Native America*. First Nations Development Institute. Accessed on December 9, 2022 online at: <https://www.usetinc.org/wp-content/uploads/bvenuti/WWS/2017/May%202017/May%208/Twice%20Invisible%20-%20Research%20Note.pdf>

⁶¹ U.S. Dept. of Health and Human Services. Indian Health Service. (2023). *Congressional Justifications*. Accessed October 4, 2022 online at: <https://www.ihs.gov/budgetformulation/congressionaljustifications/>

⁶² Pacheco CM, Daley SM, Brown T, Filippi M, Greiner KA, Daley CM. Moving forward: breaking the cycle of mistrust between American Indians and researchers. *Am J Public Health*. 2013;103(12):2152-2159. doi:10.2105/AJPH.2013.301480

⁶³ United States Commission on Civil Rights. (2018). *Broken Promises: Continuing Federal Funding Shortfall For Native Americans*. (Report No. GA00-21-97) Accessed October 2, 2022 online at: <https://www.usccr.gov/files/pubs/2018/12-20-Broken-Promises.pdf>

- lack of consistent race and ethnic data collection,⁶⁴
- inadequate data collection on urban AI/AN people,^{65 66}
- low response rates on local, state, and national surveys from small populations,⁶⁷
- mistrust of researchers resulting from historic and present-day ethical violations in the use of data and knowledge collected from Native people, and a lack of benefit returned to Native communities that participated in the research,⁶⁸ and
- frequent misclassification of AI/AN individuals' race and ethnicity in studies,^{69 70 71} and in death certificates.⁷²

Bias found in the biomedical-epidemiological scientific model often leaves out small population data, habitually collapses smaller racial data into "other" or names it "missing data," and is grounded in self-limiting parameters that fail to collect both race and geography, while also lacking cultural relevance,⁷³ and can be dangerous in perpetuating disenfranchisement inherited from a colonial view of identity composed of blood pedigree.⁷⁴ A 1999 Joint Report of the Department of Health and Human Services (DHHS) Data Council's Working Group on Racial and Ethnic Data⁷⁵ and the Data Work Group for the DHHS Initiative to Eliminate Racial

⁶⁴ California Department of Public Health, Maternal, Child and Adolescent Health Division. (2018). *California American Indian/Alaska Native Maternal and Infant Health Status Report*. Accessed on December 5, 2022 online at: <https://www.cdph.ca.gov/Programs/CFH/DMCAH/MIHA/CDPH%20Document%20Library/AIAN-MIH-Status-Report-2019.pdf>

⁶⁵ Ibid

⁶⁶ United States Department of Health and Human Services. (2007). Office of the Assistant Secretary for Planning and Evaluation. *Gaps and Strategies for Improving AI/AN/NA Data Final Report*. Accessed online October 5, 2022 online at: https://aspe.hhs.gov/sites/default/files/migrated_legacy_files/42276/report.pdf

⁶⁷ Korngiebel DM, Taulii M, Forquera R, Harris R, Buchwald D. (2015). Addressing the Challenges of Research With Small Populations. *Am J Public Health*. 2015;105(9):1744-1747. doi:10.2105/AJPH.2015.302783

⁶⁸ National Congress of American Indians. (2021). *Introduction to Research*. Accessed on October September 20, 2022 online at: <https://www.ncai.org/policy-research-center/research-data/introduction-to-research>

⁶⁹ Bertolli J, Lee LM, Sullivan PS; AI/AN Race /Ethnicity Data Validation Workgroup. Racial misidentification of American Indians/Alaska Natives in the HIV/AIDS Reporting Systems of five states and one urban health jurisdiction, U.S., 1984-2002. *Public Health Rep*. 2007;122(3):382-392. doi:10.1177/003335490712200312

⁷⁰ Rhoades DA. Racial misclassification and disparities in cardiovascular disease among American Indians and Alaska Natives. *Circulation*. 2005;111(10):1250-1256. doi:10.1161/01.CIR.0000157735.25005.3F

⁷¹ California Department of Public Health, Maternal, Child and Adolescent Health Division. (2018). *California American Indian/Alaska Native Maternal and Infant Health Status Report*. Accessed on December 5, 2022 online at: <https://www.cdph.ca.gov/Programs/CFH/DMCAH/MIHA/CDPH%20Document%20Library/AIAN-MIH-Status-Report-2019.pdf>

⁷² Jim, M. A., Arias, E., Seneca, D. S., Hoopes, M. J., Jim, C. C., Johnson, N. J., & Wiggins, C. L. (2014). Racial misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area. *American journal of public health*, 104 Suppl 3(Suppl 3), S295-S302. <https://doi.org/10.2105/AJPH.2014.301933>

⁷³ Urban Indian Health Institute. (2019). *Who Counts? Racial Misclassification and American Indian/Alaskan Natives*. SIHB/UIHI Presentation online at: <https://www.uihi.org/resources/who-counts-racial-misclassification-and-american-indians-alaska-natives/>

⁷⁴ Haozous, E. A., Strickland, C. J., Palacios, J. F., & Solomon, T. G. (2014). Blood politics, ethnic identity, and racial misclassification among American Indians and Alaska Natives. *Journal of environmental and public health*, 2014, 321604. <https://doi.org/10.1155/2014/321604>

⁷⁵ United States Department of Health and Human Services. (1999). Office of the Assistant Secretary for Planning and Evaluation. *Improving the Collection and Use of Racial and Ethnic Data in HHS*. Accessed on October 2, 2022 online at: <https://aspe.hhs.gov/reports/improving-collection-use-racial-ethnic-data-hhs>

and Ethnic Disparities in Health⁷⁶ outlined a number of novel strategies that are in process and have yet to be instated to address the small population conundrum.

For example, the joint report recommends identifying small population statistical analysis procedures, including aggregating data across multiple years, oversampling, creating new analysis that capture a highly mobile populations, developing new methods for accurately analyzing highly mobile small populations, creating standardized procedures for racial and ethnic data collection, training data collectors, utilizing self-report of racial identity, and creating and providing relationships with AI/AN communities to assist in data collection, augmenting federal data collection strategies, and building sub-sets of population data.⁷⁷ Therefore, the following recommendations aim to mobilize federal and state agencies to accurately and completely identify and count AI/AN people, so that the depth of disparities and inequities are identified, creating a clearer foundation to improve upon.

And, essential in prioritizing the health of AI/AN mothers and infants are actions to build trust and honor sovereignty in data and research. Methods employed by many researchers have generated a long history of creating mistrust among AI/AN people,⁷⁸ including stealing biological samples, revealing identities of AI/AN communities and individuals participating in sensitive studies, leading to public humiliation and negative economic impact on AI/AN communities; and “helicopter” and “ethics dumping” research approaches that left have communities without promised collaboration and/or access to the research results.⁷⁹ In 2018, as a result of pervasive abuse and lack of agency among AI/AN communities being studied, the National Congress of American Indians developed the concept of data sovereignty:⁸⁰ *“the right of a nation to govern the collection, ownership, and application of its own data, including any data collected on its Tribal citizens.”*

Specific to existing maternal and infant morbidity and mortality review initiatives, the level of Tribal involvement is widely variable, with very few Tribal-led review projects and limited Tribal representation in review staffing and committees. Maternal Mortality Review Committees (MMRCs), Fetal and Infant Mortality Reviews (FIMRs), and Child Death Reviews (CDRs) vary in

⁷⁶ United States Department of Health and Human Services. (2015). *HHS Action Plan to Reduce Racial and Ethnic Health Disparities: Implementation Progress Report 2011-2014*. Accessed online on October 3, 2022 online at: https://minorityhealth.hhs.gov/assets/pdf/FINAL_HHS_Action_Plan_Progress_Report_11_2_2015.pdf#:~:text=The%20U.S.%20Department%20of%20Health%20and%20Human%20Services,eventually%20eliminating%20disparities%20in%20health%20and%20health%20care

⁷⁷ United States Department of Health and Human Services. (1999). Office of the Assistant Secretary for Planning and Evaluation. *Improving the Collection and Use of Racial and Ethnic Data in HHS*. Accessed on October 2, 2022 online at: <https://aspe.hhs.gov/reports/improving-collection-use-racial-ethnic-data-hhs>

⁷⁸ Harding A, Harper B, Stone D, et al. Conducting research with Tribal communities: sovereignty, ethics, and data-sharing issues. *Environ Health Perspect.* 2012;120(1):6-10. doi:10.1289/ehp.1103904

⁷⁹ Pacheco, C. M., Daley, S. M., Brown, T., Filippi, M., Greiner, K. A., & Daley, C. M. (2013). Moving forward: breaking the cycle of mistrust between American Indians and researchers. *American journal of public health, 103*(12), 2152–2159. <https://doi.org/10.2105/AJPH.2013.301480>

⁸⁰ National Congress of American Indians. (2021). *Introduction to Research*. Accessed on October September 20, 2022 online at: <https://www.ncai.org/policy-research-center/research-data/introduction-to-research>

how they may adapt data collection, interviews and case review methods for AI/AN populations and communities with cultural sensitivity.⁸¹

Sudden Infant Death Syndrome (SIDS) and Sudden Unexpected Infant Death (SUID) consistently and disproportionately affect AI/AN infants.^{82 83 84} The magnitude of these disparities is suspected to be larger, given known flaws misclassifying and/or undercounting AI/AN identity.^{85 86} For example, when AI/AN race was re-coded to include any AI/AN identity from single, multiracial, or “other” category, the number of identified AI/AN SUID cases increased by 30%,⁸⁷ demonstrating the need for consistent data collection methods. Current theories for SIDS/SUIDS point to synergistic interactions among social, cultural, economic, environmental and biological factors across the infant life span.^{88 89} Successful SIDS/SUIDS prevention and risk reduction programs within AI/AN communities should be built upon community cultural strengths and values such as: traditional infant sleep practices (e.g. cradleboard use), emphasizing political and cultural sovereignty, self-determination, spirituality, cultural connectedness, cultural resiliency, connection to land and place, and strengthening social connections.^{90 91}

Additionally, qualitative research has been recognized as a crucial data collection method to gain insight on phenomena that evade quantitative measurement and meaning, especially among AI/AN women.⁹² Among AI/AN women, qualitative methods have shed light on

⁸¹ National Indian Health Board. (2020). *Maternal Mortality Review: A Potential Strategy for Optimizing Native Women’s Health. Fact Sheet, 2020*. Accessed on October 6, 2022 online at:

<https://www.nihb.org/docs/11232020/Tribal%20MMRC%20Fact%20Sheet%205.21.20.pdf>

⁸² Womack, L. S., Rossen, L. M., & Hirai, A. H. (2020). Urban-Rural Infant Mortality Disparities by Race and Ethnicity and Cause of Death. *American journal of preventive medicine*, 58(2), 254–260. <https://doi.org/10.1016/j.amepre.2019.09.010>

⁸³ Parks, S. E., Erck Lambert, A. B., & Shapiro-Mendoza, C. K. (2017). Racial and Ethnic Trends in Sudden Unexpected Infant Deaths: United States, 1995–2013. *Pediatrics*, 139(6), e20163844. <https://doi.org/10.1542/peds.2016-3844>

⁸⁴ Bartick, M., Barr, A. W., Feldman-Winter, L., Guxens, M., & Tiemeier, H. (2022). The Role of Breastfeeding in Racial and Ethnic Disparities in Sudden Unexpected Infant Death: A Population-Based Study of 13 Million Infants in the United States. *American journal of epidemiology*, 191(7), 1190–1201. <https://doi.org/10.1093/aje/kwac050>

⁸⁵ Boehmer, U., Kressin, N. R., Berlowitz, D. R., Christiansen, C. L., Kazis, L. E., & Jones, J. A. (2002). Self-reported vs administrative race/ethnicity data and study results. *American journal of public health*, 92(9), 1471–1472. <https://doi.org/10.2105/ajph.92.9.1471>

⁸⁶ Dankovchik, J., Hoopes, M. J., Warren-Mears, V., & Knaster, E. (2015). Disparities in life expectancy of pacific northwest American Indians and Alaska natives: analysis of linkage-corrected life tables. *Public health reports (Washington, D.C. : 1974)*, 130(1), 71–80. <https://doi.org/10.1177/003335491513000109>

⁸⁷ Collier, A. (2022). *Unexpected Deaths: Alaska Native and American Indian. Advisory Committee on Infant and Maternal Mortality June 2022 Meeting*. Virtual. <https://www.youtube.com/watch?v=cRBikdSFhEE>

⁸⁸ Bartick, M., & Tomori, C. (2019). Sudden infant death and social justice: A syndemics approach. *Maternal & child nutrition*, 15(1), e12652. <https://doi.org/10.1111/mcn.12652>

⁸⁹ Filiano, J. J., & Kinney, H. C. (1994). A perspective on neuropathologic findings in victims of the sudden infant death syndrome: the triple-risk model. *Biology of the neonate*, 65(3-4), 194–197. <https://doi.org/10.1159/000244052>

⁹⁰ Healthy Native Babies Project (2021). *Literature Review Summary*. Accessed online October 3, 2022 online at: https://safetosleep.nichd.nih.gov/sites/default/files/inline-files/HNBP_Lit_Rev_Summ_4.16.21_508.pdf

⁹¹ California Department of Public Health, Maternal, Child and Adolescent Health Division. (2018). *California American Indian/Alaska Native Maternal and Infant Health Status Report*. Accessed on December 5, 2022 online at: <https://www.cdph.ca.gov/Programs/CFH/DMCAH/MIHA/CDPH%20Document%20Library/AIAN-MIH-Status-Report-2019.pdf>

⁹² Strickland C. J. (1999). The importance of qualitative research in addressing cultural relevance: experiences from research with Pacific Northwest Indian women. *Health care for women international*, 20(5), 517–525. <https://doi.org/10.1080/073993399245601>

pregnancy,^{93,94} parenting,^{95,96} substance use,⁹⁷ diabetes during pregnancy,⁹⁸ and reproduction coercion.⁹⁹ Qualitative research, including storytelling, can serve both as a means of data collection but also as a method for intervention.¹⁰⁰ To better understand AI/AN women's experiences during the perinatal time period, qualitative methods must be used for data collection and continued investigation in the use of "story" as intervention is needed.

ACIMM Recommends to HHS the following Strategies and Actions toward making the health and safety of AI/AN mothers and infants a national priority:

A. ENGAGE AND CENTER AI/AN COMMUNITIES AS ACTIVE, EMPOWERED LEADERS AND DECISION MAKERS IN WORKING TOWARDS SOLUTIONS.

1. Adopt, embrace, and employ the concept of AI/AN Data Sovereignty, as defined by the National Congress of American Indians (2018).
 - a. Assure meaningful AI/AN leadership and decision making on how to collect, analyze, use, disseminate data and be funded for studies and programs related to the health and safety of all AI/AN people.
 - b. Establish an Urban Indian Organization Confer Policy across all HHS agencies to ensure that urban AI/AN maternal and infant needs are accounted for.
 - c. Ensure that funding opportunities for studies and programs relating to AI/AN maternal and infant health employ more inclusive language such as, "*Tribes, Tribal organizations and urban Indian organizations*" in HHS communications and directives.

