Breaking the Cycle of Maternal Health Inequality in American Indian/Alaska Native Women

Empowering Self-Determination of Health in Indigenous Women by Fostering Critical Health Literacy and Promoting Effective Client-Provider Relationships

POSITION STATEMENT

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Phoenix, Arizona
July 4, 2021

Preface

Body and Soul Sovereignty, United is committed to be a "trauma-informed" service system and/or organization in which all components of the system have been reconsidered and evaluated in the light of a basic understanding of the role that violence and trauma play in the lives of people seeking our services. We are committed to:

- supporting and sustaining "trauma-specific" services as they develop
- recognizing that trauma results in multiple vulnerabilities and affects many aspects of a survivor's life over the lifespan
- coordinating and integrating trauma-related activities and trainings with other systems of care serving trauma survivors.
- All staff will have a basic understanding of trauma and trauma dynamics, including those caused by childhood or adult abuses in any form, to be used to design systems of services in a manner that accommodates the vulnerabilities of trauma survivors and allows services to be delivered in a way that will avoid retraumatization and facilitate consumer participation in treatment.

Body and Soul Sovereignty, United is committed to be a trauma informed service system that is knowledgeable and competent to recognize and respond effectively to adults and children traumatically impacted by any of a range of overwhelming adverse experiences in adult or childhood, both interpersonal in nature and/or caused by natural events and disasters.

Community-based Participatory Framework

Abstract from a study in 2018

Patient empowerment, a concept that focused on patient-centeredness and patient's autonomy, is a well-discussed topic in health literature. However, translating the theory into practice is a challenge. The purpose of this study was to assess the effectiveness of interventions on patient empowerment and to identify and compare the modalities of these interventions. The most recurrent behavioral change technique identified in our review was "knowledge", though this is not sufficient to be empowered. "Goal setting" and "action planning" were more likely to be applied in successful interventions. "Knowledge" could be combined with "goal setting" and "action planning" to empower. Thorough understanding of the concept of patient empowerment remains necessary.

- Werbrouck, et al. (2018)

» Translation. *The message of this abstract is that empowerment, especially if we look at it from the perspective of health, is defined by not only understanding the knowledge but also using that knowledge and applying it to improve your health and the health of your community. This is* **true empowerment** *– to purposefully become a partner and take responsibility in the learning, sharing, and contributing to address the health disparities experienced by Native women.*

Bass, United is committed to support the empowerment of Indigenous women in maternal and/or women's health using the **Community-based Participatory Framework** (CBPF). **CBPF** is a partnership approach to obtain health knowledge that is equitable and involves community members, practitioners, and academic educators in all aspects by providing their expertise and sharing responsibility.

Indigenous peoples are linguistically, culturally, and genetically diverse peoples. The notion of the structure of indigenous kinship systems as parallel to non-indigenous is a leading example as to how easily our inalienable spiritual responsibilities are misunderstood by these fragmented systems who only see our relationships to each other through the lens of an Anglo-American concept. CBPF is one approach for addressing the understandable distrust of academic research within Tribal communities which in turn, can help to ensure the cultural vitality of future generations.

In light of this approach, the development of Bass, United will be considered iterative, an ever-changing process involving the ongoing participation of Native women from any and all Tribes who wish to be part of the process.

We welcome all feedback during this journey for it is the only path to truly refine and align with the needs of the women, their families and their communities.

In addition, the information in this document and on the **BASS, United** website consists of evidence-based research mostly completed within the last 5 years. At the 5-year point, the information will be reviewed and renewed. However, if the research is considered "foundational" in other words, knowledge that although, may be beyond 5 years but still influences practice today, then it will remain. It is important to understand that if we only consider literature that is recent, and value that more highly than if it is robust, then we will be missing important evidence to inform the patients and to guide clinical practice.

Thank you.

The BASS, U team.

