

# Policy Brief

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## Strengthening Maternal Health Data to Improve Health and Wellbeing in American Indian and Alaska Native Communities

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## Executive Summary

The maternal health crisis in American Indian and Alaska Native (AI/AN) communities is both urgent and preventable. AI/AN women are two to three times more likely to die of pregnancy-related causes than White women.<sup>1-3</sup> Some state-level data and research suggests rates of AI/AN pregnancy-related mortality may be even higher due to systemic data issues, like racial misclassification in vital records.<sup>4</sup> Maternal Mortality Review Committees (MMRCs) found that 100% of recent pregnancy-related deaths among AI/AN women were preventable in 2021.<sup>5</sup> This report emphasizes the critical role of data in addressing maternal health disparities.

Data about American Indian and Alaska Native (AI/AN) populations are frequently undercounted, misclassified, or suppressed in public health surveillance datasets. While the US National Vital Statistics System (NVSS) offers comprehensive birth and death data that could benefit small populations like AI/AN communities, the inaccuracy of racial and ethnic information weakens its effectiveness as a resource for understanding AI/AN health.<sup>6</sup> Misclassification in mortality data leads to an inaccurate understanding of health outcomes for these groups.<sup>7,8</sup> Additionally, national reporting sites such as NVSS or The U.S. Centers for Disease Control and Prevention (CDC)'s WONDER database often suppress data due to concerns of identifiable data in small sample sizes.<sup>9,10</sup> These data issues lead to underestimates about the scope of health problems and gaps in knowledge that lead to insufficient responses in programming, funding, and policy. Accurately assessing health and wellness among AI/AN can be supported by addressing data erasure in public health surveillance systems.

In order to address the shortcomings of data regarding maternal health, it is imperative to understand the high rates of maternal mortality among AI/AN populations, the factors contributing to undercounting, and the limitations to the surveillance systems that monitor maternal mortality and other indicators of health and wellbeing. Data quality improvements can be achieved by increasing understanding of Tribal Public Health Authority and Indigenous Data Sovereignty, improving funding for public health surveillance, and supporting community attuned solutions led by AI/AN people. Several examples of AI/AN-led work and legislation relevant to data improvements in AI/AN health and wellbeing are presented. In order to strengthen the data quality, improve data access, and address the erasure of AI/AN people in data, we must:

- Uphold Indigenous Data Sovereignty
- Engage Tribes, UIOs, TECs and AI/AN People on Maternal Health Data
- Improve Data Quality by Including Indigenous Frameworks
- Ensure Access to Federal Health Data

The background, discussion, examples from practice, and recommendation included in this section reflect the authors' learning from AI/AN communities, matriarchs, and other leaders who have and continue to share their knowledge and experience. The content reflects direct community experience in addition to formal research and data sovereignty training. As Abigail Echo-Hawk, Executive Vice President of the Seattle Indian Health Board, has said many times, "When undertaking any efforts toward improving data collection among AI/AN people, come to AI/AN people because we have the answers, not because you think we have the most problems." The need for data sovereignty and new approaches to epidemiology have emerged in response to ongoing efforts to eradicate us from data systems and information that would strengthen our presence on these lands. Our people have solutions to the data issues that are documented herein – what is needed are resources and investments in those solutions.

## **Background**

### **American Indian/Alaska Native Maternal Mortality and**

According to the most recent data, the national maternal mortality rate (MMR) was 18.7 deaths per 100,000 live births in 2023, a slight decline from 21.5 in 2022.<sup>11</sup> Yet, racial and ethnic disparities persist. American Indian and Alaska Native (AI/AN) women are two to three times more likely to die of pregnancy-related causes than White women, with an MMR of approximately 54.4 per 100,000 as compared to 17 per 100,000 among the White mothers (2022).<sup>2</sup> Disparities in AI/AN maternal deaths also vary by age and timing of death. Data from MMRCs in 46 states show that in 2021, about 32% of AI/AN maternal deaths occurred among women aged 20-29, and about 57% among those aged 30-39.<sup>12</sup> Additionally, over half of the deaths occurred 7–365 days postpartum (57%).<sup>13</sup> The pregnancy-related deaths among AI/AN women were 100% preventable in 2021.<sup>13</sup> These statistics thus fail to capture the full picture of AI/AN maternal health: the intergenerational trauma of forced family separation, the erosion of traditional birthing practices, the geographic barriers to prenatal care in rural and reservation communities, and the pervasive inequality within health care systems that AI/AN mothers routinely encounter.