⁹³ Palacios, J., & Kennedy, H. P. (2010). Reflections of Native American teen mothers. *Journal of obstetric, gynecologic, and neonatal nursing : JOGNN*, 39(4), 425–434. <https://doi.org/10.1111/j.1552-6909.2010.01149.x>

⁹⁴ Hanson J. D. (2012). Understanding prenatal health care for American Indian women in a Northern Plains tribe. *Journal of transcultural nursing : official journal of the Transcultural Nursing Society*, 23(1), 29–37. <https://doi.org/10.1177/1043659611423826>

⁹⁵ Palacios, J. F., Strickland, C. J., Chesla, C. A., Kennedy, H. P., & Portillo, C. J. (2014). Weaving dreamcatchers: mothering among American Indian women who were teen mothers. *Journal of advanced nursing*, 70(1), 153–163. <https://doi.org/10.1111/jan.12180>

⁹⁶ Palacios, J., Chesla, C., Kennedy, H., & Strickland, J. (2012). Embodied meanings of early childbearing among American Indian women: a turning point. *Journal of midwifery & women's health*, 57(5), 502–508. <https://doi.org/10.1111/j.1542-2011.2012.00165.x>

⁹⁷ McCarron, H., Griese, E. R., Dippel, E., & McMahon, T. R. (2018). Cultural and Social Predictors of Substance Abuse Recovery among American Indian and Non-American Indian Pregnant and Parenting Women. *Journal of psychoactive drugs*, 50(4), 322–330. <https://doi.org/10.1080/02791072.2018.1481546>

⁹⁸ Carson, L. D., Henderson, J. N., King, K., Kleszynski, K., Thompson, D. M., & Mayer, P. (2015). American Indian Diabetes Beliefs and Practices: Anxiety, Fear, and Dread in Pregnant Women With Diabetes. *Diabetes spectrum : a publication of the American Diabetes Association*, 28(4), 258–263. <https://doi.org/10.2337/diaspect.28.4.258>

⁹⁹ Giacci, E., Straits, K. J. E., Gelman, A., Miller-Walfish, S., Iwuanyanwu, R., & Miller, E. (2022). Intimate Partner and Sexual Violence, Reproductive Coercion, and Reproductive Health Among American Indian and Alaska Native Women: A Narrative Interview Study. *Journal of women's health* (2002), 31(1), 13–22. <https://doi.org/10.1089/jwh.2021.0056>

¹⁰⁰ Palacios, J. F., Salem, B., Hodge, F. S., Albarrán, C. R., Anaebere, A., & Hayes-Bautista, T. M. (2015). Storytelling: A Qualitative Tool to Promote Health Among Vulnerable Populations. *Journal of transcultural nursing : official journal of the Transcultural Nursing Society*, 26(4), 346–353. <https://doi.org/10.1177/1043659614524253>

- d. Include consultation and partnership with AI/AN Elders and others with relevant lived experiences to gain historical context and perspective on factors related to high rates of AI/AN infant mortality and poor maternal health, and identify solutions that draw upon intergenerational and collective strengths of the culture and community to improve, support, and sustain optimal AI/AN maternal and infant health and safety.
- 2. Establish, augment, and support AI/AN-specific mortality and morbidity prevention and review activities through Tribal, local, state, regional, and/or national Maternal Mortality Review Committees (MMRC), Fetal and Infant Mortality Reviews (FIMRs), and Child Death Reviews (CDR); and provide adequate funding to support and sustain long-term capacity for including AI/AN perspectives on mortality and morbidity review committees. Where standalone Tribal fatality review processes are not feasible, ensure inclusion of AI/AN perspectives on existing mortality review processes and committees to include:
 - a. Assuring that existing and expanded maternal, infant, and child mortality review boards and committees include specific consideration of AI/AN issues and outcomes, including historical context, contemporary social and environmental issues affecting AI/AN health and safety, and variations in Tribal cultural practices and norms,
 - b. Building capacity for and adequately funding the interview component of FIMR and other prevention review processes, for the inclusion of stories, lived experiences, and family perspectives in sentinel event review,
 - c. Supporting all FIMR, CDR, and MMRCs in states, localities, districts, Tribal communities, and territories in using and transitioning to the National Fatality Review Case Report System (NFR-CRS) and the Maternal Mortality Review Information Application (MMRIA) systems, and
 - d. Supporting efforts of MMRCs, FIMR, and CDR entities to further diversify participation in their prevention review processes, to include AI/AN experience and expertise.
- 3. Assure greater diversity and expertise through expanded AI/AN representation among ACIMM members, to include representation from Tribal communities and Urban Indian Organizations.

B. MOBILIZE FEDERAL, STATE, AND LOCAL AGENCIES AND FUNDING TO END DATA INVISIBILITY AND ERASURE

To accurately identify, count, and include AI/AN women, infants, and families in program and policy development:

4. Federal, state, and local health-related agencies should utilize valid small number statistical approaches, such as those recommended by the 1999 Joint Report referenced earlier, to accurately collect and analyze data relating to the health and safety of AI/AN women and infants. National standards on small number analysis should be developed and education should be provided on how to use and disseminate these statistical methods to improve data surveillance.
5. Establish an interagency working group, which includes a focus on women and infants, to share expertise and develop and improve systems and methodologies that federal government agencies could replicate for the collection of accurate and disaggregated data on American Indians, Alaska Natives, Native Hawaiians, other Pacific Islanders, and other small and hard to count racial populations.
6. Work directly with Tribes and UIOs to address racial misclassification in data collection and analysis including women and infants.
 - a. ACIMM and other stakeholders should collaborate with UIOs to gather critical and accurate information on urban AI/AN populations.
 - b. The National Vital Statistics System (NVSS) should address the statistical and policy implications of choices about using single vs. multiple race identification and provide ready access to multiple race identified data.
7. Create reporting standards that account for self-identified race/ethnicity on birth certificates and death certificates (e.g., family members are asked) across all states, districts, and territories, and add additional data points allowing Tribal identities to be named.
8. Implement national state-wide training on birth certificate and death certificate data collection and review systems of check and balances to correctly identify race and ethnicity.
9. Produce timely and comprehensive regional reports, using quantitative and qualitative data, on the health and safety of AI/AN mothers and infants, through a Life Course framework, to include intergenerational, social, and environmental threats and protective factors.
10. Strengthen the capacity of Tribal Epidemiology Centers (TEC) to serve AI/AN populations for better maternal and infant health outcomes through robust surveillance and community-driven research.
 - a. Reinstate, provide, and sustain funding to Tribal Epidemiological Centers and other AI/AN serving organizations with data and surveillance, assessment, and evaluation responsibilities.

- b. Clarify and assure that TECs and other AI/AN serving organizations have access to timely and comprehensive maternal and child health data, as required by federal law.¹⁰¹

C. PRIORITIZE SHORT-TERM OPPORTUNITIES FOR ACTION WITHIN HRSA AND MCHB

11. Strengthen accountability for how Title V (of the Social Security Act) resources are employed within, by and for Tribal communities, and impacting health outcomes of AI/AN mothers and infants, by requiring inclusion of AI/AN specific information (as available) in Title V-related (e.g., MCH Block Grant) guidance, applications and annual reports.
12. Foster and maintain relationship between States and Tribal communities by:
 - a. Increasing Title V funding specifically designated for Tribal communities, urban and rural, to promote equitable partnerships between states and the Tribal communities and populations within their jurisdictions,
 - b. Expanding the Tribal home visiting program, as a culturally appropriate and validated method for providing perinatal education and healthcare,
 - c. Leveraging the Title V National Resource Center to prioritize and support State-Tribal partnerships to improve the health of AI/AN mothers and infants, and
 - d. Developing and strengthening working relationships between Title V and States' Offices of Indian Affairs.
13. Increase the number of Tribal entities that receive Federal Healthy Start funding.
 - a. Engage Tribal entities and UIOs in providing feedback on the design, implementation, and evaluation of Healthy Start programs.
 - b. Ensure that data requirements and eligibility for Healthy Start funding allow Tribal entities to meet the required program qualifications.
 - c. Provide support for community-driven solutions that allow for Tribal cultural practices as part of the Healthy Start program.
14. Decrease the disproportionate burden of Sudden Infant Death Syndrome and Sudden Unexpected Infant Deaths (SIDS/SUID) in AI/AN families by:
 - a. Supporting measures that require SIDS/SUID case registries and databases in all states, territories, and localities, with inclusion of AI/AN cases and information,

¹⁰¹ United States Government Accountability Office. (2022). *Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access*. GAO-22-104698 Accessed October 5, 2022 online at: <https://www.gao.gov/products/gao-22-104698>

- b. Incorporating AI/AN and/or Tribal involvement and leadership in consultations on how to collect, analyze, use, and disseminate data related to SIDS/SUID among AI/AN people, and
- c. Providing support for community-driven solutions that focus on social, environmental, and economic conditions, in addition to individual actions, that impact SIDS/SUID by:
 - (1) Recognizing and valuing AI/AN knowledge and cultural practices as interventions, and supporting and funding linguistically and/or culturally tailored methods aimed at improving safe infant sleep practices (e.g., providing cribs, portable safe sleeping spaces, cradle board making, and commercial tobacco cessation),
 - (2) Reinstating and adequately funding the proven *Healthy Native Babies Project*, and
 - (3) Reauthorizing the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program at a higher funding amount, to support doubling the Tribal set-aside from 3% to at least 6%.

II. IMPROVE THE LIVING CONDITIONS OF AI/AN MOTHERS AND INFANTS AND ASSURE UNIVERSAL ACCESS TO HIGH QUALITY HEALTHCARE

Like every other population group, a healthy social and physical environment and high-quality care are essential to good birth outcomes. However, social, economic, geographic, and environmental conditions, along with policy/political choices have negatively affected the living conditions of AI/AN populations and inhibited them from accessing essential high-quality healthcare.¹⁰² Life course theory should frame how policy, program, and funding decisions are used in improving the social, economic, and environmental conditions of AI/AN mothers and infants and assure universal access for all residents of the United States to high quality healthcare across the lifespan.¹⁰³

Context for improving living conditions and assuring access to healthcare through the Indian Health Service, Workforce Development, and addressing Social Determinants of Health

¹⁰² California Department of Public Health, Maternal, Child and Adolescent Health Division. (2018). *California American Indian/Alaska Native Maternal and Infant Health Status Report*. Accessed on December 5, 2022 online at: <https://www.cdph.ca.gov/Programs/CFH/DMCAH/MIHA/CDPH%20Document%20Library/AIAN-MIH-Status-Report-2019.pdf>

¹⁰³ Misra, D. P., Guyer, B., & Allston, A. (2003). Integrated perinatal health framework. A multiple determinants model with a life span approach. *American journal of preventive medicine*, 25(1), 65–75. [https://doi.org/10.1016/s0749-3797\(03\)00090-4](https://doi.org/10.1016/s0749-3797(03)00090-4)

As a trust responsibility established by the U.S. Constitution, treaties, numerous Public Laws, and Presidential Executive Orders, the federal government is obligated to provide healthcare to AI/AN people through Indian Health Service facilities, Tribally controlled facilities and Urban Indian Organizations, otherwise referred to as the I/T/U system.¹⁰⁴ An alternative approach is through Indian Health Service contracting directly with outside private medical providers in the private sector (Purchased/Referred Care).¹⁰⁵

“When we talk about Indian Health Services, I couldn't even name some of those positions at IHS at an individual level because we just don't have conversations with them. Our conversations and our relationships have been with Jackie Dionne (MDH). We have quarterly Tribal health directors meetings where we come together. Having that quarterly meeting with all the Tribal health directors from all the at the table and have Jackie moderate that is huge. During COVID, they were our support. I know IHS was out there somewhere, but our relationship and our acquisition of all the immunizations and all of that, all our support came from the State.

Stacy Hammer (Bdewakantunwan Dakota)
Director of Community Health, Lower Sioux Health Care Center

The Indian Health Service is the only federal healthcare provider funded solely via the annual congressional appropriation process, leaving the I/T/U system chronically underfunded, and susceptible to federal budget sequestration and government shutdowns. This creates challenges for I/T/U providers in planning and budgeting for long-term services, recruiting and retaining medical personnel, and maintaining and constructing health care facilities.¹⁰⁶ A review by the Tribal Budget Formulation Workgroup (TBFWG), identified extensive disparities in per capita spending between IHS and other federal health care programs.

“...what's happening in New Mexico in regard to hospitals closing, Santa Fe Indian Hospital closed their OB unit in 2008, San Juan Medical Regional Centers closing. Their midwives are having to go elsewhere to provide care. The Phoenix Indian Medical Center has closed their obstetrical units. Las Vegas, New Mexico does not provide OB care. Los Alamos does not provide OB care. Native women are now required to navigate a very complex health care system because their IHS services are not providing care to them anymore or they're having to transfer at some point during their prenatal care visits. A lot of the women that I see, have not received care up to 20 weeks into their pregnancy because; A, they can't access a care provider; B, they have to travel more than 30 miles to get access to care; or they have to wait more than six weeks to get in with a health care provider to get care for their pregnancy. And so when we see the statistics around obesity, diabetes, hypertension, postpartum, hemorrhage, native women not accessing care in the first trimester increase maternal mortality rates because of car accidents just trying to get an appointment, it's because these hospitals are closing or labor and delivery unit causing women to have to travel further, but also, IHS is not fulfilling their treaty obligations to the Tribes around maternal health care and women's health care in general.”

Nicolle Gonzalez (Dine’)
Nurse Midwife, Navajo Nation

¹⁰⁴ Rural Health Information Hub. (2022). *Rural Tribal Health*. Accessed on October 8, 2022 online at: <https://www.ruralhealthinfo.org/topics/rural-Tribal-health>

¹⁰⁵ United States Commission on Civil Rights. (2018). *Broken Promises: Continuing Federal Funding Shortfall For Native Americans*. (Report No. GA00-21-97) Accessed October 2, 2022 online at: <https://www.usccr.gov/files/pubs/2018/12-20-Broken-Promises.pdf>

¹⁰⁶ Ibid.

In fiscal year 2017, IHS per capita spending was \$4,078, compared with \$8,109 for Medicaid, \$10,692 for the Veterans Health Administration, \$13,185 for Medicare,¹⁰⁷ and \$8,600 for federal prisoners.¹⁰⁸ In 2011, an

IHS Facilities Report demonstrated that federally operated IHS facilities were an average age of 31 years, while fourteen of the 35 IHS hospitals and 22 of the 61 IHS health

centers were older than 40 years.¹⁰⁹ Not much has changed in the subsequent 11 years.

"We have to recognize that IHS is not a failed system. It's a starved system. It's never been adequately resourced. We don't know how good IHS could be if it was actually funded."

Donald Warne, MD (Oglala Dakota)

Co-Director, Center for Indigenous Health, Johns Hopkins University

Linked to the funding crisis is a provision of care crisis largely attributed to recruiting and retaining health care personnel.¹¹⁰ Since 2016, the General Accounting Office (GAO) has documented the healthcare personnel shortage within IHS, linking this to the largest obstacle for AI/AN people accessing timely primary care (e.g., sometimes waiting 2 to 6 months for an appointment). The GAO reported that nearly one-quarter of all IHS staffing positions are vacant, and in some facilities the vacancy rate has reached 50%, ultimately leading many IHS facilities to rely upon temporary personnel, acting personnel, and contracted providers through the Purchased/Referred Care program,¹¹¹ which in turn increases IHS health care costs.