Additional copies of this publication are available from *Body and Soul Sovereignty, United.*

www.bassunite.org (Website in development)

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Printed in the United States of America

Suggested citation:

Rodriguez, L. (2021). Breaking the cycle of maternal health inequality in American Indian/Alaska native women: empowering self-determination of health in indigenous women by fostering critical health literacy and promoting effective client-provider relationships, position statement, Body and Soul Sovereignty, United, retrieved from ***www.bassunite.org.***

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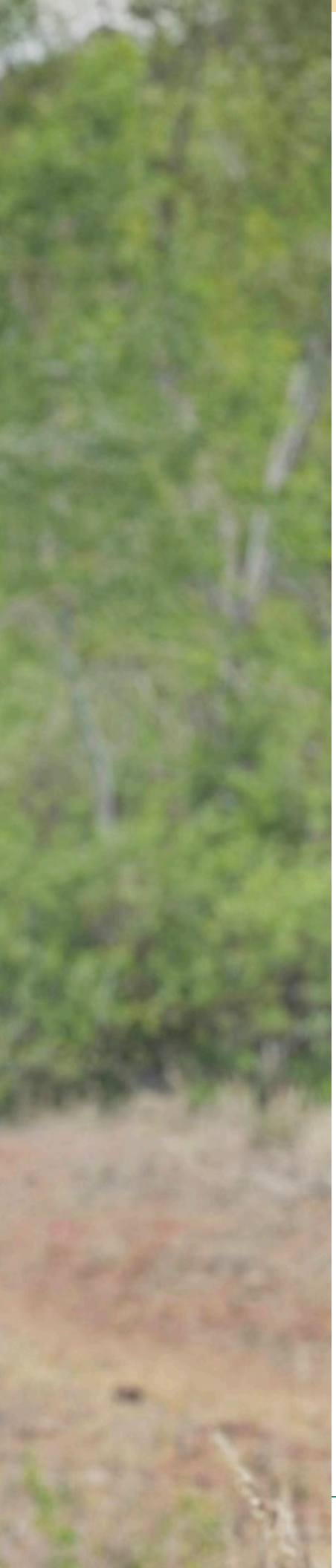

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Welcome to **Body and Soul Sovereignty, United**

Executive Summary

Mission

To provide Native women with access to all-inclusive, evidence-based maternal and women's health knowledge while promoting improved client – provider relationships. **Knowledge is power,** the power for Native women to have personal sovereignty in their right to make informed health decisions in health and end healthcare disparities.

Vision

To empower Native women to reach for their highest potential of maternal and women's health and break the barrier of healthcare inequality.

The first task of the mission is to address the national maternal health crisis in Native women by empowering them to become self-advocates in their own health and in the management of their own healthcare. The second task is to improve the relationship between the patient and provider by educating both parties on how to open the lines of communication within healthcare settings. Women of color have for centuries, been oppressed, marginalized, abused and their worth minimized. For many of the women, these elements of conquest may be enough to make them walk away and not pursue their full potential. In their interactions with healthcare providers, they may be more accepting and less likely to question certain situations. When a woman feels like she is being overcome, this feeling can translate into her children and grandchildren, with the potential of perpetuating the very same feelings into her future generations. It is referred to as **'Ghosts in the Nursery,'** as noted by the child Psychoanalyst Selma Fraiberg. Such unresolved feelings have been associated with the development of many chronic conditions such as hypertension, diabetes and obesity today.

The progression of our mission will be iterative indicating that after addressing the **Maternal/child health inequalities** in Native women as the first goal, we will then continue on to the next health topic in the women's chronology of body and soul health needs. We will continue striving to provide an alternative forum of education, resources and advocacy to care for the Native woman's **body,** that negates reproductive coercion and supports contraceptive choice, to provide guidance in gynecological health, to empower Native girls during adolescence, to offer comfort and well-being during the menopausal years and to support the health of our Native elder women. On the other side of the spectrum, **BASS U** aims to nurture the healing of the **soul** which embodies a woman's psyche, heart and spirit in the experiences of violence, trauma and mental health wounds through education, community resources, behavioral health services and traditional support. On a global scale, violence against women has been used as a tool of warfare, ensuring the collapse of the community as a collateral consequence. The foundational research of the Adverse Childhood Experiences (ACEs) study has provided supportive evidence confirming the negative effects of untreated or inadequately managed health issues by conventional healthcare systems which in turn, can have damaging effects on Indigenous women and Tribal communities, similar to the damaging effects of warfare.