Some state-level data and research suggests rates of AI/AN pregnancy-related mortality may be even higher due to systematic data challenges, like racial misclassification in vital records.<sup>14</sup> In Washington state, where the state Maternal Mortality Review Panel has taken deliberate steps to address racial misclassification, AI/AN mothers experience a rate of pregnancy-related death 8.5 times higher than non-Hispanic White mothers.<sup>15</sup> This rate (84 per 100,000 births) far exceeds the national average, while other racial/ethnic groups in the state experience lower pregnancy-related death than the national averages (e.g., 36 per 100,000 births among Black mothers and 8 per 100,000 among Asian American mothers).<sup>15</sup> The AI/AN population in Washington

experiences the highest rate of maternal mortality and 80% of deaths are preventable.<sup>16</sup> The maternal health crisis in Indigenous communities is both urgent and preventable.

## **Maternal Mortality Surveillance Systems**

The above data is derived from the United States (U.S.) Maternal Mortality Surveillance Systems, which evolved and came into existence during a 100-year period. This history, which is detailed extensively in other publications, contributes to the complexity in maternal mortality surveillance systems.<sup>17–19</sup> Public health surveillance, like the Maternal Mortality Surveillance Systems, have jurisdictional complexity because governments at the Tribal, local, state, and federal levels have different authorities, responsibilities, rules, regulations, and reporting processes. The history and jurisdictional complexity results in fragmentation and data sharing challenges. Some significant historical milestones in the development of the U.S. Maternal Mortality Surveillance Systems worth noting include:

- 1915 - 1930s: Maternal mortality surveillance activities started when basic vital records, in the form of death records, were submitted to the National Center for Health Statistics. The data was used to create the inaugural national maternal mortality ratio, and the first Maternal Mortality Review Committees seek to find prevention strategies.
- 1980s - 1990s: Maternal mortality in the United States declined, and many MMRCs eventually ended their work. The Centers for Disease Control and Prevention (CDC) created Pregnancy Mortality Surveillance System (PMSS) and Pregnancy Risk Assessment Monitoring System (PRAMS) as a response to disappearing MMRCs, limitations of vital statistics data, and the need for more data about pregnancy and parenthood knowledge, attitudes, and behaviors. Improvements in maternal mortality eventually began to erode, and maternal mortality rates rose.
- 2000s - 2020s: Disparities in maternal mortality, especially by race and ethnicity, indicate a need to again prioritize maternal mortality surveillance activities. The pregnancy checkbox is added to death certificates as a strategy to improve the identification of pregnancy-related deaths on death certificates. Support for MMRCs is revitalized and funding is provided to modernize data tools and enhance participation in MMRCs.

Today, the surveillance system for maternal mortality in the U.S. includes the National Vital Statistics System (NVSS), Pregnancy Mortality Surveillance System (PMSS), and Maternal Mortality Review Committees (MMRC). Scholars have described each of these systems and provided in-depth summaries of strengths and weaknesses.<sup>18,19</sup> Each surveillance system was created with a distinct purpose, scope, data source, measure, and terminology as summarized below.

U.S. Maternal Mortality Surveillance Systems: A Comparison			
	CDC – National Vital Statistics System (NVSS)	CDC – Pregnancy Mortality Surveillance System (PMSS)	State and Local Maternal Mortality Review Committees (MMRCs)
<b>Data source</b>	Death certificates	Death certificates linked to fetal death and birth certificates	Death certificates linked to fetal death and birth certificates, medical records, social service records, autopsy, informant interviews, etc.
<b>Time frame</b>	During pregnancy — 42 days	During pregnancy — 365 days	During pregnancy — 365 days
<b>Source of classification</b>	ICD-10 codes	Medical Epidemiologists	Multidisciplinary committees
<b>Terms</b>	Maternal death	Pregnancy-associated, (Associated and) Pregnancy-related, (Associated but) Not pregnancy related	Pregnancy-associated, (Associated and) Pregnancy-related, (Associated but) Not pregnancy related
<b>Measure</b>	Maternal mortality rate — number of maternal deaths per 100,000 live births	Pregnancy-related mortality ratio — number of pregnancy-related deaths per 100,000 live births	Pregnancy-related mortality ratio — number of pregnancy-related deaths per 100,000 live births
<b>Purpose</b>	Show national trends and provide a basis for international comparison	Analyze clinical factors associated with deaths; publish information that may lead to prevention strategies	Understand medical and nonmedical contributors to deaths; prioritize interventions that effectively reduce maternal deaths