Despite initiating steps to recruit and retain providers, IHS cannot match local market salaries, nor is there enough housing to meet its demand for IHS healthcare providers.¹¹² IHS funding largely serves rural populations, which reside in maternity care deserts, burdened with deficient perinatal access. Allocating annual funding to expand the maternal/infant workforce is essential in meeting the needs of AI/AN people.

¹⁰⁷ United States Government Accountability Office. (2018). *Indian Health Service: Spending Levels and Characteristics of IHS and Three Other Federal Health Care Programs*. GAO-19-74R. Accessed October 1, 2022 online at: <https://www.gao.gov/products/gao-19-74r>

¹⁰⁸ United States Government Accountability Office. (2017). *Bureau of Prisons: Better Planning and Evaluation Needed to Understand and Control Rising Inmate Health Care Costs*. GAO-17-379. Accessed October 1, 2022 online at: <https://www.gao.gov/products/gao-17-379>

¹⁰⁹ United States Government Accountability Office. (2016). *Indian Health Service: Actions Needed to Improve Oversight of Patient Wait Times*. GAO-16-333. Accessed on October 3, 2022 online at: <https://www.gao.gov/assets/gao-16-333.pdf>

¹¹⁰ United States Government Accountability Office. (2005). *Indian Health Service: Health Care Services Are Not Always Available to Native Americans*. GAO-05-789. Accessed on October 3, 2022 online at: <https://www.gao.gov/assets/gao-05-789.pdf>

¹¹¹ United States Government Accountability Office. (2005). *Indian Health Service: Health Care Services Are Not Always Available to Native Americans*. GAO-05-789. Accessed on October 3, 2022 online at: <https://www.gao.gov/assets/gao-05-789.pdf>

¹¹² United States Government Accountability Office. (2018). *Indian Health Service: Agency Faces Ongoing Challenges Filling Provider Vacancies*. GAO-18-580. Accessed on October 3, 2022 online at: <https://www.gao.gov/assets/gao-18-580.pdf>

In addition to inadequacies in funding, physical infrastructure, and staffing, a GAO report¹¹³ found that IHS oversight of federally operated health care facilities' decision-making process about the use of funds has been limited and inconsistent. The recommendation was given to IHS to have the director of IHS develop a process for evaluating how area IHS offices will meet the needs of Native people and have the director of IHS develop a process where area offices review spending proposals.

"IHS isn't our answer. We're sicker now than we ever have been. IHS has never saved us, and to act like we didn't have health service pre-IHS is disrespectful to our ancestors who carry traditional medicines."

Marisa Miakonda Cummings (Umonhon/Omaha)
President and CEO, Minnesota Indian Women's
Resource Center

Related to this (and specific to maternal and infant health) is an ongoing 50-year contract between the IHS and the American College of Obstetrics and Gynecology (ACOG) for the purpose of improving maternity care and birth outcomes among those served by IHS. A recent publication of this 50 year contract relationship illustrated that over this time frame basic standards of care were recommended and instituted, work force development included a novel OBGYN fellowship where fellows volunteer their time at a IHS facility, and more recently a collaboration to promote the use of the Alliance for Innovation on Maternal Health safety bundles, and a 2019 white paper recommending universal drug screening among all childbearing AI/AN aged women with accompanying treatment measures.¹¹⁴ Despite this publication and the 2019 white paper¹¹⁵ on substance use disorder among AI/AN women, ACIMM has not been able to find a report on this contract, nor has ACIMM, despite multiple attempts, obtained clear and comprehensive insight from IHS leadership on how this contract relationship has improved AI/AN perinatal outcomes.

For centuries, AI/AN people were systematically targeted by policies and practices favoring a Western-European dominant worldview that disenfranchised this population based on perceived biological race (racism) and the "Doctrine of Discovery"¹¹⁶ (place), which led to loss of land and sequestration on remote, isolated, rural Indian reservations. The nexus of race and place contribute to the cumulative and compounding effects of systemic racism and isolation for this population, as today AI/AN people residing on reservations and in urban areas still have poor access to housing, electricity, clean water, broadband internet, paved highways, food, and healthcare. These social, political, economic, and environmental determinants of health are severely impacted by chronic underfunding of the IHS, difficulties recruiting and retaining

¹¹³ United States Government Accountability Office. (2020). *Indian Health Service: Actions Needed to Improve Oversight of Federal Facilities' Decision-Making About the Use of Funds*. GAO-21-20 Accessed on October 3, 2022 online at: https://www.gao.gov/products/gao-21-20#summary_recommend

¹¹⁴ Waxman, A. G., Haffner, W. H. J., Howe, J., Wilder, K., Ogburn, T., Murphy, N., Espey, E., Tucker, J. M., Bruegl, A., Locke, E., & Malloy, Y. (2020). A 50-Year Commitment to American Indian and Alaska Native Women. *Obstetrics and gynecology*, 136(4), 739–744. <https://doi.org/10.1097/AOG.0000000000004040>

¹¹⁵ American College of Obstetricians and Gynecologists. Recommendations to the Indian Health Service on American Indian Alaska Native pregnant women and women of childbearing age with opioid use disorder. Washington, DC: ACOG; 2019.

¹¹⁶ Wikipedia. (2022, October 2). *Doctrine of Discovery*. Accessed October 18, 2022 online at: https://en.wikipedia.org/wiki/Discovery_doctrine

healthcare personnel, maintaining an aging IHS facility infrastructure, and inadequacies in administrative oversight within IHS.

Testimony by AI/AN leaders repeatedly underscored persisting inadequacies of the IHS and its failure to meet the needs of the populations it is charged to serve. Frustration created by the lack of meaningful improvement in access and quality of IHS services over the last 50 years has led to a belief among those

“So, what has changed (in the IHS) in the past 45 years? Not much.”

Rhonda Clairmont Swaney, JD (Salish & Kootenai), Past Tribal Council Chair for Confederated Salish & Kootenai Tribes

testifying that transformative change will never happen. There was consensus among testifiers that strong, bold actions must be taken now for significant improvements in IHS systems and services, and/or dismantle IHS in its current form and create a better system.

ACIMM recommends the following Strategies and Actions for improving living conditions and assuring access to healthcare through the Indian Health Service, Workforce Development, and addressing Social Determinants of Health:

A. EVALUATE, SUFFICIENTLY FUND, AND IMPROVE THE INDIAN HEALTH SERVICE (IHS)

15. Provide adequate and mandated funding to the Indian Health Service to ensure a standard of care that is of high quality, consistent, and assures that AI/AN mothers experience healthy perinatal outcomes.
 - a. Support annual IHS perinatal outcomes evaluation associated with increased funding.
 - b. Initiate a comprehensive assessment of the quality of care delivered in IHS facilities and use the findings to identify and implement strategies to mitigate IHS’s longstanding challenges.
 - c. Evaluate and compare the maternal and infant outcomes across the I/T/U system of those using IHS facilities to those employing Tribal Compact Health Center or Tribal Contract relationships with IHS, and make the results publicly available.
16. Support actions to improve Tribal communities in designing, implementing, and evaluating their care when served by IHS.
 - a. Support Tribal membership and leadership when IHS develops, implements, and evaluates services.
 - b. IHS should consult and confer with Tribes and UIOs about policy changes and program implementation and provide timely communication with I/T/U facilities when changes in policies and programs are implemented.
 - c. Support measures promoting respect for cultural and spiritual practices of AI/AN people within IHS facilities.

17. Evaluate the IHS and American College of Obstetricians and Gynecology maternal and infant health contract and publicly report the findings.

B. EXPAND AND DIVERSIFY THE WORKFORCE

18. Require all federal grant applications for healthcare professions, i.e., medical, midwifery education programs, etc., to include accountability metrics in the applications to monitor efforts to improve the number of Black, Hispanic, and AI/AN students in the workforce that reflects the diversity of the population being served.
19. Develop and implement an external evaluation report on the “life-span” training (e.g., recruitment thru initial employment) for Black, Hispanic, and AI/AN students in the medical, midwifery and health fields that support maternal/child health to develop and/or identify best practice guidelines for training institutions.
20. Invest in “pathway” programs that identify and nurture future health care professionals from elementary through high school, promoting graduation from high school and success in college.
21. Require land grant universities to have AI/AN-focused health science workforce development programs.
22. Encourage partnerships between land grant institutions and Tribal Colleges.
23. Encourage all states, territories, and districts to allow Certified Professional Midwives (CPM) and Certified Midwives (CM) who graduate from accredited midwifery education programs to be licensed and provide care in their jurisdictions.
24. Indian Health Service should recognize Certified Midwives and Certified Professional Midwives with accredited education as providers.
25. The National Health Service Corp should recognize Certified Midwives and Certified Professional Midwives with accredited education for loan repayment.
26. Invest in training of AI/AN doulas and traditional birth workers.
27. Support workforce trainings that include a historical basis for health disparities within our nation.

“Doulas carry ancestral knowledge and are an integral part of strengthening traditional birthing practices as studies have shown evidence-based improvements with decreased rates of cesareans and instrumented deliveries, like vacuums or forceps and increased breastfeeding rates. They can often identify signs of postpartum depression and anxiety which will help a mother in need of services even before their routine six-week follow-up.”
 Socia Love-Thurman, MD
 (Cherokee/Yuchi/Delaware)
 Chief Health Officer, Seattle Indian Health Board

C. STRENGTHEN APPROACHES TO ADAPT AND AUGMENT SOCIAL DETERMINANTS OF HEALTH

28. Assess and address root causes and consequences of systemic racism across the life-course on social determinants of health by supporting Tribal community-driven assessment, planning, and evaluation.
29. Expand cross agency relationships with the Department of Housing and Urban Development (HUD) to assess, prioritize, and address housing insecurity amongst families and birthing individuals in the pre-natal and post-partum periods, through at least the first year of life.
30. Assure the availability of transportation services for AI/AN women living on reservations and in urban and sub-urban areas to ensure that AI/AN mothers have access to essential healthcare and birthing centers during scheduled appointments and during the birthing process.
31. Dedicate funding to support telemedicine services for maternal health and mental health appointments for AI/AN individuals.
32. Research and consider the maternal health benefits and fiscal impacts of paid maternity leave models for mothers, fathers, and same-sex couples in order to promote the health of AI/AN parents and infants.
33. In consultation with Tribes and UIOs, review Medicaid access eligibility criteria and develop best practices to expand Medicaid eligibility to include the provision of culturally safe care for more AI/AN mothers. For example, despite the urgent need for AI/AN doulas and the growing number of AI/AN doula training programs, state doula accreditation standards restrict Medicaid coverage to doulas who have attained nationally accredited training. National doula accrediting organizations are cost-prohibitive and do not adequately address the cultural and social determinants of AI/AN maternal health.

“Investing in our communities can't be overstated. We want to live on our traditional lands because -- not because it's the best land. It's often times some of the worst land, but that's where our communities are. That's where we're doing our stuff. That's where families gather. Support those areas and give us some economy, some ways to do that.”

Patrice H. Kunesh (Standing Rock Lakota)
Director, Peñín Haha Consulting, Major Gifts Officer, Native American Rights Fund

“We really need to develop, a Tribal determinants of health wheel that respects the medicine wheel and respects the fact that when the “social determinants of health” were developed, they were never intended for our people. Our people were not involved in creating them. Our voices are nowhere. There are several portions of the social determinants of health that apply to us, but when you're American Indian/Alaskan Native, health is defined by the full health of your mind, body, and your spirit. That lends itself to the cultural integrity of traditional values, traditional healing, and ways of knowing that are necessary for our people to achieve full health. And the social determinants of health simply do not address or capture that.”

Stacy Bohlen (Sault Ste. Marie Chippewa Tribe)
CEO, National Indian Health Board

N.B. Medicaid: Another major source of funding for the provision of healthcare is Medicaid. It is a resource that is not being optimally used to maximize its benefits to AI/AN populations. It is also not being used uniformly across the country to the maximum benefit of AI/AN. Even though there are provisions in federal law related to Medicaid that would benefit Tribes, states often interfere with receipt of those benefits. While ACIMM did not have the resources to adequately address the issues related to Medicaid and AI/AN, it recognizes that shaping strategic opportunities to better utilize Medicaid should receive future attention.

“The Federal Medical Assistance Percentages is 100 percent (coverage for AI/AN). So, we have 100 percent federal dollars for AI patients. And then you have a state legislature standing in the way saying no, you can't have access to those federal dollars. That's the circumstance that we're dealing with right now in places like South Dakota where I am from. That is unacceptable. Part of advocacy is get the state legislatures out of the way of access of American dollars for American Indians.
Donald Warne, MD (Oglala Dakota)
Co-Director, Center for Indigenous Health,
Johns Hopkins University

III. ADDRESS URGENT AND IMMEDIATE CHALLENGES THAT DISPROPORTIONATELY AFFECT AI/AN WOMEN BEFORE, DURING, AND AFTER PREGNANCY.

Context for addressing issues of particular concern to AI/AN women and infants

Life course research has consistently demonstrated exposures to social, environmental, political and cultural factors impact human development and health. It has also shown that among AI/AN communities, a strengths-based culturally resilient approach across the life course, is key to making meaningful and lasting changes.¹¹⁷

Because of racism and the devaluing of AI/AN women, this population is both disproportionately affected by and targeted for abduction, violence, sexual exploitation,¹¹⁸ and incarceration.¹¹⁹ The lack of effective data collection and surveillance systems around incarceration, Missing and Murdered Indigenous Women and Girls (MMIWG), and violence hides the magnitude and significance of these problems and hinders the development of appropriate programs and

Violence against Indian women is rooted in colonization. Indian women are murdered at a rate ten times higher than the national average. Homicide is the third leading cause of death for native women. 75 percent of Indian women murdered were killed by an intimate partner, and as Indian women, we live our lives in the dangerous intersection of gender and race.
Gwendolyn Packard (Ihanktonwan Dakota)
Senior Housing Specialist, National
Indigenous Women's Resource Center

¹¹⁷ Oré, C. E., Teufel-Shone, N. I., & Chico-Jarillo, T. M. (2016). American Indian and Alaska Native resilience along the life course and across generations: A literature review. *American Indian and Alaska native mental health research (Online)*, 23(3), 134–157. <https://doi.org/10.5820/aian.2303.2016.134>

¹¹⁸ Echo-Hawk, A. (2022). *Our Bodies, Our Stories: Sexual Violence Among Native Women*. MMIW Resource Guide. Accessed October 18, 2022, <https://mmiwresources.org/items/show/51>

¹¹⁹ Wang, L. (2021). *The U.S. criminal justice system disproportionately hurts Native people: the data, visualized*. Prison Policy accessed October 18, 2022 at: <https://www.prisonpolicy.org/blog/2021/10/08/indigenouspeoplesday/>

policies to address these issues. Yet what is known manifests a major public health concern for AI/AN women, mothers, and infants.