When considering the actions of those who were historically in power, the sudden closure of the labor and delivery unit at *Phoenix Indian Medical Center* (PIMC) toward the latter part of 2020, and the resulting impact on the patients was an event reminiscent of colonialistic trauma that still affects Native mothers and babies today. The decision was made and acted on without timely notice and without adequate direction for the women. The mandate for closure was traumatizing especially for those women close to their expected dates of birth. It is one example of many destructive practices that continue to affect Indigenous women within the very organization that asserts the need to *raise the physical, mental, social and spiritual health of AI/AN people to the highest level*, definitely not to jeopardize the health of Native mothers and babies. The women were not given choices nor guidance on how to proceed in seeking equitable care or options on how to manage unexpected bills when seeking care outside of the PIMC community. The experience deprived them of their right to be part of the equation and to act as advocates in the decisions they needed to make regarding their healthcare. The community has determined that the decision to discontinue maternity services was wrongly managed, unjustified and unacceptable. Indigenous women have the right to the self-determination and governance of their bodies and soul.

This mission will enact the first step of many, to break the vicious cycle of an inequitable and depraved history in the lives of First Nation women and children. When it comes to the inequality of care and the lack of inclusivity of all resources that Native women are eligible for, it is vital that our efforts provide direction for the women to take control for themselves and navigate the system of Western conventional medicine to their benefit. Despite the general dissatisfaction in the ways of Western conventional medicine, Native women will instead become the experts so that they are not only privy to their own traditional healing ways but also to a supplementary body of health knowledge from which to make decisions from. Native women have entitlement to and should possess all gender-specific, health-related wisdom, whether it be Tribal, Western or both, so that choices can be made that best suit themselves and the health of their families.

We are fortunate for the gifts that Native women bring forth to the global community and the essence of their being on both the evolution of our nations and on humanity overall.

The Universe is aware and reciprocates,

– The solution will begin with us, Body and Soul Sovereignty, United.

American Declaration on The Rights of Indigenous Peoples, 2016

Main Tenets Addressing the Health of Native Women

Article XVIII – **Health**

1. Indigenous peoples have the collective and individual right to the enjoyment of the highest attainable standard of physical, mental, and spiritual health.
2. Indigenous peoples have the right to their own health systems and practices, as well as to the use and protection of their vital medicinal plants, animals and minerals, and other natural resources for medicinal use in their ancestral lands and territories.
3. States shall take measures to prevent and prohibit Indigenous peoples and individuals from being subjects of research programs, biological or medical experimentation, or sterilization without their free, prior and informed consent. Likewise, Indigenous peoples and individuals have the right, as appropriate, to access to their data, medical records, and documentation of research conducted by individuals and institutions, whether public or private.
4. Indigenous peoples have the right to use, without discrimination of any kind, all the health and medical care institutions and services accessible to the general population. States, in consultation and coordination with indigenous peoples, shall promote intercultural systems and practices in the medical and health services provided in Indigenous communities, including training of Indigenous technical and professional health care personnel.
5. States shall ensure the effective exercise of the rights contained in this article.

Article VII – **Gender equality**

1. Indigenous women have the right to the recognition, protection, and enjoyment of all human rights and fundamental freedoms provided for in international law, free from discrimination of any kind.
2. States recognize that violence against Indigenous peoples and individuals, particularly women, hinders or nullifies the enjoyment of all human rights and fundamental freedoms.
3. States shall adopt, in conjunction with Indigenous peoples, the necessary measures to prevent and eradicate all forms of violence and discrimination, particularly against Indigenous women and children.