Source: Eugene Declercq and Laurie C. Zephyrin, *Maternal Mortality in the United States, 2025*<sup>19</sup>

In order to identify prevention and intervention opportunities to reduce disparities in maternal mortality, it is important to understand the history and differences between the maternal mortality surveillance systems. This knowledge can inform understanding of the unique challenges and opportunities these systems present for describing the trends and contributors to pregnancy-related death for AI/AN people. The lack of accuracy in recording race and ethnicity for AI/AN people is a well-documented challenge in surveillance data, especially vital statistics like birth and death records<sup>6,7,20,21</sup>. Methodological decisions about racial classification in data can affect the size and characteristics of the population used in analysis.

**Racial Misclassification**

Racial misclassification occurs when an individual’s self-reported race is incorrectly recorded in official data collection forms, like birth and death records.<sup>22</sup> This issue, frequently seen among AI/AN populations, is common throughout federal, state, and local government-sponsored data collection efforts.<sup>23</sup> A study linking state vital records mortality data to the Indian Health Service master patient file found that in Oklahoma all-cause mortality for AIANs was underestimated by nearly 29% between 2011 and 2015.<sup>8</sup> In the case of maternal mortality, Heck et al.<sup>14</sup>, describe:

“Racial/ethnic misclassification on death certificates potentially leads to underreporting and compromised estimates of mortality, with as many as 45% of AI/AN deaths being misclassified as another race. Given the relatively small AI/AN population, even negligible misclassifications can markedly affect data analyses, likely resulting in an underestimation of AI/AN maternal mortality.” (p. 226)<sup>14</sup>

The methods used for racial classification vary across data sources and surveillance systems. These methodological decisions impact size and characteristics of populations. For example, the PMSS uses separate categories for Hispanic origin and race.<sup>24</sup> Any AI/AN person who identifies as Hispanic is classified as Hispanic. Any AI/AN individual who identifies as non-Hispanic is classified as non-Hispanic single-race AI/AN while people who identify as more than one race are classified as non-Hispanic Multi-Race.<sup>25</sup> These racial classifications result in an undercount of AI/AN people who identify as Hispanic or more than one race or suppresses AI/AN data into a Multi-Race category that cannot be disaggregated.

Racial misclassification is problematic because it obscures data and erodes allocation of resources. For this reason, Echo-Hawk et al.<sup>26</sup> argue racial misclassification contributes to the “the elimination of AI/AN people resulting in the non-fulfillment of treaty and trust responsibilities due to lack of data on urban and rural tribal communities.” For nearly 30 years, scholars have examined racial misclassification and proposed methods for correcting misclassification in AI/AN data.<sup>27–29</sup> The Urban Indian Health Institute (UIHI) recommends an inclusive standard where all AI/AN people – alone, multiple races, and Hispanic origin – are counted.<sup>30</sup>

The UIHI recommendation to correct racial misclassification was applied to maternal mortality data. A report titled *Pregnancy-Related Deaths: Data from Maternal Mortality Review Committees in 36 US States, 2017–2019* demonstrated how applying the UIHI recommendation resulted in increased identification of pregnancy-related deaths among AI/AN people from 9 to 17 cases.<sup>12</sup> In a second example from 2021, identified cases increased from 24 deaths to 37 deaths when AI/AN people was counted if they reported AI/AN alone and in combination with other racial identities. The authors of these reports cautioned that despite the increase in cases, the number was likely still an undercount due to persistent limitations in how vital records classify AI/AN women.<sup>31</sup> Without accurate data collection and racial classification, the true burden of maternal mortality in AI/AN communities remains underestimated, further obscuring the need for resources and policy change.