The National Crime Information Center reports that in 2016, there were 5,712 reports of missing AI/AN women and girls, though the US Department of Justice's federal missing person database, only logged 116 cases. This discrepancy is due to multiple factors; at the forefront is that 78% of AI/AN people live off reservations, with 60% of those residing in an urban area. When someone who lives on Tribal land goes missing, the community, and Tribal law enforcement band together in search efforts. Urban areas generally offer few ties to AI/AN cultures, communities, and Tribal law enforcement, so MMIWG cases are given a lower priority.¹²⁰

The number of women incarcerated in the United States has increased nearly 700 percent since 1980.¹²¹ In 2019, it was estimated that approximately 231,000 women and girls were incarcerated in the US.¹²² That equates to 133 women in correctional facilities per every 100,000 female citizens. With 4% of the world's female population, the United States is responsible for 33% of the entire world's incarcerated female population. Over 60 percent of the women in state and federal prisons are mothers of minor children¹²³ and most others are of childbearing age. Incarcerated women are disproportionately Black and/or AI/AN. The legal financial obligations incurred among AI/AN people are larger than those incurred by other races, especially among criminal court systems bordering Indian reservations.¹²⁴ Regional differences also exist. While AI/AN women make up 1% of Minnesota's prison population state wide, they make up 20% of those incarcerated in Minnesota's women's only prison in Shakopee, Minnesota.¹²⁵

American Indian and Alaskan Native girls are a small fraction of the total population, but they are over-represented in the juvenile and adult justice systems, whether they are living on or off the reservation. AI/AN girls have the highest rates of incarceration of any ethnic group. They are nearly five times more likely than white girls to be confined to a juvenile detention facility, according to the U.S. Office of Juvenile Justice and Delinquency Prevention.¹²⁶ The reasons for this high rate of incarceration are numerous, but most are due to a conglomerate of factors

¹²⁰ Native Hope. (2022). *Why is there Wide Spread Silence on the MMIW Issue?*. Accessed on October 13, 2022 at: <https://www.nativehope.org/missing-and-murdered-indigenous-women-mmiw>

¹²¹ Shlafer, R. J., Hardeman, R. R., & Carlson, E. A. (2019). Reproductive justice for incarcerated mothers and advocacy for their infants and young children. *Infant mental health journal*, 40(5), 725–741. <https://doi.org/10.1002/imhj.21810>

¹²² Kajstura, A. (2019). *Women's Mass Incarceration: The Whole Pie 2019*. Prison Policy Initiative. Accessed on December 7, 2022 online at: <https://www.prisonpolicy.org/reports/pie2019women.html>

¹²³ Glaze, L., & Maruchak, L. (2010). *Parents in prison and their minor children*. United States Department of Justice. Accessed on October 1, 2022 at: <https://bjs.ojp.gov/content/pub/pdf/pptmc.pdf>

¹²⁴ Stewart, R., Watters, B., Horowitz, V., Larson, R.P., Sargent, B., & Uggen, C. (2022). Native Americans and Monetary Sanctions. *RSF: The Russell Sage Foundation Journal of the Social Sciences* 8(2), 137-

156. <https://www.muse.jhu.edu/article/846834>

¹²⁵ Gunderson, D. (2022). *Native Women Work to Break the Cycle of Poverty, Prison in Minnesota*. MPR News. North Star Journey. Accessed October 1, 2022 at: <https://www.mprnews.org/story/2022/04/21/native-women-incarcerated>

¹²⁶ Wiltz, T. *American Indian Girls Often Fall Through the Cracks*. PEW. Stateline. Access on October 1, 2022 at: <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2016/03/04/american-indian-girls-often-fall-through-the-cracks>

including: a mixture of jurisdiction policies and targeted profiling (e.g. differences in penalties among Tribal court systems, state, county and federal systems depending upon offense and location of crime and documented higher financial legal fees targeting AI/AN people in court systems bordering Indian reservations),^{127 128} historical trauma, criminalization of Indigenous women's survival strategies, poverty, alcohol and drug use, being victims of sexual abuse and violence, unemployment, lack of education, being in foster care, and domestic violence. These life situations put AI/AN women and girls at high risk for arrest and incarceration,^{129 130 131} and when compounded with universal drug screening among all childbearing aged women, as ACOG recommended to IHS, can further disenfranchise AI/AN childbearing women in states and tribal jurisdictions that criminalize women who test positive,¹³² thereby, continuing the cycle of harm.

Determining the full scale of incarcerated AI/AN women and girls has proven difficult due to overlapping jurisdictions, differences between Tribal jurisdictions and Federal prison systems that make data collection inconsistent and unclear. However, incarceration among this population has profound individual, family and community effects leading to escalating poverty, children separated from mothers, and devastating psychological and economic impact. Parental incarceration has been viewed as an Adverse Childhood Experience (ACE) linked to poor physical, social, emotional, and educational outcomes across the life course.¹³³ This has long term implications given that nearly 3 million U S children have an incarcerated parent.¹³⁴

To understand and effectively address the effects of incarceration, violence, and MMIWG on AI/AN maternal and infant health, approaches must integrate and support intersectionality and life course approaches. This must include data collection, data reporting, interventions, and evaluation across all sectors of DHHS, and collaboration with the Departments of Justice, Education, Housing and Urban Development, Transportation, Labor and others, which influence and fund programs and policies addressing the myriad social determinants of health, which in

¹²⁷ Wang, L. (2021). *The U.S. Criminal Justice System Disproportionately Hurts Native People: The Data, Visualized*. Prison Policy Initiative. Accessed on October 2, 2022 at: <https://www.prisonpolicy.org/blog/2021/10/08/indigenouspeoplesday/>

¹²⁸ Stewart, R., Watters, B., Horowitz, V., Larson, R.P., Sargent, B., & Uggen, C. (2022). Native Americans and Monetary Sanctions. *RSF: The Russell Sage Foundation Journal of the Social Sciences* 8(2), 137-156. <https://www.muse.jhu.edu/article/846834>.

¹²⁹ Wiltz, T. *American Indian Girls Often Fall Through the Cracks*. PEW. Stateline. Access on October 1, 2022 at: <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2016/03/04/american-indian-girls-often-fall-through-the-cracks> <http://www.wccf.org/native-american-girls-face-highest-incarceration-rates/>

¹³⁰ Montana Innocence Project. (2022). *Impacts of the Disproportionate Incarceration of Indigenous Peoples, Why We Should All Care*. Accessed October 3, 2022 online at: <https://mtinnocenceproject.org/impacts-of-the-disproportionate-incarceration-of-indigenous-peoples-why-we-should-all-care/>

¹³¹ Montana Innocence Project. (2022). *Criminalization of Indigenous Women's Survival Contributes to Mass Incarceration*. Accessed October 3, 2022 online at <https://mtinnocenceproject.org/criminalization-of-indigenous-womens-survival-contributes-to-mass-incarceration/>

¹³² American College of Obstetricians and Gynecologists. Recommendations to the Indian Health Service on American Indian/Alaska Native pregnant women and women of childbearing age with opioid use disorder. Washington, DC: ACOG; 2019.

¹³³ Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., Marks, J. S. (2019). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine*, 14(4), 245–258.

¹³⁴ Ghandnoosh, N., Stammen, E., Muhitch, K. (2021). *Parents in Prison*. The Sentencing Project. Accessed on December 8, 2022 at: <https://www.sentencingproject.org/app/uploads/2022/09/Parents-in-Prison.pdf>

turn contribute to high rates of incarceration and violence among AI/AN women. These measures also must include asset-based frameworks, such as cultural resilience, to identify best methods and approaches of individual, family and community level interventions.¹³⁵

ACIMM Recommends the following Strategies and Actions to address Issues of Particular Concern to AI/AN Women and Infants:

A. EXPAND EFFORTS TO IDENTIFY MMIWG AND PREVENT ITS OCCURRENCE

34. Encourage the development and support of regional and state offices on Missing and Murdered AI/AN Women and Girls, while encouraging state-to-state and regional collaboration. This will require an investment of resources in every state to investigate cases of MMIWG and support collaboration between state and Tribal communities.
35. Support interdisciplinary and intradisciplinary collaboration across all DHHS sections and collaboration with the Departments of Justice, Transportation, Housing and Urban Development, Labor, and Justice to identify root causes and risk factors for MMIWG.
36. Develop and require use of standardized data collection protocols and data reporting related to MMIWG.
37. Assure measures (beyond FOIA requests) are available for community access to information on MMIWG.
38. Support measures that facilitate Tribal Nations ability to advocate for their community members living in urban areas when they are missing or killed.
39. Support measures that facilitate the ability of Tribal Nations to track data on missing or killed members of their community.
40. All policies addressing MMIWG (including Savanna's Act) must address the violence AI/AN communities' experience.

B. IMPROVE CARE OF INCARCERATED PREGNANT AND POSTPARTUM WOMEN

41. Provide universal health screening, assessment, and follow up for all incarcerated women, following national prevention screening guidelines.
42. Provide evidence-based interventions which support physical, emotional, mental, and spiritual health given in culturally appropriate manners, to improve the health and pregnancy counseling for all incarcerated women.
43. Support the creation of guidelines and accommodations for pregnant and postpartum incarcerated women that include cultural resiliency.

¹³⁵ Oré, C. E., Teufel-Shone, N. I., & Chico-Jarillo, T. M. (2016). American Indian and Alaska Native resilience along the life course and across generations: A literature review. *American Indian and Alaska native mental health research (Online)*, 23(3), 134–157. <https://doi.org/10.5820/aian.2303.2016.134>

44. Encourage breastfeeding and provide pumping and lactation support services for incarcerated individuals following delivery, for the duration they choose to breastfeed.
45. Evaluate and expand programs for pregnant and parenting incarcerated women (e.g., the Mothers and Infants Together [MINT] Program, Doula Birth-Support Program, the Residential Parenting Program [RPP], and prison nursery programs, as exist in 8 states) to facilitate healthy pregnancy, labor and delivery, and maternal/infant bonding following delivery.¹³⁶
 - a. Assure that these programs offer culturally and linguistically appropriate services for AI/AN women.
 - b. Partner with states so that every state with AI/AN populations has one or more incarceration facilities that provide these programs.

C. EXPAND VIOLENCE SURVEILLANCE AND UNIVERSAL SCREENING

46. Expand surveillance strategies, including Interpersonal Violence (IPV)-related modules, substance use, and mental health questions, as part of participating state Pregnancy Risk Assessment Monitoring System (PRAMS) surveys. IPV-related modules should include the issue of reproductive coercion and/or birth control sabotage.
47. Provide ongoing support and capacity building for Tribal PRAMS programs to include multi-state, AI/AN-specific initiatives (e.g., Navajo PRAMS, South Dakota Tribal PRAMS).
48. Encourage the inclusion of universal screening with referral for intimate partner violence, substance use disorder, depression, and anxiety, in the evaluation of pregnant and postpartum individuals. Safeguards need to be in place to assure that screening results don't initiate a cascade of adverse events, including: further separating mothers and children, placing children in foster care, and deterring AI/AN women from engaging with healthcare precisely because they fear legal and involvement of child protective services.
49. Support measures to incentivize identification and assessment of intimate partner violence at least once during each trimester of prenatal care and up to 1 year postpartum.
50. Improve identification of pregnant/postpartum women in the first year after delivery who go to the emergency department or hospital, who may be at risk for homicide, suicide, and/or drug overdose.
51. Require that state Maternal Mortality Review Committees who use federal funds review all forms of pregnancy-associated and pregnancy-related deaths, including homicide,

¹³⁶ Shlafer, R. J., Gerrity, E., & Duwe, G. (2015). Pregnancy and Parenting Support for Incarcerated Women: Lessons Learned. *Progress in community health partnerships : research, education, and action*, 9(3), 371–378. <https://doi.org/10.1353/cpr.2015.0061>

intimate partner violence, suicide and suicidality, substance use and overdose deaths, during pregnancy and 1 year postpartum.

52. Require all states, districts, territories, and Tribes to include the pregnancy and interpersonal violence fields in CDC's National Violent Death Reporting System (NVDRS) database, and provide CDC technical assistance in this effort.
53. Support studies that identify the impact of generational IPV, trauma, and psychiatric disorders on risk of suicide and suicidal ideation among pregnant and postpartum women in general and, more specifically, among groups of women already at high risk for maternal morbidity and mortality, including AI/AN women, refugees/immigrants, and American Descendants of Slaves (ADOS).
54. Build cultural resilience by funding culturally congruent interventions for pregnant and parenting people facing interpersonal violence, including grief counseling and trauma recovery that serve mothers, partners, and children.

D. IMPROVE TREATMENT OF SUBSTANCE USE & MENTAL HEALTH PROBLEMS

N.B. Substance use and mental health issues are a major concern in AI/AN communities.

Adequately addressing these issues and developing actionable recommendations will require resources and time beyond the capacities of ACIMM. ACIMM offers the following recommendations as a starting point for a dedicated and concentrated focus on these issues that must occur in the near future.

55. Support culturally and language appropriate/specific prevention and treatment programs for mental health and substance use.
56. Expand access to naloxone, with supporting education about its use among first

"The colonization model has made us dependent on a system that is not serving us, hasn't served us, and wasn't created to serve us intentionally. So decolonization from that model, is more about creating systems and health care that reflect the communities that they're serving, which means redistributing funding and access to things that maybe we might not think are part of our health care. We are experiencing high rates of suicide and depression in our maternal communities and not having access to a mental health care provider. But understanding the trauma that native women have experienced and continuing to experience is partially because of having to navigate a complex system, not being able to practice our traditional ways of life; having our families fragmented so our support systems are not there. But as a native woman, wanting to go talk to somebody about my problems, is not traditionally what we did. Rather, we would go to sweat lodge. We'd go to ceremony. We would go see a medicine person. And so when I say decolonizing our way of thinking about what we think mental health care looks like is incorporating those practices and centering them in our care as well as going to people and providing care for them in their home and not putting all of that burden on a family to access care and then reading statistics that make us look bad as native women that we don't care about ourselves, As native women, our bodies are highly-regulated and, decisions around what we can have access to or can't have access to is tied to funding and to government decisions that we can't even be a part of, and that's a problem. ."

Nicolle Gonzalez (Dine')
Nurse Midwife, Navajo Nation

responders, community, and family members.

57. Develop standardized, culturally and language appropriate patient education materials that explain the link between mental health conditions, IPV and SUD with pregnancy-associated deaths.
58. Identify strategies to facilitate access and engagement with maternal mental health services, including promoting trauma informed systems of care while promoting cultural safety.

FINAL RECOMMENDATION:

In 24 months of developing this report, ACIMM heard testimony from representatives of federal, state, local, and Tribal agencies, non-governmental organization, and academic institutions who are working on AI/AN maternal and child health issues. The work culminated in an ACIMM meeting on the Tribal land of the Shakopee Mdewakanton Sioux Community (SMSC) in Minnesota in September 2022. The meeting at the Shakopee Mdewakanton Sioux Community was unprecedented in that it was the first ACIMM meeting ever held outside of Rockville, MD and the first held, by invitation, on Tribal land. ACIMM meeting participants (on site and live streamed) heard the firsthand stories and experiences of Tribal leaders, elders, and members, along with organizations serving urban and Tribal AI/AN from across the country.