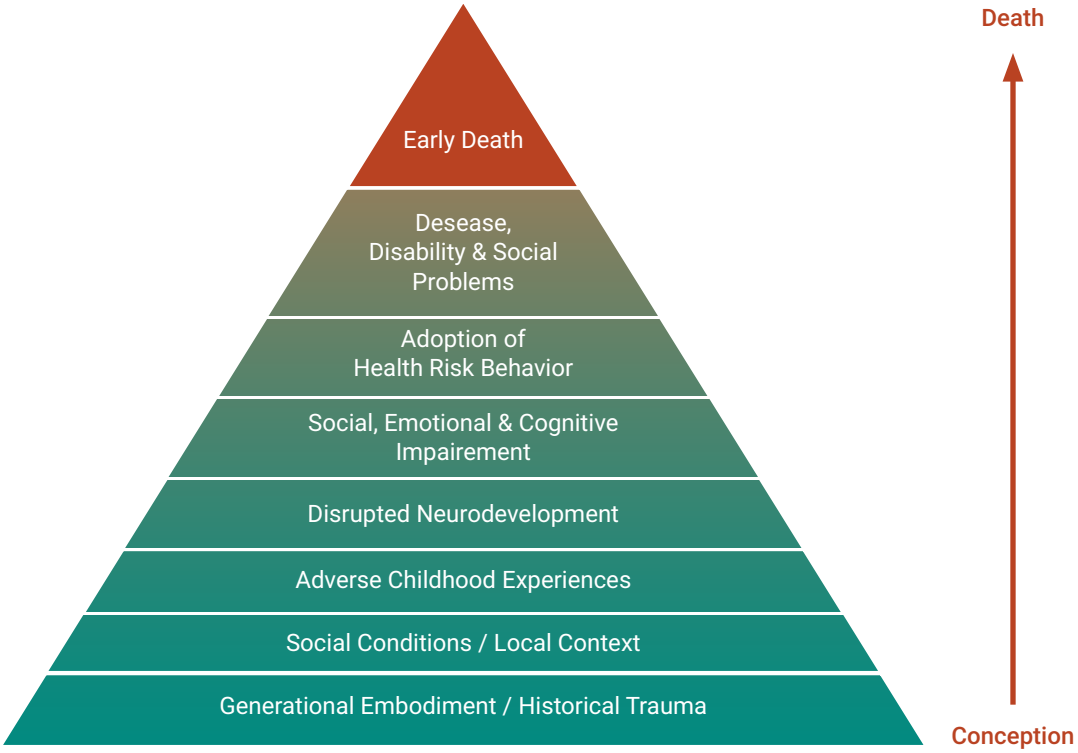
> ***Self-Determination Begins in the Womb – it is a call for women to exercise "Sovereignty over their own bodies,"***
>
> - Theobold, 2019

Adverse Childhood, Adult and Historic Experiences

One of the largest, most comprehensive landmark studies of the effects of childhood trauma on adulthood disease was in the work of Dr. Vincent Felitti from Kaiser Permanente and Dr. Robert Anda from the Center for Disease Control (CDC) called the Adverse Childhood Experiences (ACEs) Study back in the 1990s. The research ushered in a more mainstream understanding of the impact of childhood trauma on lifelong health, now with the understanding of how compounded adult trauma makes the outcomes even more complex. The initial study population, consisted of all insured, college-educated, middle class and mostly Caucasian subjects and 63.9% of the participants had experienced at least one ACE category and 12.5% had experienced four or more ACE categories. The research showed that in this patient population, a history of child sexual abuse was also common (Felitti, 1993, F).

The ACE study conveyed that the patients reporting greater numbers of ACEs had increased risk for smoking, severe obesity, physical inactivity, depressed mood, and suicide attempts (Felitti, 1993, F). In addition, there was a dose–response relationship between the number of ACEs and health conditions such as ischemic heart disease, cancer, chronic bronchitis/emphysema, liver disease, skeletal fractures, and poor overall self-rated health (Figure 1).