## **Discussion**

### **Public Health Authority**

Public health authority is one of the legal foundations for a sovereign government to oversee the health and wellbeing of their citizens within their jurisdiction.<sup>32</sup> The inherent sovereignty of a Tribal nation upholds this legal foundation regardless of whether a Tribe operates their own public health department.<sup>32</sup> Tribal Epidemiology Centers (TECs), many founded as tribal public health organizations nearly 30 years ago, were designated Public Health Authorities in the Indian Healthcare Improvement Act of 2010. A total of 12 TECs serve AI/AN communities across the U.S., including 11 regional TECs founded to support the 574 federally recognized Tribes and 1 national TEC serving urban Indian organizations.<sup>33</sup> Designation as public health authorities, gives TECs the legal authority to engage in public health activities as a sovereign government would to promote and protect the health of the people within their jurisdiction.<sup>34</sup>

Congressionally authorized scopes of work for TECs specify public health activities, including access to data for epidemiologic and public health functions.<sup>33,35</sup> However, Tribes and TECs face barriers in accessing and obtaining federal and state health data and few pathways or policy guidelines exist for state or federal government agencies to implement data sharing.<sup>35</sup> While concerns about protecting individual health data are valid, it is important to consider the implications of not developing adequate pathways and support for Tribes and TECs to regularly access their protected health information. Upholding Indigenous data sovereignty and improving data collection practices are critical steps toward supporting AI/AN maternal and infant health.

### **Indigenous Data Sovereignty**

Data sovereignty—the right of Indigenous communities to govern the collection, ownership, and application of their own data—is fundamental to addressing maternal health disparities affecting AI/AN communities. According to several scholars<sup>35,36</sup>, the legal frameworks of sovereignty, treaties, and trust obligations apply to AI/AN data and form the basis of automatically sharing public health data with Tribes and TECs. Furthermore, data sovereignty extends to any and all data collected about AI/AN people.<sup>26</sup> Data sovereignty practices also combat ongoing issues in which AI/AN peoples have been subjects of surveillance and research rather than partners in it, and have had data extracted from communities, interpreted through colonial frameworks, and rarely returned in ways that support community-defined priorities. This legacy of data exploitation and extraction has contributed to persistent knowledge gaps, misclassification, and invisibility in maternal health statistics that obscure the true extent of disparities and hinder effective intervention. Conversely, the Urban Indian Health Institute's Data Defender model positions Tribes, AI/AN organizations, and AI/AN people as stewards of their own information by employing data governance structures that honor Indigenous values, protecting privacy, and

ensuring data serves community wellness rather than merely outside academic or governmental interests. These frameworks challenge conventional research paradigms and call for fundamental restructuring of how maternal health data is collected, analyzed, and utilized.

## **Strengths-Based Data Approaches**

Western data collection on the health and wellbeing for AI/AN populations, describes the health problems and deficits in AI/AN communities, without acknowledging or often even considering the community-based approaches that have begun solving these issues. In recent years, researchers working to measure AI/AN health have taken important steps to move the focus of the field from a “deficit-based” focus to one that is more “strengths-based. Where deficit-based health models focus on what is wrong, strengths-based approaches focus on identifying and supporting the various protective factors that support people improving or maintaining health. There are several examples of data collection tools being modified and adapted to be strengths based and community-attuned to provide more robust data on the health and well-being in AI/AN communities. A Dakota community created the Wicozani Instrument , a nine-item self-report tool that measures mental, physical, and spiritual health and the impact on the quality of li<sup>37</sup>.<sup>37</sup> Dr. Angela Snowshoe and colleagues developed the Cultural Connectedness Scale (CCS), a 29-item instrument that measures the degree of cultural connection in First Nations you.<sup>38</sup> Building off Snowshoe’s work, members from six Urban Indian Health Organizations worked to adapt the CCS to be appropriate for the multi-Tribal communities of urban California.<sup>39</sup> In a 2024 paper, Maudrie et al. developed an Indigenous Nourishment Scales in collaboration with AI/AN communities in Baltimore and Minneapolis that captures indicators of Indigenous nutrition.<sup>40</sup> These Indigenous-led measurement development efforts demonstrate how to improve the completeness of data collected that is useful, relevant, and community-attuned.