The importance of holding an ACIMM meeting on Tribal land dedicated to AI/AN maternal and child health cannot be overstated. It allowed the ACIMM to engage and listen directly to the voices of both urban and rural AI/AN from multiple Tribes in a welcoming and supportive environment. It allowed Tribal advocates for maternal and child health from around the country to come together to collectively highlight the needs of their people. It demonstrated to Tribal leaders and advocates that the federal government, at least in one small way, was willing to do something different to accommodate the AI/AN population.

59. **Based on its experience, ACIMM recommends that priority be given to having federal advisory committee meetings, regardless of the topic, that focus on issues of specific communities be held in those communities to assure greater engagement, understanding, representation, and accountability.**

"I have more hope now than I have in a long time because of the decolonization movement that's going on and the movements like Land Back that we're seeing that we've never seen and the fact that we finally have a show on television, Reservation Dogs, that represents us, that looks like us, right, not these silly stereotypes. So, there are things that are happening that give me hope, for one thing. And also, the fact that Dr. Ehlinger was able to get you all to finally meet on Tribal land. Things like that that are critically important. It's hard to hear about how many people don't know about who we are over and over and over again. So, what can you do today? You can help us. You can help movements like Shakopee, help them spread that information about who we are in our textbooks. You can go to your school districts and ask, "Where is our history about native people in the school?" You know, enough of just having our art on the walls or our art up throughout town to attract the tourists. You can help encourage others to learn more about us all the time.

Mary Owen, MD (Tlingit)

Associate Dean of Native Health, University of Minnesota Medical School

Appendix A

Making Amends: Recommended Strategies and Actions to Improve the Health and Safety of Native American and Alaska Native Mothers and Infants

Non-federal agency presenters to ACIMM in developing the report:

- **Lenice Antel-White**, a former client with Minnesota (MN) Prison Doula Project
- **Annie Belcourt, PhD, (Blackfeet, Chippewa, Mandan & Hidatsa)**, Professor, Community and Public Health Sciences, College of Health, University of Montana
- **Sylvia Bennett-Stone**, Director of Voices of Black Mothers United
- **Scott Berns, MD, MPH**, Chief Executive Officer, National Institute for Children's Health Quality (NICHQ)
- **Stacy Bohlen (Sault Ste. Marie Tribe of Chippewa)**, Chief Executive Officer, National Indian Health Board
- **Diane Bohn, RN, CNM, PhD, FACNM**, School of Nursing, University of Minnesota
- **Kendra King Bowes, (Miami Tribe of Oklahoma)**, managing director, Miami Environmental & Energy Solutions, LLC
- **Joanna Bryant (Shakopee Dakota)**, Tribal Public Health Administrator at Shakopee Mdewakanton Sioux Community (SMSC)
- **Jocelyn Brieschke (Leech Lake Band of Ojibwe)**, Doula
- **Joni Buffalohead, PhD (Bdewákhathunwan Dakota)**, Chair, Minneapolis Indian Health Board
- **Heather Burner, RN, BSN**, Executive Director, National Safe Haven Alliance; Director, Arizona Safe Baby Haven Foundation; Director, NSHAC Crisis Pregnancy Safety & Prevention
- **Stephanie Bustillo, MPH** Epidemiologist II, Tribal Epidemiology Center, Inter Tribal Council of Arizona
- **Jacquelyn Campbell, PhD, MSN, RN, FAAN**, Professor and the Anna D. Wolf Chair at the Johns Hopkins University School of Nursing.
- **Heidi Christensen**, Maternal Health Innovation Program Manager, Arizona Department of Health Services
- **Marisa Miakonda Cummings (Umonhon/Omaha)**, President/CEO Minnesota Indian Women's Resource Center
- **Jackie Dionne (Turtle Mountain Chippewa)**, Director of American Indian Health, Minnesota Department of Health
- **Janelle Palacios, PhD, CNM, RN (Salish-Kootenai)**, Nurse-Midwife, Researcher and Founder Encoded 4 Story
- **Peggy Flanagan (White Earth Nation)**, Lieutenant Governor, State of Minnesota

- **Linda Bane Frizzell, PhD, MS (Eastern Cherokee/Lakota)**, Director American Indian Health and Wellness Studies, University of Minnesota
- **Deborah Frazier**, Chief Executive Officer, National Healthy Start Association
- **Nicolle Gonzales, MSN, CNM (Dine'/Navajo)**, Nurse-Midwife, Founder, Midwife Director, Board Member, Changing Woman Initiative
- **Stephanie Graves, BSN, PHN (Red Lake Ojibwe)**, Board Chair, CityMatCH; Minneapolis Health Department
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Appendix B

Statements and Stories About the Experiences Facing American Indian and Alaska Native Mothers and Infants and Their Communities.

Terminology

“I share with you some terminology concerns ... from the tribal perspective. I've heard talk about serving indigenous populations, but there is a correction that the tribes would like to see, and that is the American Indian and Alaskan Native term. Those are legal terms. They portend a legal status of our people in the United States. These are the correct terms to use when discussing federal policy as it pertains to the sovereign nations and their citizens. This is found in the United States Constitution and because of treaties and our special relationship, again codified in law Supreme Court cases and the constitution, the United States government has a special trust and treaty obligation to the tribes it attaches to the 574 federally recognized tribal nations. Yes, we are indigenous to these lands, but when working on policy and discussing American Indian/Alaskan Native in any kind of a policy-making environment, those are the correct terms to use, because they are the legal terms of art and expressions of our people, and they respect our political status that our people have in this country.”

Stacy Bohlen (Sault Ste. Marie Chippewa Tribe), CEO, National Indian Health Board

Historical Context

“We need to talk about this in a historical context. We know that native people are the top of every disparity that exists in education, health. What we don't often talk about is that the root cause of these disparities is colonialism and white supremacy. This country built its wealth and status as a world superpower through stolen land and stolen people, and the industrial revolution would not have taken place without the extraction of our land and resources and the extraction of free labor. The lack of resources infused into our communities is a continuation of genocide. Hundreds of years of federal Indian policy has had a direct horrific effect on our health and well-being. We live a country of extreme wealth, and the hoarding of this wealth is both unethical and immoral when our people are literally dying. The hoarding of resources directly impacts our people's health, wellness, and the quality of life.”

Marisa Miakonda Cummings (Umonhon/Omaha), President and CEO, Minnesota Indian Women's Resource Center

“So I've done a lot of work in this space trying to understand the impact of historical trauma and how that directly links to current day health disparity. And we just have to be honest. There was genocide in the United States. That's what created opportunities for this country to grow. And, again, it's not comfortable to think about or talk about. And I talk about these things not to make anyone feel bad, that's not the intention. I talk about these things because it's the truth. We have to understand the truth if we're going to get to real solutions.”

Donald Warne, MD (Oglala Dakota), Co-Director, Center for Indigenous Health, Johns Hopkins University

“We have to heal from what has occurred. We have to have truth and reconciliation on what happened with the 100-year boarding school policy. (We need to be) looking at the disease and not its symptoms, the symptoms are these horrible rates that we have in maternal deaths and so forth, our health disparities. But the disease itself is something far more insidious. And legislation which would establish a truth and healing commission on U.S. boarding schools will be part of healing that underlying cause.”

Stacy Bohlen (Sault Ste. Marie Chippewa Tribe), CEO, National Indian Health Board

Colonization

“The colonization model has made us dependent on a system that is not serving us, hasn't served us, and wasn't created to serve us intentionally. So decolonization from that model, is more about creating systems and health care that reflect the

communities that they're serving, which means redistributing funding and access to things that maybe we might not think are part of our health care. We are experiencing high rates of suicide and depression in our maternal communities and not having access to a mental health care provider. But understanding the trauma that native women have experienced and continuing to experience is partially because of having to navigate a complex system, not being able to practice our traditional ways of life; having our families fragmented so our support systems are not there. But as a native woman, wanting to go talk to somebody about my problems, is not traditionally what we did. Rather, we would go to sweat lodge. We'd go to ceremony. We would go see a medicine person. And so when I say decolonizing our way of thinking about what we think mental health care looks like is incorporating those practices and centering them in our care as well as going to people and providing care for them in their home and not putting all of that burden on a family to access care and then reading statistics that make us look bad as native women that we don't care about ourselves, As native women, our bodies are highly-regulated and, decisions around what we can have access to or can't have access to is tied to funding and to government decisions that we can't even be a part of, and that's a problem."

Nicolle Gonzalez (Dine'), Nurse Midwife, Navajo Nation

"51 years ago, in 1971, Representative Julia Butler Hansen of Washington, who ran the Appropriations Committee serving Indian health, said, "The problem arises when Indians leave a reservation on their own and are clustered in cities such as Minneapolis-Saint Paul." She also stated that "Improving the health of mothers and children has always had the highest priority in the Indian Health Service." Here we are today, hearing the exact same issues over and over and over again. The language of the colonizer is apparent here when it says that Indians left the reservation on their own, (knowing the reality of)... how people were relocated, displaced, and terminated."

Meredith Raimondi, Vice President of Public Policy, National Council on Urban Indian Health,

"I think the system is white supremacy and how it shows up within our judicial system, our law enforcement system, our health care system, our educational systems. These stories of trauma that our people go through are visible in every one of those systems. And we had our own systems. We have traditional governance. We had food systems that now feeds -- 80 percent of the food that feeds the world comes from us. We were incredibly bright people who had social structures that didn't need prisons. We weren't perfect, but we had our way of life that worked would for us that was intentionally and systematically dismantled and replaced. Our seeds end up in museums, and we're given commodity foods, and then we wonder why we have obesity rates. When we talk about these disparities in health and we talk about these social factors that directly impact health, we need to touch each one of those. And a social return on investment shows how housing can impact a woman's sobriety, can impact her child not being removed and put into the foster care system. All of these things are intersectional, but that's not how it's done. It's piecemealed. We have to take a grant piece here that we can do this with and a piece of a grant here and we have to make it work for us."

Marisa Miakonda Cummings (Umonhon/Omaha), President and CEO, Minnesota Indian Women's Resource Center

Sovereignty and Trust Responsibility

"American Indians are unique in United States because our tribes have a government-to-government relationship with the federal government. It's not like other underserved minority populations because we have the separate political entities. We're nations within the nation. It's very clear in the U.S. Constitution, Article I, Section 8 in the Commerce Clause, that, "Congress shall regulate commerce with the foreign nations and the Indian tribes." We are put on par with foreign nations so that's recognition of tribal sovereignty"

Donald Warne, MD (Oglala Dakota), Co-Director, Center for Indigenous Health, Johns Hopkins University

"Even though the tribes have a relationship with the federal government, states do not. So an American Indian person who is entitled to health care, because we do have the world's first prepaid health care system, which we paid for with our land, the -- the gold, the iron ore, the oil, the trees, the water, everything that the land has provided and the robust riches of the United States, which are land-based. Those were all our lands. We forfeited those. And I know that some folks think, well, you know, you were a defeated people. No. We negotiated because we were a terrifying people and we fought as hard as we

could with our resources that were not on par with those of the invaders who came here. And what we have is a result of negotiations that were entered into, and the Supreme Court of the United States has repeatedly said that the treaties are the supreme law of the land. So even though our people have the right to that health care, through Medicaid, if you're in Arizona, because states control Medicaid and they have a Medicaid expansion, you have access to all that that means. But if you're in South Dakota where there are huge tribal nations, huge populations of American Indian people, and they did not do Medicaid expansion, our mothers, our expectant mothers and their children do not have access in the way that they need to."

Stacy Bohlen (Sault Ste. Marie Chippewa Tribe), CEO, National Indian Health Board

"We've heard about the federal government's trust responsibility. This is a sacred promise that the United States made to American Indians and Alaska Natives to provide health care. So when we talk about a return on investment, there is no return on investment. This is a prepaid health care plan, and it is the United States government's responsibility to provide the highest health status, highest possible health status, and to provide all the resources."

Meredith Raimondi, Vice President of Public Policy, National Council on Urban Indian Health,

Indian Health Service

"When we talk about Indian Health Services, I couldn't even name some of those positions at IHS at an individual level because we just don't have conversations with them. Our conversations and our relationships have been with Jackie Dionne (MDH). We have quarterly tribal health directors meetings where we come together. Having that quarterly meeting with all the tribal health directors from all the at the table and have Jackie moderate that is huge. During COVID, they were our support. I know IHS was out there somewhere, but our relationship and our acquisition of all the immunizations and all of that, all our support came from the State. "

Stacy Hammer (Bdewakantunwan Dakota), Director of Community Health, Lower Sioux Health Care Center

"My dad was not born in the community because at the time, native people were not allowed to visit or be seen at the clinic hospital system eight miles down the road. They had to drive two hours to the nearest IHS facility. So when he was born you had to figure out how to get there. We've got a lot of stories of our elders sharing what that felt like, if they had five kids at home and they had to somehow get to that IHS facility to have their baby, and what if there were complications? And so there's a lot of distrust, I guess I could say, and there still is with our neighboring white community."

Stacy Hammer (Bdewakantunwan Dakota), Director of Community Health, Lower Sioux Health Care Center

"IHS isn't our answer. We're sicker now than we ever have been. IHS has never saved us, and to act like we didn't have health service pre-ISH is disrespectful to our ancestors who carry traditional medicines."

Marisa Miakonda Cummings (Umonhon/Omaha), President and CEO, Minnesota Indian Women's Resource Center

"We have to recognize that IHS is not a failed system. It's a starved system. It's never been adequately resourced. We don't know how good IHS could be if it was actually funded."

Donald Warne, MD (Oglala Dakota), Co-Director, Center for Indigenous Health, Johns Hopkins University

"When you hear someone that has the opportunity to utilize the Indian Health Service and they say they wouldn't even send their four-legged pet there, there's something wrong with that system that is deeply ingrained."

ACIMM member reflecting on a comment by a member of the audience

"I remember being on a conference call and someone from one of the federal agencies said, "Well, if native women don't like the way they're getting their health care, they should go seek another place." Well, if you're living on Pine Ridge, you don't have a car, you're poor, you have Indian Health Service there, which has limited capacity. Where are you supposed to go to get your other health care? I mean, it's just not rational. It's not rational from our world perspective. So if we had housing, we could have physicians who would have a place to live. Doula's, midwives, our health care providers would not have to commute four hours each way, which, as you can imagine, isn't going to happen. It's not happening. So that's a place that is

a block to our success in our health systems.”

Stacy Bohlen (Sault Ste. Marie Chippewa Tribe), CEO, National Indian Health Board

“I do not work for Indian Health Services. Many of us have chosen not to work for Indian Health Services because of the racism and a lot of violence we experienced as health care providers trying to serve our own communities.”

Nicolle Gonzalez (Dine’), Nurse Midwife, Navajo Nation

“When I look at the data since 1980 to current, the maternal mortality rate for native women has tripled despite all the health care advances that we like to talk about. I’m seeing structural racism impede access to quality care because funding isn’t in getting where it needs to go. I know that Biden gave nine billion more to IHS facilities to take care of our health, but that funding isn’t getting to grass roots organizations or even nonprofits who are trying to fill the gaps where they are not filling the gaps.”