Although, women from Tribal communities were not part of the initial study, the social determinants of health (SDOH) including the effects of historical and current day racism, bias, discrimination and stereotyping, that Native people have been subjected to far surpass the scope of the challenges of the average White, insured, middle class, and college-educated communities. In fact, the overall burden of trauma in both urban and rural Tribal communities is felt to have been equated with conflict-ridden developing countries (Miller, et al., 2007, F). The following links to ***www.AZAces.org***, ***www.Acesaware.org*** and ***www.numberstory.org*** will provide further details on the ACEs research and the impact on health.



Mechanism by which Adverse Childhood Experiences Influence Health and Well-Being Throughout the Lifespan

Credit: Centers for Desease Control and Prevention

Figure 1. **ACEs are the most powerful determinants of Maternal/Child health.**

The Effects of Trauma on the Body

1. The word "trauma" is derived from the Greek word for "wound," and accounts of interpersonal trauma dated back to antiquity (Jones & Cureton, 2014, F-DSM-6 has not been released yet).

2. In a traumatic event, an individual may respond by either fighting, running away, freezing and/or fainting. If the traumatic event happens repeatedly over time, there is the potential for **Toxic Stress.**

3. Toxic stress starts to affect 3 systems in what is called the **HPA axis** (hypothalamic – pituitary – adrenal) which encompasses the central nervous system, the neuroendocrine and the immune system.
https://developingchild.harvard.edu/guide/a-guide-to-toxic-stress/

4. The **HPA** axis within the body releases stress hormones after trauma. However, the chronic activation of this system from toxic stress can lead to generalized and sustained **inflammation** in the body.

5. Chronic inflammation from repeated trauma and toxic stress can lead to, **"Allostatic Load,"** a cumulative imbalance of stress hormones (from recurrent traumatic experiences) which have been associated with the higher prevalence of disease and premature mortality seen in adulthood. Allostatic load also causes ill-health when the individual engages in behaviors such as tobacco or alcohol consumption as coping mechanisms. In a study by Guidi, J et al., (2021) the findings indicated that allostatic load is associated with poorer health outcomes. Allostatic load is also affected by the social determinants of health (SDOH), namely one's social economic status (SES), ethnicity, age, and work stress in women just to name a few. In a study regarding early pregnancy, allostatic load was noted to be significantly higher in a sample of women with pre-eclampsia compared to controls. There is also an association between maternal PTSD and birth outcomes (i.e. – pregnancy complications, preterm birth).

6. Toxic stress has been implicated in the epigenetic changes within the body affecting chromosomes. **Telomeres** (protein caps on the ends of chromosomes) progressively shorten with toxic stress and have been used as a marker for aging and the potential for earlier death. A dose-dependent association between early-life stressors and telomere shortening has also been noted (Asok, et al., 2013, F).

7. Historical trauma in Indigenous populations has been linked to adverse health effects, the mechanisms of which are complex. Sotero (2006, F) describes four distinct assumptions that link historical trauma and adverse health:

    - Mass trauma is deliberately and systematically inflicted upon a population by a dominant group,
    - Trauma is not limited to a single catastrophic event but continues over an extended period of time,
    - Traumatic events resonate for the entire population creating a universal experience of trauma, and
    - The enormity of the trauma experience deranges the population's natural, projected historical course, resulting in physical, psychological, social, and economic disparities that span generations.