## **Workforce Development**

Support the development of a professional workforce, including AI/AN scientists, who are knowledgeable about data issues and capable of training people (e.g hospital staff, funeral directors, coroners, etc.) about strategies for improving AI/AN data. Scientists from AI/AN communities remain underrepresented within government, academic, Tribal, private, and nonprofit research settings. According to the Postsecondary National Policy Institute, American Indian and Alaska Native higher educational attainment is less than half of the national rate, with 16.8% of adults earning a bachelor’s degree or higher compared with 36.2% of all America.<sup>41</sup> While training programs and recruitment efforts exist at varying levels of education, higher education attainment in data science, public health, and related fields remains a core issue undermining AI/AN data leadership. At the same time, there is a highly qualified cadre of AI/AN

researchers in maternal health who are at the forefront of addressing the policy and data issues highlighted in this report.

Existing models for workforce development for AI/AN, such as the Centers for Disease Control and Prevention (CDC) Tribal Epidemiology Center Public Health Infrastructure (TECPHI) program, should continue to be funded. After a 5-year investment from 2017-2022, TEC workforce grew by 72%, the proportion of staff with a health-related degree increased by 27%, and representation of AI/AN staff increased to 33% of all TEC staff.<sup>42</sup> Workforce investments in TECs led to improved data infrastructure, increased data sharing, and increased dissemination of health data specific to AI/AN population.<sup>42</sup> More support for workforce development improves AI/AN-led maternal and child health data efforts, including racial misclassification data trainings, which is addressed further under our recommendations.

## **Funding**

Current funding structures significantly shape—and often constrain—the ability of AI/AN communities to exercise data sovereignty in maternal health research and program evaluation. Indian Health Service funding, chronically inadequate and subject to discretionary appropriations, limits infrastructure for robust data systems within Tribal health programs. Federal research grants frequently require data sharing arrangements that conflict with Tribal sovereignty and data governance protocols. Philanthropic funding, while sometimes more flexible, often supports short-term projects that cannot sustain the long-term data infrastructure AI/AN communities need to monitor and improve maternal health outcomes over time. Furthermore, AI/AN communities continue to receive a small fraction of philanthropic investment dollars.

According to a report by Native Americans in Philanthropy, “In relation to Native communities, approximately 0.04% of funding goes to AI/AN people,<sup>43</sup> according to a 2018 publication by First Nations Development Institute; on average, 0.15% of community foundation funding goes to Native American organizations and causes annually.”<sup>44</sup> These challenges are compounded by the current federal funding environment. Recent administrative actions have disrupted ongoing maternal health initiatives, creating uncertainty for programs, longitudinal studies, and community-based participatory research projects that are essential for understanding and addressing AI/AN maternal health disparities. The defunding of federal mechanisms not only threatens to widen existing knowledge gaps but also undermines Tribal sovereignty, treaty rights, and trust responsibility. In this context, protecting and expanding AI/AN-led data sovereignty initiatives becomes not merely a matter of research ethics, but a critical strategy for Tribal Public Health Authority, maternal health equity, and survival.

## **Community Engagement, Governance, and Data**

Considering the data gaps, underreporting and absence of AI/AN-defined indicators, it is important to look to AI/AN-led efforts.

### **Albuquerque Area Southwest Tribal Epidemiology Center**

Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC) leads multiple Tribal Maternal Child Health programs and projects with partners in their service area. In 2018, AASTEC launched the Tribal Pregnancy Risk Assessment Monitoring System (PRAMS), a Tribal public health surveillance system. The project, a collaboration with the Navajo Nation Tribal Epidemiology Center and the New Mexico Department of Health, delivers a culturally adapted public health survey designed to gather vital data on the experiences, attitudes and behaviors of AI/AN mothers before, during, and after pregnant.<sup>46</sup> In 2024, AASTEC hosted workshops with AI/AN communities to co-create a Tribal PRAMS Toddler Survey. The initiatives aim to strengthen the availability of high-quality AI/AN-specific data for Tribes and Tribal health programs to monitor trends, plan targeted programs, and inform policy based on rigorous, culturally attuned data.