Nicolle Gonzalez (Dine’), Nurse Midwife, Navajo Nation

“So, what has changed (in the IHS) in the past 45 years? Not much.”

Rhonda Clairmont Swaney, JD (Salish & Kootenai), Past Tribal Council Chair for Confederated Salish & Kootenai Tribes

Community

“Investing in our communities can’t be overstated. We want to live on our traditional lands because -- not because it’s the best land. It’s often times some of the worst land, but that’s where our communities are. That’s where we’re doing our stuff. That’s where families gather. Support those areas and give us some economy, some ways to do that.”

Patrice H. Kunesch (Standing Rock Lakota), Director, Peñín Haha Consulting, Major Gifts Officer, Native American Rights Fund

“I can’t think of our mothers and our children without thinking of our elders and thinking of those elders that are helping to raise a lot of our little ones and so their needs as well. So I always think about all 4 generations when we talk about one particular generation, how we are all related and we are all part of a family. We all are in our communities, and so we all look out for each other, and I think of a lot of our elders that are now raising their great grandchildren too, that’s the reality for us at Lower Sioux.”

Stacy Hammer (Bdewakantunwan Dakota), Director of Community Health, Lower Sioux Health Care Center

“Some of you may be familiar with the work of Dr. Michael Chandler. He is a clinical research psychologist in Canada. And he did a seminal work on First Nations in Canada and suicide rates. And he had a hypothesis that if you have strong cultural presence in community, then suicide rates will be lower. And when I heard him speak on this, he said, the first things that you -- you throw out when discussing suicide rates among First Nations’ people is depression and poverty, because they are, quote, “As common as the sand.” That makes me very sad as a native person and as an American because we have normalized suffering for American Indian/ Alaskan Native people, and -- and that cannot continue. But my point is that he did, in fact, prove his hypothesis that where culture, community, traditional values, traditional feelings were present in community, suicide rates declined in direct relation to the strength of cultural presence increasing.”

Stacy Bohlen (Sault Ste. Marie Chippewa Tribe), CEO, National Indian Health Board

Indigenous Knowledge/Wisdom/Resilience

“We’ve talked about other things like the cradle boards and back to sleep. There’s a lot of things that we have done throughout history that are consistent with what we’re calling evidence-based practices. It might even be worth pointing out that modern science is finally catching up to indigenous knowledge.”

Donald Warne, MD (Oglala Dakota), Co-Director, Center for Indigenous Health, Johns Hopkins University

“I think that if you want to impact the indigenous population, you need to recognize that they have the ability, will, and drive, and I think the knowledge that you're searching for to improve the health of their own people.”

Joanna Bryant (Shakopee Dakota), Tribal Public Health Administrator at Shakopee Mdewakanton Sioux Community (SMSC)

“We should also make reference to the strengths, resilience, and wisdom that exists in our communities and that we have a lot of culturally-based solutions as well. We tend to focus so much on the disparities and the negativity because that's a compelling story, but in truth, we have a lot of answers within our communities and a lot of strengths that should be a part of that.”

Donald Warne, MD (Oglala Dakota), Co-Director, Center for Indigenous Health, Johns Hopkins University

“Doulas carry ancestral knowledge and are an integral part of strengthening traditional birthing practices as studies have shown evidence-based improvements with decreased rates of cesareans and instrumented deliveries, like vacuums or forceps and increased breastfeeding rates. They can often identify signs of postpartum depression and anxiety which will help a mother in need of services even before their routine six-week follow-up.”

Socia Love-Thurman, MD (Cherokee/Yuchi/Delaware), Chief Health Officer, Seattle Indian Health Board

There needs to be an acknowledgement of our traditional wisdom, our understanding that we were scientists. We were mathematicians. We are intelligent people that are capable of running our own lives, and we are also capable of taking care of our communities as we know best.

Marisa Miakonda Cummings (Umonhon/Omaha), President and CEO, Minnesota Indian Women's Resource Center

“I have more hope now than I have in a long time because of the decolonization movement that's going on and the movements like Land Back that we're seeing that we've never seen and the fact that we finally have a show on television, Reservation Dogs, that represents us, that looks like us, right, not these silly stereotypes. So, there are things that are happening that give me hope, for one thing. And also the fact that Dr. Ehlinger was able to get you all to finally meet on tribal land. Things like that that are critically important. It's hard to hear about how many people don't know about who we are over and over and over again. So, what can you do today? You can help us. You can help movements like Shakopee, help them spread that information about who we are in our textbooks. You can go to your school districts and ask, “Where is our history about native people in the school?” You know, enough of just having our art on the walls or our art up throughout town to attract the tourists. You can help encourage others to learn more about us all the time.

Mary Owen, MD (Tlingit), Associate Dean of Native Health, University of Minnesota Medical School

Urban Indians

“Congress first established urban Indian health clinics in 1976, when only 40 percent of native people were residing in cities. 50 years later (when 75% of AI/AN live in urban areas), the budget for Indian health service for Urban Indian programs is 1 percent of all Indian health care. there is no dedicated funding for urban Indian health in the maternal area.”

Meredith Raimondi, Vice President of Public Policy, National Council on Urban Indian Health

“76 percent of American Indians and Alaskan Natives reside in urban areas. Many urban American Indian and Alaskan Native communities were established through federal termination and removal policies that began in the 1950s. This movement to cities directly led to socioeconomic disparities as the promise of a better life, opportunities like jobs, health care, education were not available when they got there. We have faced longstanding historical and cultural genocide that has led to the loss of many of our traditional birthing practices and the racial disparities that we see today. Many of our native pregnant mothers do not seek care right away due to barriers to care such as lack of transportation, financial means, or geographic location. But often, the unspoken reason is their fear of the stigma and racism that they will face entering a health care system that was not made for them and has actively harmed them”.

Socia Love-Thurman, MD (Cherokee/Yuchi/Delaware), Chief Health Officer, Seattle Indian Health Board

“Many urban American Indian and Alaskan Native communities were established through federal termination and removal policies that began in the 1950s. This movement to cities directly led to socioeconomic disparities as the promise of a better life, opportunities like jobs, health care, education were not available when they got there. We have faced longstanding historical and cultural genocide that has led to the loss of many of our traditional birthing practices and the racial disparities that we see today.”

Socia Love-Thurman, MD (Cherokee/Yuchi/Delaware), Chief Health Officer, Seattle Indian Health Board

Lack of a Voice

So I'm half Native American and half black, but I grew up on the reservation. So I can say that as an indigenous woman, we are angry. Like, we don't even have voices. It's not fair. Like, you have people just shutting us up just because they don't want us to have a voice. And that's what's hard about it.

Lenice Antel-White Incarceration Survivor

“I remember sitting up in Mille Lacs participating in the first Indian-only infant mortality review process that the Minnesota Department of Health was hosting, and it was the first time where the majority of people sitting there and reviewing these deaths and talking about the circumstances that surrounded those deaths and talking about solutions and recommendations were American Indian people, and that's the way it should be done. When we're talking about health disparities, whether it be in my community or any other community, those people that are impacted need to be part of the conversation, and they need to be the strongest and biggest voice in those 2 conversations.”

Noya Woodrich (Athabaskan) Director, Child and Family Health Division, MN Department of Health

“My mom was traumatized by her childhood as well as being in an abusive relationship. Yet she decided to raise five children by herself in an urban area without any family support. It was a real struggle. She had so many interactions with the system who pretty much told her, I don't care about you. I don't care if you survive or if you don't. She just had to fight her way through. And I think we do as Indian women, we just make the decision to fight the systems because every step of the way somebody's going to say, you don't matter. Then we shut down. We close up. And when there is a warm hand that reaches out, we don't trust it. We don't trust it because of what happened to my mom and how she instilled into us the message. ‘You know, they just think we're dirty Indians.’ When you're a child and you hear that, it just hits you, and you don't trust the system. There's no native person in this room that hasn't been told by the system you don't matter.”

Jackie Dionne (Turtle Mountain Chippewa), Director, American Indian Health, Minnesota Department of Health

Data

“Life expectancy in the United States has dropped for the second year in a row in 2021. That's the largest two-year drop since 1922-'23. While there's been a 0.9-year drop for all Americans in the aggregate, American Indian and Alaskan Native life expectancy dropped 6.6 years in 2021. That puts our people down to 1944 levels for all Americans. This is unacceptable. And if these facts do not portend an emergency, I don't know what will get the attention of policymakers. They are not the canary in the mine shaft they are laying on the bottom of the cage. We're tired of winning the race to the bottom.”

Stacy Bohlen (Sault Ste. Marie Chippewa Tribe), CEO, National Indian Health Board

“So you can think about where you're from, and you might be from a state that has relatively few American Indians, but there's a reason for that. There's policy-based reasons put forth by the federal government that removed people or killed them. That's why we have such a small population now”

Donald Warne, MD (Oglala Dakota), Co-Director, Center for Indigenous Health, Johns Hopkins University

“I fully understand the need for evidence-based care and the research and everyone's favorite word - data. Unless you have personally been in a situation where your health care potentially is being impacted because someone doesn't have enough numbers on a piece of paper or a checkbox isn't done, it's a very, I would say humbling, but I'm going to change that to devastating place to be.”

Report submitted by ACIMM, December 2022, to Health and Human Services Secretary Xavier Becerra

Joanna Bryant (Shakopee Dakota), Tribal Public Health Administrator at Shakopee Mdewakanton Sioux Community (SMSC)

“We’ve talked about is the lack of data. One of our UIO leaders has said, “Data is dollars.” So the stories are incredibly important and moving and critically important to understanding the issues, but we also need to invest in the ability to provide data. Without data, there are gaps in care that are inevitable and unwanted health outcomes will continue. Data concerning native and maternal infant health and mortality is not collected or extremely limited. A report by the South Dakota Advisory Committee on Civil Rights said there is a lack of consistent, comprehensive data available regarding maternal health of American Indian populations. And this lack of data makes it difficult to develop explanations for the present maternal health disparities.”

Meredith Raimondi , Vice President of Public Policy, National Council on Urban Indian Health

Medicaid and Public Programs

“The Federal Medical Assistance Percentages is 100 percent (coverage for AI/AN). So we have 100 percent federal dollars for AI patients. And then you have a state legislature standing in the way saying no, you can't have access to those federal dollars. That's the circumstance that we're dealing with right now in places like South Dakota where I am from. That is unacceptable. Part of advocacy is get the state legislatures out of the way of access of American dollars for American Indians.”

Donald Warne, MD (Oglala Dakota), Co-Director, Center for Indigenous Health, Johns Hopkins University

“A mom who is American Indian either on a reservation or not, ... because of the way ... we were put on reservations, relied on governmental services, relied on the government to survive..., 80 percent of all American Indian women who give birth are on public programs in Minnesota. ... So from the time of conception to the time of delivery to after, there's a bunch of (public) systems interacting with us.”

Jackie Dionne (Turtle Mountain Chippewa) Director of American Indian Health, Minnesota Department of Health

Social Determinants of Health

“We really need to develop, a tribal determinants of health wheel that respects the medicine wheel and respects the fact that when the “social determinants of health” were developed, they were never intended for our people. Our people were not involved in creating them. Our voices are nowhere. There are several portions of the social determinants of health that apply to us, but when you're American Indian/Alaskan Native, health is defined by the full health of your mind, body, and your spirit. That lends itself to the cultural integrity of traditional values, traditional healing, and ways of knowing that are necessary for our people to achieve full health. And the social determinants of health simply do not address or capture that.”

Stacy Bohlen (Sault Ste. Marie Chippewa Tribe), CEO, National Indian Health Board

My younger sister, my baby sister, she's eight years younger than me, and she got pregnant, and I was gone. I was in school. And before I even knew, they set her up. My parents, they set her up. They were living in St. Paul and convinced her to set the baby up for adoption. And I'm like, wait a minute. I can do it, but by that time, it was too late. My sister then got into more trouble, suicidal. She was raped. Dropped out of school but went back. Got her GED. Got married. Had a couple children, and then struggled with alcoholism. She was the closest to me to have to deal with and learn the systems of someone who has all this trauma, who is native, and with alcoholism. I learned the systems were not there to cure you or support you. It was, you do this for 30 days or you fail. Do it again or fail. Medicaid you're done. You know, and she ended up passing away two years ago this month, and she was only 44 at the time. And this is something that she carried on from her from when she was 16 all the way to 44 and the systems failed them. And us bein in urban areas and having lack of family support also has failed us as well.”

Joni Buffalohead, Ph.D., (Bdewákhathunwan Dakota), Chair Minneapolis Indian Health Board

“We were looking at a bunch of statistics, and if an American Indian woman gets a college degree, the disparity goes away. If an American Indian woman gets a master's degree, their birth outcomes are better than anybody else's. So, the answers are right there. This is a solvable problem, and why we can't get it solved? We need to do more. We need to do better.”

Noya Woodrich (Athabaskan) Director, Child and Family Health Division, MN Department of Health

“If you give people with chronic disease housing, hey, they do better. Go figure.? If you give them food and nutrition, they do better. If you address these social determinants, they do better. When I was trying to get a patient into treatment, I can't tell you the number of times I heard this: “We don't have an option open right now. We don't have a slot open right now. You're going to have to wait a month.” Well, they're not going to need me in a month. They need me now. And think about those young native women who could become pregnant, and they want to stop using. We need those treatment options now anytime they walk in the door. And not only cultural treatment options, but treating our entire community because we know, if you treat someone for six weeks, that's not enough. If you treat them for six months, that's not enough. And if you only treat them and not their family and not the people around them, that's not enough. (We need to be) investing in our communities. We want to live on our traditional lands - not because it's the best land. It's often times some of the worst land, but that's where our community is. That's where we're doing our stuff. That's where families gather. Support those areas and give us some economy, some ways to do that.”

Patrice H. Kunesch, (Standing Rock Lakota) founder and director of Peñín Haha Consulting, Major Gifts Officer at the Native American Rights Fund

“The adverse childhood experiences affect you across the lifetime from even before birth until death (and) substance use is a way to self-medicate and not just through adulthood but for childhood as well. I started drinking when I was nine years of age and huffing gas at that time as well to deal with my traumas. A close friend who lived in our HUD housing project died huffing gas, and that was when I stopped. That was at age ten. So it is very much alive and continues today. So these are not things that are delayed that happen only to adults but also while you're children, this is what we are doing to help us self-medicate and heal but not really heal.”

Janelle Palacios Ph.D., CNM, RN (Salish/Kootenai)

Reproductive Freedom/Justice

“I hear stories around the rights as indigenous people, native women not being honored in their birthing experience, people still getting episiotomies that they don't need and did not ask for. Un-consented procedures is still an issue. I don't see an apology from Indian Health Services for their forced sterilizations (of) our people in the 1970s.”