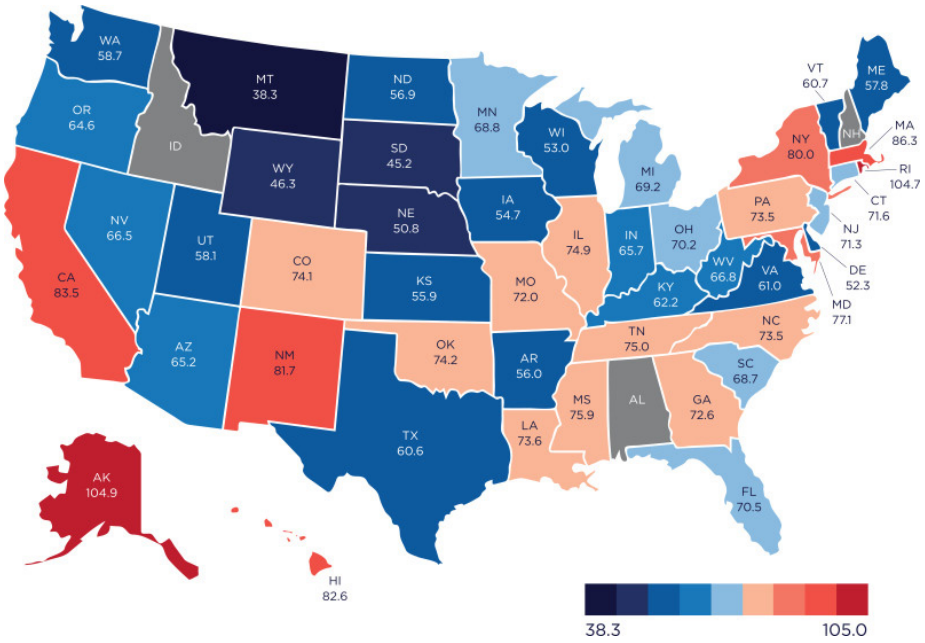
The State of Maternal Health Nationally

According to the World Health Organization (WHO), maternal mortality around the world declined nearly 38% between 2000 and 2017, however, maternal mortality in the United States has increased by over 26%. Globally, ninety-four percent of all maternal deaths occur in low and lower middle-income countries (WHO, 2019).

The U.S. has one of the most technologically advanced heath care systems in the world and should be able to ensure the delivery of safe, high-quality maternity care. However, the maternal mortality rate remains stubbornly high, at 17.4 deaths per 100,000 live births totaling 658 deaths in 2018 alone. This is higher than most other developed and high-income countries. **Most importantly, 66 percent of all pregnancy-related deaths were preventable.** Thousands of women experience unintended outcomes of labor and delivery that result in significant short or long-term consequences to their health. These complications are referred to as severe maternal morbidity or **SMM** (Figure 2). Furthermore, the significant difference has been largely noted in women of color (HHS, 2020).

66%

of all pregnancy-related deaths were preventable.

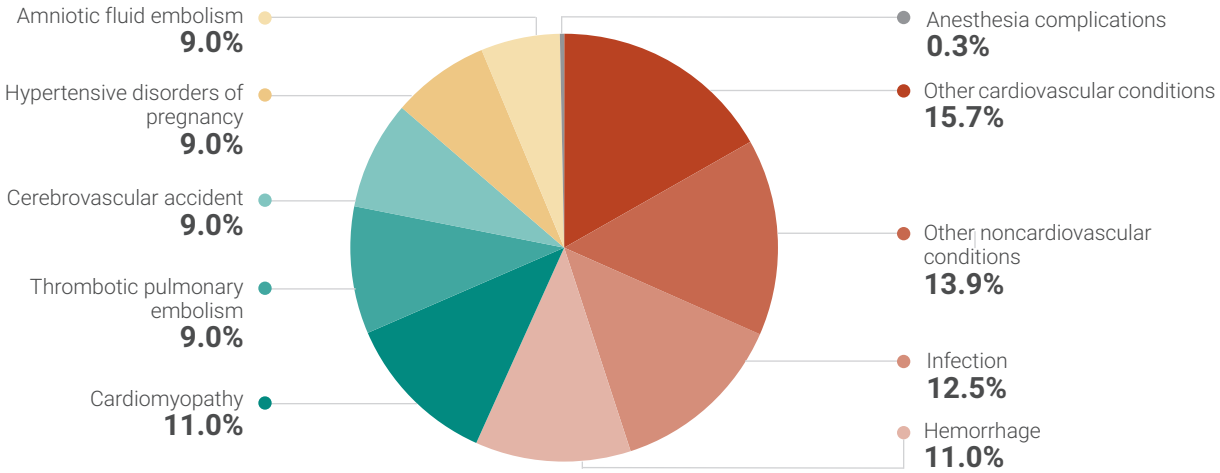


Note: States colored grey indicate that HCUP data was not available in 2017. Data do not include blood transfusion.