### **Arizona Tribal Maternal Health Task Force<sup>47</sup>**

Arizona Department of Health Services (ADHS) created the Tribal Maternal Health Task Force (Tribal MHTF) as part of their Maternal Health Innovations Program. The Tribal MHTF was a response to data from 2018-2019 showing AI/AN mothers had the highest pregnancy associated preventable mortality compared to all racial and ethnic groups in Arizona. The Tribal MHTF was formed with a mandate to engage AI/AN people in implementing community-driven, culturally attuned, and tailored solution<sup>48,49</sup> A Program Manager, who is a member of Navajo Nation with over a decade of experience working with the AI/AN community, supports the Tribal MHTF. In this role, the Program Manager works with Arizona's 22 federally recognized Tribes, Dine College, and the Intertribal Council of Arizona to implement culturally appropriate initiatives to decrease maternal morbidity and mortality. The creation of the Tribal MHTF has built a pathway toward Indigenous data sovereignty as Arizona's Maternal Mortality Review Committee now convenes a AI/AN subcommittee to review pregnancy-related deaths for AI/AN people.

### **Hummingbird Indigenous Family Services<sup>50</sup>**

The Nest pilot, led by Hummingbird Indigenous Family Services, is an example of strengthening data systems to support American Indian, Alaska Native, Native Hawaiian, or Pacific Islander families expecting a child. The five-year guaranteed income pilot relieves financial stress by providing up to \$1,250 monthly to 150 families in King and Pierce Counties until their child's third birthday. The program has advanced maternal health and well-being data quality and efficiency through an Indigenous-led design process, while providing financial support. Hummingbird partners with Aidkit, which provides a customized platform to include a lineage

tracker without requiring Tribal identification numbers, respecting sovereignty while gathering needed eligibility data. The system also enforces strong data governance protections, ensuring that data is not monetized, and streamlines enrollment and reporting through a secure, mobile-friendly platform. For the evaluation component of the Nest, Hummingbird retains full data ownership while collaborating with an external university partner and collecting novel data on Indigenous maternal health and economic well-being indicators. This approach demonstrates how investments in cash assistance programs can combine culturally responsive design with rigorous data integrity. The Nest pilot offers a model of ethical data systems work that delivers measurable results, upholds sovereignty, and supports family.<sup>50</sup>

### **Tulalip Nation and Washington State Data Sharing Agreement<sup>51</sup>**

In early 2025, the Tulalip Tribe and Washington State Department of Health signed the first ever Tribal specific data sharing agreement.<sup>52</sup> The landmark agreement advances Tribal Data Sovereignty by giving Tribes direct access, ownership, and governance of public health data collected by the state. This includes surveillance data, disease reporting, birth records, labs, and environmental health metrics. With this agreement, the Tulalip Tribe has the data to lead investigations of community health threats, set priorities based on real-time local data, and control how the data is used. This partnership embodies a government-to-government model grounded in transparency, respect for Tribal self-determination and improved health outcomes.

## **Legislative History and Issues for Congress**

### **H.R.1318 - Preventing Maternal Deaths Act of 2018 (115th Congress)**

This bipartisan bill, first introduced in 2017, became law in December 2018. It was passed with the goal of addressing maternal mortality rates, including thorough provisions specifically meant for Tribes. It led to the establishment of Tribe- or Tribal organization-operated maternal mortality review committees (MMRCs) to identify pregnancy-associated or related deaths; identify outcomes, trends, and patterns that may contribute to such deaths; and make recommendations to improve maternal care and reduce the rate of such deaths. Under the law, recommendations could be provided to health care professionals and facilities, coroners, medical examiners, and other professionals tasked with completing death records. This allowed Tribes and Tribal organizations to lead efforts to improve AI/AN maternal health data, which is the critical foundation for increased investments in AI/AN maternal health. A bill to reauthorize this Act was introduced in 2023 and passed the House of Representatives in 2024 but failed to advance in the Senate. H.R.1318 included funding to support these efforts through fiscal year 2023. The reauthorization bill would have provided additional funding through fiscal year 2028. Access to quality data is critical for appropriate funding, as many government funding decisions are data-driven. A new reauthorization bill, introduced in March 2025, currently sits with the

House Committee on Energy and Commerce. The Preventing Maternal Deaths Act of 2018 should be reauthorized to support continued data improvement efforts, which in turn will lead to better awareness of factors impacting maternal mortality rates and increased targeted investments to address them.