Nicolle Gonzalez (Dine'), Nurse Midwife, Navajo Nation

Accountability

“Systems are people and people are benefitting from almost all of the tragedies that we see driving these outcomes, the housing crisis, someone is benefitting, the prison crisis someone is benefitting, substance use, someone is benefitting, and even sexual exploitation, someone is benefitting. (These people) shouldn't have the privilege of the comfort of ignorance about what's happening, and they shouldn't have the comfort of not knowing or hearing the stories, and at a minimum, we should know who is benefitting and, they should be accountable to knowing the information we have.”

Marisa Miakonda Cummings (Umonhon/Omaha), President and CEO, Minnesota Indian Women's Resource Center

Violence

“Violence against Indian women is rooted in colonization. Indian women are murdered at a rate ten times higher than the national average. Homicide is the third leading cause of death for native women. 75 percent of Indian women murdered were killed by an intimate partner, and as Indian women, we live our lives in the dangerous intersection of gender and race.”

Gwendolyn Packard (Ihanktonwan Dakota), Senior Housing Specialist, National Indigenous Women's Resource Center

Incarceration

"There has been a nearly 700 percent increase in the number of women incarcerated in this country since 1980. We know that most women behind bars are of childbearing age, and incarcerated women have high rates of chronic health conditions. We also know that the people that we lock up in this country are disproportionately women of color, majority of whom are black and/or indigenous. We know that black and indigenous women are disproportionately represented in both the criminal/legal and child welfare systems. (It is) critical to think about the forced separation and what white supremacy has done for mothers and children of indigenous families. It is these two systems coming together for many of our clients with the Minnesota Prison Doula Project that have separated moms and babies across generations in horrific ways. At the Minnesota Correctional Facility Shakopee, our state's only women's prison, which is only five miles down the road, it is not lost on me that we are very close to the prison, 20 percent of the women in that facility identify as American Indian and Alaskan Native. Among pregnant people at the prison, 35 percent of them are American Indian. The disproportionate rates are really astronomical."

Rebecca Shlafer PhD, MPH, Associate Professor, University of Minnesota's Medical School and School of Public Health

Birthing Experience

"I was born at Indian Health Service in Winnebago, Nebraska at the Omaha Winnebago Service Unit... My great grandmother came to the hospital to name me. That might seem like a little thing, but in her naming she set forth the projection of my entire life. My identity, my purpose is all rooted in my name. She was a midwife, and she gave me her name. For me, knowing that love that she showed (was important.) It wasn't easy to get to the IHS hospital. People didn't have cars. She had to walk, this old little grandma. Her unconditional love, the love of our grandmas and aunties as we bring life into this world - she thought of me as this little person that she didn't even know yet, this great grandchild, and she made that effort for me. When my sisters had their babies I was the one that was there, helping deliver those babies and acting as a doula. I didn't even know what a doula was. It was just natural for me. And they also had to have an advocate because where I'm from, Indians didn't go to the hospital without advocates because they don't listen to you, and if you're not educated (with no) letters behind your name, they don't even value what you have to say. (When) my recently delivered was born the midwife and the doulas in the room actually just backed away and they let me take care of him. His first words were in our language. He was acknowledged to Creation, and he's the first one in four generations that had that traditional way of being brought into the world. And his life looks different."

Marisa Miakonda Cummings (Umonhon/Omaha), President and CEO, Minnesota Indian Women's Resource Center

"In the hospital system that I worked there's just a stigma as soon as our women hit the door that is truly a system of racism. The people taking care of our women in our hospital don't understand us and they don't understand our history, and I don't even know if they care. I, as a native person, would feel like I was their best advocate and their doctor., fortunately. However, even the way that I was treated is truthfully what led to me really wanting to leave obstetrics, and that was very disheartening for me because I wanted to continue to be there for my patients, but just seeing how difficult it was for me to even navigate and advocate to not interventionize all of the people I was taking care of and rush them through this process that is so funded -- so heavily focused on funding in fear of litigation that the system was not built for the way we that we would normally allow people to birth. And I found that very difficult. and so since I've left, it's been eye opening to actually meet with several people I see here in the public that the native community has really come around this together. We have our own committees where we're starting to talk about this, how we need to be open to different ways of birthing, right, that hospital birth is not for everybody, but we've -- we've sort of created such a fear of birthing in our entire nation that women feel like that's the only way, and it may not be the only way. And that was difficult for me to hear as a western-trained physician, but it's the truth, that there are other ways that many of our native women are actually low

risk, but we often find ways to make them high risk only just because they are native, and that's not enough."

Socia Love-Thurman, MD (Cherokee/Yuchi/Delaware), Chief Health Officer, Seattle Indian Health Board

"...what's happening in New Mexico in regard to hospitals closing, Santa Fe Indian Hospital closed their OB unit in 2008, San Juan Medical Regional Centers closing. Their midwives are having to go elsewhere to provide care. The Phoenix Indian Medical Center has closed their obstetrical units. Las Vegas, New Mexico does not provide OB care. Los Alamos does not provide OB care. Native women are now required to navigate a very complex health care system because their IHS services are not providing care to them anymore or they're having to transfer at some point during their prenatal care visits. A lot of the women that I see, have not received care up to 20 weeks into their pregnancy because; A, they can't access a care provider; B, they have to travel more than 30 miles to get access to care; or they have to wait more than six weeks to get in with a health care provider to get care for their pregnancy. And so when we see the statistics around obesity, diabetes, hypertension, postpartum, hemorrhage, native women not accessing care in the first trimester increase maternal mortality rates because of car accidents just trying to get an appointment, it's because these hospitals are closing or labor and delivery unit causing women to have to travel further, but also, IHS is not fulfilling their treaty obligations to the tribes around maternal health care and women's health care in general."

Nicolle Gonzalez (Dine''), Nurse Midwife, Navajo Nation

"I was a very young mother, away from my family. I was receiving a number of social services, public health, public housing, food stamps, WIC. And I was very vulnerable. One of the cultural things that we pride ourselves in our family as women, as mothers was how to be a caregiver. I thought I knew how to take care of babies. One of the most important elements of being a mother in our family was breastfeeding. I was very diligent and committed to nursing my daughter. And one day when my daughter was about four months old, a visiting nurse came to see me. She stepped into my apartment and took one look at my little girl and said, "Failure to thrive." I had no idea what that meant. I never heard that term before. For all I knew, I was doing the absolute most important thing, and that was nursing my baby. And she said in the next breath, "If you don't feed that baby, we are going to take her away from you." That was harsh. That was hurtful. That was judgmental. And there were no questions about what is your life circumstances and how is this going for you? And right then and there, she fixed a bottle of formula and, certainly, my baby was hungry, and she needed that nutrition. I share this because we know that poor outcomes in American Indian infants are also related to poor outcomes and poor health care for American Indian women."

Patrice H. Kunesch, (Standing Rock Lakota) founder and director of Peñín Haha Consulting, Major Gifts Officer at the Native American Rights Fund

"I hear stories over and over about their rights as indigenous people, native women not being honored in their birthing experience, people still getting episiotomies that they don't need and did not ask for. Un-consented procedures is still an issue. I don't see an apology from Indian Health Services for their forced sterilizations that our people have gone under in the 1970s, but there's no formal apology about that act ever happening to our people. President Joe Biden talks about protecting our reproductive rights and I'm seeing these things happen at a high level, but they're not trickling down to the state. And so where is that break happening?"

Nicolle Gonzalez (Dine''), Nurse Midwife, Navajo Nation

"Alaskan Native people speak with their eyebrows and nose, and non- Native health care providers don't know that. I've seen, so many times, people charting at the computer with their backs turned to the patient and asking questions and the person is answering, and they will answer like five times without saying a word, and it's really frustrating - they are not being listened to because they're not using words. But that is our language and when I'm there, I hear that. I hear those words that are not words. I hear that body language. It's so important."

Abra Patkotak, (Inupiaq), Alaska Native Birth Workers

"Sometimes I travel three hours to a hogan out on the Navajo reservation with a fireplace and the medicines are all there and these women are supported by their healers and by doulas that look like them and by their midwife that looks like them. Their babies are granted and presented into this world with song and prayer and the smell of cedar. And that's so

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different from the hospital setting, and I think we need to create opportunities for places like that where birth can happen. I see hogans all over the Navajo reservation. They're right next to hospitals but they don't use them to birth in. They don't use them to do care in. And so I believe there's this understanding that care has to happen in a clinic and it has to happen in facility, but it doesn't. You can do a prenatal visit in a hogan. You can do a prenatal visit in a teepee. If someone can't come to appointments, you can go to their house and do their prenatal visit. But I think we all have this idea in our head that it needs to look a certain way, but it doesn't."

Nicolle Gonzalez (Dine’), Nurse Midwife, Navajo Nation

"Around funding for indigenous health care workforce. I believe that we have blinders on and who can do this work, we're leaving out the ability for our own communities to be trained as doulas, to be trained as birth assistants, to be trained as licensed midwives. Not everybody has the capacity to go to school to be a doctor. I'm a nurse midwife, I've been in a school for eight years. Considering the communities that we come from where the families are fractured, transportation, electricity, not having a computer, single-family members, having to work at Walmart for their job, like how do we expect those individuals to go to school, to be doctors and then come back to their communities to serve them? I think we need to think outside the box and be innovative in our options, in our choices around serving our communities."

Nicolle Gonzalez (Dine’), Nurse Midwife, Navajo Nation

"it was 45 years ago. I was 25 years old at the time of my first pregnancy. I had been to college. I was married, I was working for my tribes, and my husband was a heavy drinker just like many other men his age. I attended all prenatal appointments with my family doctor through purchased care. On the six-month appointment, it was a Friday afternoon late in the day, the nurse told the doctor I had protein in my urine. He said I was fine to go, and he didn't give me any warnings about what to look for or problems should occur. The next night, I developed what they called toxemia then, they now call preeclampsia. And it was my first pregnancy, so I didn't know what was normal but it began to feel that something was very wrong. About 5:00 in the morning, I drove to the local emergency room but the nurse told me that they didn't have my blood type on hand so they would be transferring me by ambulance to a bigger hospital about 60 miles away. The on-call doctor didn't ever look at me, didn't come in. When I began my trip to the larger hospital, my baby's heart was still beating. When I arrived at my destination, the heartbeat couldn't be detected. I began to hemorrhage heavily. The on-call doctor in the larger hospital induced labor. He told me I couldn't have a C-section because I'd lost too much blood and I wasn't clotting. I delivered my dead baby, and was hospitalized for several more days, given units of blood and anti-seizure medication and was released without instruction how to care for myself or how long to wait before getting pregnant again. Being young and thinking it was just a terrible accident that wouldn't happen again. I did learn recently that preeclampsia occurs when there's stress in your life. I want to say that most reservation residents have stress in their life every minute of every day; just going to work, trying to get equal treatment, knowing that you're a second-class citizen is very stressful and you know you're never going to get ahead, never be as good as everybody else. You try harder, but you're never successful. As I was young and wanting to move on, I became pregnant again rather quickly. I was given a high-risk designation because of the still birth I had, and I was sent to a specialist about 60 miles away. I chose the same OB-GYN that delivered my first baby because he knew my problems. I drove a 120 miles each way for each 15-minute appointment. He didn't take any special care or any special tests. And one night right after New Year's, I began spotting and was told by the hospital to drive in. It was January. It was cold and the roads were icy. I remember we slid through one or two stop lights in Missoula. When I arrived, I was informed that I was in preterm labor, and I delivered a little tiny baby at midnight. I was told my son probably would not live until the next morning. He was put in an isolette in the nursery, and they gave me something to sleep. My son weighed in at 1 pound 12 ounces with the umbilical clamp on. Measured 13 inches. My husband's hand was bigger than the baby. The next morning, my son was still alive, and the doctor decided to transfer him to the University of Utah Medical Center, neonatal unit 500 miles away. I did get to see my son and touch his hand before he left but couldn't hold him. I was also able to visit him twice while he was in that medical center. I was told that children born as early as my son did not live and his chances of surviving was 1 in 100. I was asked to sign paperwork promising not to sue the medical center if anything happened to my son because they would be providing him experimental treatment. I learned that I delivered at about 26 weeks and the cause of the early delivery was attributed to DES syndrome, that is my uterus couldn't

support the weight of anything over two pounds. I still don't know if that's true. The only thing the doctors told me was keep trying. Eventually, you'll have one that lives. My son did live. Today, he's a 44-year-old man with severe cerebral palsy, profound deafness, and an intellect that can't be accurately measured. I love him more than words can describe. He accepts his disabilities with humor and grace and lives defiantly to this day, that is, if you tell him he can't do something, he'll find a way to do it. Oh, but what he could have been, what they both could have been. Again these events happened over 45 years ago and, really, nothing has changed. The reservation I live on is still very rural. Providers are not plentiful. They use an on-call system on the weekends. And, frankly, Indian people are considered disposable. That's what I felt, and that's what I feel today. Although these events happened 45 years ago, I challenge you to think about what's changed over that time. Native women are still at high risk for complicated pregnancies. Our babies die at the highest rate compared to other populations in our nation. Scarcity of funds for health care is an ongoing issue, particularly if you go to the Indian Health Service for help. Health literacy among our population remains low. We are deficient in providers in our communities. Many of our people are under housed or considered homeless or live in a unit that's too small because several other family members live there. Access to transportation and good roadways are still an issue. And through this, I have not even touched on the mental health needs of our community; suffering from intergenerational trauma, endless daily encounters of racism in our communities, violence, and substance misuse. So what has changed in 45 years? Not much. I understand your efforts to bring all the problems of native American pregnant women to the forefront and provide them better care, but I just challenge each and every one of you just to help one person."