Source: Estimates provided by the Agency for Healthcare Research and Quality based on analysis of the Healthcare Cost and Utilization Project (HCUP), State Inpatient Database (SID), 47 States and the District of Columbia (from all states except Alabama, Idaho, and New Hampshire), 2017. www.hcup-us.ahrq.gov/sidoverview.jsp. HCUP SIO Partners: https://www.hcup-us.ahrq.gov/partners.jsp?SID

Figure 2. **The geographical distribution of SMM (severe maternal morbidity) across states in 2017. It demonstrates the wide disparity in outcomes across the states and hospitals in the U.S.**

The most common causes of pregnancy-related death from 2011 to 2016 were: cardiovascular conditions, infection, and hemorrhage (See Figure 3). Cardiovascular-related were responsible for more than 33% of pregnancy-related deaths when combined. Approximately two-thirds of all pregnancy-related deaths were preventable, with hemorrhage, severe hypertension, and infection being the most common preventable conditions.



Note: The above pie chart not sum to 100 percent, because the cause of death is unknown for 6.4 percent of all 2011-2-16 pregnancy-related deathes

Source: Centers for Desease Prevention and Control Pregnancy Mortality Surveilllance System

Figure 3. **Centers for Disease Prevention and Control Pregnancy Mortality Surveillance System:** *https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm.*

The State of Maternal Health in Women of Color:

A Special Focus on American Indian/Alaska Native (AI/AN) Women and the Indian Health Service

From 2007-2016, the pregnancy-related mortality ratio for AI/AN women were two to three times higher than for white, Hispanic, and Asian/Pacific Islander women (Figure 4). Even among women with a college degree or higher, the pregnancy-related mortality ratio was over five times higher for Black and Indigenous people of color (BIPOC) compared to white, Asian/Pacific Islander, and Hispanic women. Some of these disparities are related to differences in the quality of care and clinical practice. Studies have shown that black patients for example, tend to receive care in hospitals with lower rates of effective evidence-based medical treatments and maternity care practices. It may be possible that health care organizations that serve a disproportionate number of racial and ethnic minorities tend to be underfunded and understaffed, and to the extent this is the case, some of these facilities may find it challenging to deliver a similar standard of care as what is available in more well-resourced facilities (HHS, 2020).