### **H.R.3320 - Data to Save Moms Act (118th Congress)**

Introduced in 2023, this bill, aimed at improving maternal health data collection and data quality, failed to gain traction in Congress. It would have built on the success of MMRCs by providing grants for states, Tribes, Tribal organizations, and urban Indian organizations. The grants would have been used to increase representation on MMRCs, ease participation from community members, and increase outreach to communities. The bill would have further broadened the scope of MMRCs, requiring data collection and review, when possible, on cases of severe maternal morbidity, suicide, overdose, and deaths from mental health conditions or substance use disorder. In addition to MMRCs, the bill sought to improve data by requiring the Centers for Medicare and Medicaid Services and the Agency for Healthcare Research and Quality to review and improve maternal health data collection practices. This bill should be reintroduced as it would not only contribute to supporting MMRCs but would also improve data practices within government agencies.

### **Native Children’s Commission Implementation Act**

This draft legislation focused on improving the health and well-being of AI/AN children. Certain provisions contained in the legislation could prove useful in addressing AI/AN maternal health. The legislation recommends the creation of an Office on Native Children, housed within the U.S. Department of Justice (DOJ), and the establishment of a National Clearinghouse on Native Children to better coordinate data, programs, and funding. The draft legislation also calls for the creation of an Inter-Agency Committee on Indigenous Data Sovereignty, led by the DOJ and the Office of Management and Budget, with a report due to Congress within one year. The legislation directs the HHS Secretary to conduct a study on maternal mortality and domestic violence to support understanding of solutions for Native maternal health. Other provisions call for the establishment of several Tribal Advisory Committees (TAC) including: a TAC to support the Inter-Agency Committee on Indigenous Data Sovereignty within the Bureau of Indian Affairs, a TAC on Native maternal health within HRSA’s Maternal Health Bureau, and a TAC on Early Childhood in the Office of Early Childhood Development at the Administration for Children and Families. These provisions could galvanize support, improve the quality of information across federal agencies, bolster data access for the I/T/U system, and increase resources for maternal health.

## **Department of Health and Human Services (HHS) Data Access**

25 U.S.C. § 1621m guarantees access to all HHS data for Tribes and TECs. To uphold congressional intent and ensure Tribes and TECs can carry out their duties and responsibilities as public health authorities, HHS and all HHS Divisions must work to improve access to data for use by Tribes and TECs. HHS and Divisions must update their existing internal policies to go further than HHS's Tribal Data Access Policy and Tribal Epidemiology Center Data Access Policy. HHS and its Divisions must ensure explicit deadlines are stated and upheld for data sharing, require periodic Tribal input on the ease of data access, offer training to federal employees on sharing data with Tribes and TECs, and remove any existing language in policies that prevent the sharing of data with Tribes and TECs. With improved access to HHS data, Tribes and TECs will be able to deepen our understanding of the maternal health crisis, offer data-driven solutions, and seek data-driven funding opportunities.

## **Centers for Disease Control and Prevention (CDC) Data Modernization Initiative (DMI)**

The DMI was launched by the CDC in 2019 as an effort to overhaul public health data management in the federal government, ultimately leading to the CDC's Public Health Data Strategy (PHDS), launched in 2023. The goal of the PHDS is to create an interconnected data infrastructure to be better prepared for future health crises. As CDC continues to work on an interoperable and interconnected data infrastructure, it must ensure that Tribes, Tribal organizations, urban Indian organizations, and TECs have access to this infrastructure. This would uphold congressional intent for access to all HHS data by Tribes and TECs and empower Indian Country to produce better data to continue to shine a light on the maternal mortality crisis and need for additional resources.

## **Recommendations**

The following recommendations would uphold congressional intent for access to all HHS data by Tribes and TECs, and empower Indian Country to produce better data, and galvanize AI/AN communities to continue to shine a light on the maternal mortality crisis and need for additional resources. Key recommendations to improve data, data sovereignty, and governance for American Indian and Alaska Native maternal health includes:

- Uphold Indigenous data sovereignty
- Engage Tribes, UIOs, TECs, and AI/AN about maternal health data
- Ensure data access to federal health data for Tribal Public Health Authorities
- Improve data quality by including Indigenous frameworks

## **Uphold Indigenous Data Sovereignty**

- Create an Inter-Agency Committee, led by the DOJ and the Office of Management and Budget, on Indigenous Data Sovereignty, with a report due to Congress within one year.
- This would uphold Indigenous data sovereignty, the right for Tribes to govern the collection, ownership, and application of their own data, including data collected on their Tribal citizens, in relation to maternal and infant health. Indigenous data sovereignty practices can help inform the improvement of data structures to reflect the collective interests of Tribes and urban AI/AN communities.