Rhonda Clairmont Swaney, JD (Salish & Kootenai), Past Managing Attorney and former Tribal Council Chair for Confederated Salish & Kootenai Tribes

Appendix C

TABLE OF ACIMM 2022 RECOMMENDATIONS

No	Recommendation
	MAKE THE HEALTH AND SAFETY OF AI/AN MOTHERS AND INFANTS A PRIORITY
	ENGAGE AND CENTER AI/AN COMMUNITIES AS ACTIVE, EMPOWERED LEADERS AND DECISION MAKERS IN WORKING TOWARDS SOLUTIONS
1.	Adopt, embrace, and employ the concept of AI/AN Data Sovereignty, as defined by the National Congress of American Indians (2018).
	a. Assure meaningful AI/AN leadership and decision making on how to collect, analyze, use, disseminate data and be funded for studies and programs related to the health and safety of all AI/AN people.
	b. Establish an Urban Indian Organization Confer Policy across all HHS agencies to ensure that urban AI/AN maternal and infant needs are accounted for.
	c. Ensure that funding opportunities for studies and programs relating to AI/AN maternal and infant health employ more inclusive language such as, " <i>Tribes, Tribal organizations and urban Indian organizations</i> " in HHS communications and directives.
	d. Include consultation and partnership with AI/AN Elders and others with relevant lived experiences to gain historical context and perspective on factors related to high rates of AI/AN infant mortality and poor maternal health and identify solutions that draw upon intergenerational and collective strengths of the culture and community to improve, support, and sustain optimal AI/AN maternal and infant health and safety.
2.	Establish, augment, and support AI/AN-specific mortality and morbidity prevention and review activities through Tribal, state, regional, and/or national Maternal Mortality Review Committees (MMRC), Fetal and Infant Mortality Reviews (FIMRs), and Child Death Reviews (CDR); and provide adequate funding to support and sustain long-term capacity for including AI/AN perspectives on mortality and morbidity review committees. Where standalone Tribal fatality review processes are not feasible, ensure inclusion of AI/AN perspectives on existing mortality review processes and committees.
	a. Assuring that existing and expanded maternal, infant, and child mortality review boards and committees include specific consideration of AI/AN issues and outcomes, including historical context, contemporary social and environmental issues affecting AI/AN health and safety, and variations in Tribal cultural practices and norms.
	b. Building capacity for and adequately funding the interview component of FIMR and other prevention review processes, for the inclusion of stories, lived experiences, and family perspectives in sentinel event review.
	c. Supporting all FIMR, CDR, and MMRCs in states, cities, districts, Tribal communities, and territories in using and transitioning to the National Fatality Review Case Report System (NFR-CRS) and the Maternal Mortality Review Information Application (MMRIA) systems.
	d. Supporting efforts of MMRCs, FIMR, and CDR entities to further diversify participation in their prevention review processes, to include AI/AN experience and expertise.
3.	Assure greater diversity and expertise through expanded AI/AN representation among ACIMM members, to include representation from Tribal communities and Urban Indian Organizations.
	MOBILIZE FEDERAL, STATE AND LOCAL AGENCIES AND FUNDING TO END DATA INVISIBILITY AND ERASURE
4.	Federal, state, and local health-related agencies should utilize valid small number statistical approaches such as those recommended by the 1999 Joint Report referenced earlier to accurately collect and analyze data relating to the health and safety of AI/AN women and infants. National standards on small number analysis should be developed and education should be provided on how to use and disseminate these statistical methods to improve data surveillance.
5.	Establish an interagency working group, which includes a focus on women and infants, to share expertise and develop and improve systems and methodologies that federal government agencies could replicate for the collection of accurate and disaggregated data on American Indians, Alaska Natives, Native Hawaiians, other Pacific Islanders, and other small and hard to count racial populations.

6.	Work directly with Tribes and UIOs to address racial misclassification in data collection and analysis including women and infants.
	a. ACIMM and other stakeholders should collaborate with UIOs to gather critical and accurate information on urban AI/AN populations.
	b. The National Vital Statistics System (NVSS) should address the statistical and policy implications of choices about using single vs. multiple race identification and provide ready access to multiple race identified data.
7	Create reporting standards that account for self-identified race/ethnicity on birth certificates and death certificates (e.g., family members are asked) across all states, districts, and territories, and add additional data points allowing Tribal identities to be named.
8.	Implement national state-wide training on birth certificate and death certificate data collection and review systems of check and balances to correctly identify race and ethnicity.
9.	Produce timely and comprehensive regional reports, using quantitative and qualitative data, on the health and safety of AI/AN mothers and infants, through a Life Course framework, to include intergenerational, social, and environmental threats and protective factors.
10.	Strengthen the capacity of Tribal Epidemiology Centers (TEC) to serve AI/AN populations for better maternal and infant health outcomes through robust surveillance and community-driven research.
	a. Reinstate and sustain funding to Tribal Epidemiological Centers and other AI/AN serving organizations with data and surveillance, assessment, and evaluation responsibilities.
	b. Clarify and assure that TECs and other AI/AN serving organizations have access to timely and comprehensive maternal and child health data, as required by federal law.
PRIORITIZE SHORT-TERM OPPORTUNITIES FOR ACTION WITHIN HRSA AND MCHB	
11.	Strengthen accountability for how Title V (of the Social Security Act) resources are employed within, by and for Tribal communities, and impacting health outcomes of AI/AN mothers and infants by requiring inclusion of AI/AN specific information (as available) in Title V-related (e.g., MCH Block Grant) guidance, applications and annual reports.
12.	Foster and maintain relationship between States and Tribal communities by:
	a. Increasing Title V funding specifically designated for Tribal communities, urban and rural, to promote equitable partnerships between states and the Tribal communities and populations within their jurisdictions,
	b. Expanding the Tribal home visiting program, as a culturally appropriate and validated method for providing perinatal education and healthcare,
	c. Leveraging the Title V National Resource Center to prioritize and support State-Tribal partnerships to improve the health of AI/AN mothers and infants.
	d. Develop and/or strengthen the working relationship between Title V and the state's Office of Indian Affairs.
13.	Increase the number of Tribal entities that receive Healthy Start funding.
	a. Engage Tribal entities and UIOs in providing feedback on the design and implementation of Healthy Start programs.
	b. Ensure that data requirements for Healthy Start funding allow Tribal entities to meet the required program qualifications.
	c. Provide support for community-driven solutions that allow for Tribal cultural practices as part of the Healthy Start program.
14.	Decrease the disproportionate burden of Sudden Infant Death Syndrome and Sudden Unexpected Infant Deaths (SIDS/SUID) in AI/AN families by:
	a. Supporting measures that require SIDS/SUID case registries and databases in all states, territories, and districts, with inclusion of AI/AN cases and information,
	b. Incorporating AI/AN and/or Tribal involvement and leadership in consultations on how to collect, analyze, use, and disseminate data related to SIDS/SUID among AI/AN people.
	c. Providing support for community-driven solutions that focus on social, environmental, and economic conditions in addition to individual actions that impact SIDS/SUID by:
	(4) Recognizing and valuing AI/AN knowledge and cultural practices as interventions, and supporting and funding linguistically and/or culturally tailored methods aimed at improving

	safe infant sleep practices (e.g., providing cribs, portable safe sleeping spaces, cradle board making, and commercial tobacco cessation),
	(5) Reinstating and adequately funding the proven <i>Healthy Native Babies Project</i> .
	(6) Reauthorizing MIECHV at a higher funding amount, to support doubling the Tribal set-aside from 3% to at least 6%.
IMPROVE THE LIVING CONDITIONS OF AI/AN MOTHERS AND INFANTS AND ASSURE UNIVERSAL ACCESS TO HIGH QUALITY HEALTHCARE	
	EVALUATE, SUFFICIENTLY FUND, AND IMPROVE THE INDIAN HEALTH SERVICE (IHS)
15.	Provide adequate and mandated funding to the Indian Health Service to ensure a standard of care that is of high quality, consistent, and assures that AI/AN mothers experience a healthy perinatal outcome.
	a. Support annual IHS perinatal outcomes evaluation associated with increased funding.
	d. Initiate a comprehensive assessment of the quality of care delivered in IHS facilities and use the findings to identify and implement strategies to mitigate IHS's longstanding challenges.
	e. Evaluate and compare the maternal and infant outcomes across the I/T/U system of those using IHS facilities to those employing Tribal Compact Health Center or Tribal Contract relationships with IHS and make the results publicly available.
16.	Support actions to improve Tribal communities in designing, implementing, and evaluating their care when served by IHS.
	d. Support Tribal membership and leadership when IHS develops, implements, and evaluate services.
	e. IHS should consult and confer with Tribes and UIOs about policy changes and program implementation and provide timely communication with I/T/U facilities when changes in policies and programs are implemented.
	f. Support measures promoting respect for cultural and spiritual practices of AI/AN people within IHS facilities.
17.	Evaluate the IHS and American College of Obstetricians and Gynecology maternal and infant health contract and publicly report the findings.
EXPAND AND DIVERSIFY THE WORKFORCE	
18.	Require all federal grant applications for healthcare professions, i.e., medical, midwifery education programs, etc., to include accountability metrics in the applications to monitor efforts to improve the number of Black, Hispanic, and AI/AN students in the workforce that reflects the diversity of the population being served.
19.	Develop and implement an external evaluation report on the “life-span” training (e.g., recruitment thru initial employment) for Black, Hispanic, and AI/AN students in the medical, midwifery and health fields that support maternal/child health to develop and/or identify best practice guidelines for training institutions.
20.	Invest in “pathway” programs that identify and nurture future health care professionals from elementary through high school, promoting graduation from high school and success in college.
21.	Require land grant universities to have AI/AN-focused health science workforce development programs.
22.	Encourage partnerships between land grant institutions and Tribal Colleges.
23.	Encourage all states, territories, and districts to allow Certified Professional Midwives (CPM) and Certified Midwives (CM) who graduate from accredited midwifery education programs to be licensed and provide care in their jurisdictions.
24.	Indian Health Service should recognize Certified Midwives and Certified Professional Midwives with accredited education as providers.
25.	The National Health Service Corp should recognize Certified Midwives and Certified Professional Midwives with accredited education for loan repayment.
26.	Invest in training of AI/AN doulas and traditional birth workers.
27.	Support workforce trainings that include a historical basis for health disparities within our nation.
STRENGTHEN APPROACHES TO ADAPT AND AUGMENT SOCIAL DETERMINANTS OF HEALTH	
28.	Assess and address root causes and consequences of systemic racism, across the Life Course, on social determinants of health, by supporting Tribal community-driven assessment, planning and evaluation.
29.	Expand cross agency relationships with the Department of Housing and Urban Development (HUD) to assess, prioritize, and address housing insecurity amongst families and birthing individuals in the pre-natal and post-partum period, through at least the first year of life.

30.	Assure the availability of transportation services for AI/AN women living on reservations and in urban and sub-urban areas to ensure that AI/AN mothers have access to essential healthcare and birthing centers during scheduled appointments and during the birthing process.
31.	Dedicate funding to support telemedicine services for maternal health and mental health appointments for AI/AN individuals.
32.	Research and consider the maternal health benefits and fiscal impacts of paid maternity leave models for mothers, fathers, and same-sex couples in order to promote the health of AI/AN parents and infants.
33.	In consultation with Tribes and UIOs, review Medicaid access eligibility criteria and develop best practices to expand Medicaid eligibility to include the provision of culturally safe care for more AI/AN mothers. For example, despite the urgent need for AI/AN doulas and the growing number of AI/AN doula training programs, state doula accreditation standards restrict Medicaid coverage to doulas who have attained nationally accredited training. National doula accrediting organizations are cost-prohibitive and do not adequately address the cultural and social determinants of AI/AN maternal health.
ADDRESS URGENT AND IMMEDIATE CHALLENGES THAT DISPROPORTIONATELY AFFECT AI/AN WOMEN BEFORE, DURING, AND AFTER PREGNANCY	
EXPAND EFFORTS TO IDENTIFY MMIWG AND PREVENT ITS OCCURRENCE	
34.	Encourage the development of regional, state, and local offices on Missing and Murdered AI/AN Women and Girls, while encouraging state-to-state and regional collaboration. This will require an investment of resources in every state to investigate cases of MMIWG and support collaboration between state and Tribal communities.
35.	Support interdisciplinary and intradisciplinary collaboration across all DHHS sections and collaboration with the Departments of Justice, Transportation, Housing and Urban Development, Labor, and Justice to identify root causes and risk factors for MMIWG.
36.	Develop and require use of standardized data collection protocols and data reporting related to MMIWG.
37.	Measures (beyond FOIA requests) should be available for community access to information on MMIWG.
38.	Support measures that facilitate Tribal Nations ability to advocate for their community members living in urban areas when they are missing or killed.
39.	Support measures that facilitate the ability of Tribal Nations to track data on missing or killed members of their community.
40.	All policies addressing MMIWG (including Savanna's Act) must address the violence AI/AN communities' experience.
IMPROVE CARE OF INCARCERATED PREGNANT AND POSTPARTUM WOMEN	
41.	Provide universal health screening and assessment for all incarcerated women following national prevention screening guidelines.
42.	Provide evidence-based interventions which support physical, emotional, mental, and spiritual health given in culturally appropriate manners to improve the health and pregnancy counseling for all incarcerated women.
43.	Support the creation of guidelines and accommodations for pregnant and postpartum incarcerated women that include cultural resiliency.
44.	Encourage breastfeeding and provide pumping and lactation support services for incarcerated postpartum individuals.
45.	Evaluate and expand programs for pregnant and parenting incarcerated women (e.g., the Mothers and Infants Together [MINT] Program, Doula Birth-Support Program, the Residential Parenting Program [RPP], and prison nursery programs as exist in 8 states) to facilitate healthy pregnancy, labor and delivery, and maternal/infant bonding following delivery.
	c. Assure that these programs offer culturally and linguistically appropriate services for AI/AN women.
	d. Partner with states so that every state with AI/AN populations has one or more of facilities that provide these programs.
EXPAND VIOLENCE SURVEILLANCE AND UNIVERSAL SCREENING	
46.	Expand surveillance strategies, including Interpersonal Violence (IPV)-related modules, substance use, and mental health questions, as part of participating state Pregnancy Risk Assessment Monitoring System (PRAMS) surveys. IPV-related modules should include the issue of reproductive coercion or birth control sabotage.
47.	Provide ongoing support and capacity building for Tribal PRAMS programs to include multi-state, AIAN-specific initiatives (e.g., Navajo PRAMS, South Dakota Tribal PRAMS).

48.	Encourage the inclusion of universal screening with referral for intimate partner violence, substance use disorder, depression, and anxiety in the evaluation of pregnant and postpartum individuals. Safeguards need to be in place to assure that screening results don't initiate a cascade of events that include: further separating mothers and children, placing children in foster care, and deterring AI/AN women from engaging with health care precisely because they fear legal and cps involvement.
49.	Support measures to incentivize identification and assessment of intimate partner violence at least once during each trimester of prenatal care and up to 1 year postpartum.
50.	Improve identification of pregnant/postpartum women in the first year after delivery who go to the emergency department or hospital who may be at risk for homicide, suicide, or drug overdose.
51.	Require that state Maternal Mortality Review Committees who use federal funds review all forms of pregnancy-associated and pregnancy-related deaths including homicide, intimate partner violence, suicide and suicidality, substance use and overdose deaths during pregnancy and 1 year postpartum.
52.	Require all states, districts, territories, and Tribes to include the pregnancy and interpersonal violence fields in CDC's National Violent Death Reporting System (NVDRS) database and provide CDC technical assistance in this effort.
53.	Support studies that identify the impact of generational IPV, trauma, and psychiatric disorders on risk of suicide and suicidal ideation among pregnant and postpartum women in general and, more specifically, among groups of women already at high risk for maternal morbidity and mortality, including refugees/immigrants, American Descendants of Slaves (ADOS) and AI/AN women.
54.	Build cultural resilience by funding culturally congruent interventions for pregnant and parenting people facing interpersonal violence, including grief counseling and trauma recovery that serve mothers, partners and children.
	IMPROVE TREATMENT OF SUBSTANCE USE & MENTAL HEALTH PROBLEMS
55.	Support culturally and language appropriate/specific prevention and treatment programs for mental health and substance use.
56.	Expand access to naloxone, with supporting education about its use among first responders, community, and family members.
57.	Develop standardized, culturally and language appropriate patient education materials that explain the link between mental health conditions, IPV and SUD with pregnancy-associated deaths.
58.	Identify strategies to facilitate access and engagement with maternal mental health services, including promoting trauma informed systems of care while promoting cultural safety.
59.	Priority be given to having federal advisory committee meetings, regardless of the topic, that focus on issues of specific communities be held in those communities to assure greater engagement, understanding, representation, and accountability.