## **Engage Tribes, UIOs, TECs and AI/AN People on Maternal Health Data**

- To support the growing AI/AN population, each federal agency must uphold the rights under Tribal Consultation policies and implement an Urban Confer policy, such as the Indian Health Services policy. These processes can facilitate identification of recommendations by Tribes and AI/AN communities for addressing maternal health issues, including data access and quality.
- Establish Tribal Advisory Committees (TACs) within the Bureau of Indian Affairs to support the inter-agency committee, within HRSA's Maternal Health Bureau focused on Native maternal health, in the Office of Early Childhood Development at the Administration for Children and Families on early childhood
- Direct the HHS Secretary to conduct a study on maternal mortality and domestic violence to support a further understanding of solutions for Native maternal health within executive agencies. This can galvanize support within agencies and lead to increased federal resources dedicated to this cause. Better information within the executive branch would allow federal agencies to be better partners for the I/T/U system as it continues to improve maternal health outcomes.

## **Improve Data Quality by Including Indigenous Frameworks**

- Consider cultural implications and redefine quality improvement. Federal agencies must review how quality improvement is defined, and in doing so, honor the existence of Indigenous frameworks. This should occur in federal policies, programs, funding, training, technical assistance, data and information sharing, partnerships, and collaboration.
- Improve federal data tools, like the Health Resources and Services Administration (HRSA) Maternal and Infant Health Mapping Tool, which perpetuates the erasure of AI/AN people. This work should be done in collaboration with Tribal public health authorities and TECs.
- Human Health Services (HHS) and its divisions should be required to provide technical assistance and training to States to improve data quality.

- Require CDC and other government agencies to publish annual infant and maternal health reports specific to AI/AN populations and data. Request that the agency achieve this by using small population methodologies for sampling analysis in consultation with Tribes, Tribal organizations, and urban Indian organizations as well as national organizations such as the National Indian Health Board and the Urban Indian Health Institute (UIHI). These methodologies include:
  - Aggregating data across time to include a longer time frame for the analysis which builds larger samples, thus assists in overcoming the challenge of small populations analysis.
  - Using weighted sampling for AI/AN populations, as this gives increased strength to small populations.
  - Oversampling the AI/AN population.
  - Include data that lists AI/AN alone and in combination with other races as well as including both Non-Hispanic and Hispanic.

### **Ensure Access to Federal Health Data**

- Implement recommendations from the Native Children’s Commission Implementation Act, a draft legislation focuses on improving the health and well-being of AI/AN children where certain provisions contained in the legislation could prove useful in addressing AI/AN maternal health including:
- Create an Office on Native Children, housed within the U.S. Department of Justice (DOJ), for the purpose of establishing a National Clearinghouse on Native Children. This allows for the compiling of data and reports on Native children and the sharing of information on grant opportunities. This would improve data access for the I/T/U system and promote access to federal resources.
- Implement 25 U.S.C. § 1621m **Department of Health and Human Services (HHS) Data Access** to guarantee access to all HHS data for Tribes and TECs
- Implement CDC’s Public Health Data Strategy (PHDS) and ensure that Tribes, Tribal organizations, urban Indian organizations, and TECs have access to this infrastructure.

### **Implementation Pathways**

Addressing all recommendations will require a multipronged approach that engages legislators, administrators, and federal agency partners. Ensuring buy-in from stakeholders at all levels will be critical to improving maternal health data for AI/AN communities. Congress can, through its oversight of federal agencies, support administrative-level changes. Efforts should be focused on specific committees and subcommittees relevant to the legislative efforts and administrative bodies targeted by these recommendations. These include Appropriations, Indian Affairs, Natural Resources, Energy and Commerce, Finance, and Ways and Means. While unified,

national changes are ultimately preferred, state-level changes can fill targeted gaps and demonstrate the effectiveness of certain solutions. State-level changes can serve as pilot programs that federal implementation can be modeled after, such as the example of Arizona’s Tribal MMRC. Testimony, oral or written, can be a catalyst for change, and advocates should seek opportunities to testify and give success stories. Organizations can also work with their members of Congress to organize briefings and present stories and data to members and staff. Building this base of support is critical to long-term success.

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