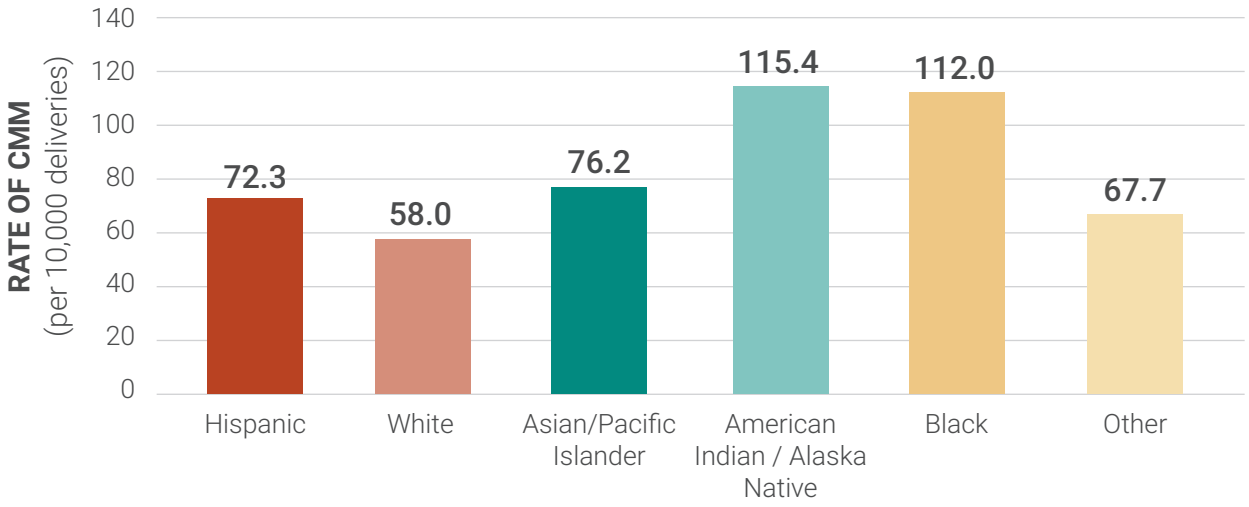
Many Indigenous women in Arizona and the surrounding states, for example, receive care from the Indian Health Service (IHS), an organization with facilities nation-wide. However, the IHS has been met with perpetual challenges in funding, staffing and aging infrastructure over the years. The IHS agency is also managed under the direction of Commission Corps officers (CCO), a strong federal presence that performs daily duties within the agency wearing militaristic attire despite being classified as noncombatants. According to the Division of Commissioned Personnel Support (DCPS) within the Indian Health Service, their mission is multifold. The officers act in the capacity of subject-matter experts and consultants to IHS leadership, program officials, other commissioned officers, their dependents and survivors on all Commissioned Corps matters, including personnel actions, recruitment and retention, career development, leave of absence, performance management, honor and service awards, discipline, standards of conduct, promotions, training, and travel. The intent of

wearing uniforms is to promote the visibility and credibility of their service and themselves and to display a profound respect for their country to the general public whom the officers are devoted to serving. (IHS.gov, 2021). However, such a presentation that exudes superiority, rank and discipline to a population wrought with centuries of heinous trauma has actually backfired, now creating an air of resistance and mistrust on behalf of the people from an already marginalized community.

There are two universal concerns regarding the involvement of the CCO's in the healthcare of Indigenous populations. First of all, the advancement of the officers to higher levels of rank within a specified time frame is sanctioned well by superiors, warranting awards, ceremony and other endowments. The experiences of many non-Commission Corps or civil individuals whether staff or patients, have brought forth the realization that the presence of CCO's within IHS agencies serves more the mission of the individual officer rather than aligning with the mission of the collective whole of the Tribal community. Secondly, when considering the health of a population that historically has been adversely affected by the recurring attempts at population degradation and extermination enacted by members of the very same federal entity, how could one not comprehend the extent to which the health of this population has been so affected?

Nevertheless, it is evident that the trauma perpetuates even today. The performance of unjust acts have been ongoing and done covertly by various levels of leadership and staff within the agency. Unfortunately, the horizontal and vertical violence that is executed by the employers and staff against Indigenous and even, non-Indigenous workers is a regular occurrence, always entangling the patients as the collateral damage in the process – actions which strongly suggest that colonialism is alive and well. The foundational and recent scientific evidence on abuse, trauma and epigenetics, have confirmed that these toxic environments can severely impact the health of women of color, apparent in the dose–response relationship between the number of traumatic experiences and health conditions such as ischemic heart disease, diabetes, obesity, cancer, chronic bronchitis/emphysema, liver disease, skeletal fractures, and poor overall self-rated health. For many Native women, these chronic conditions are present even before conception predisposing them to poorer maternal health outcomes, increasing their risk of mortality and the potential for translating this harm into the future generations. For those clinicians who fail to acknowledge the science of trauma in Native maternal health, are not only replicating the trauma, but their lack of action is outright criminal.

The effects of repeat trauma is evident and manifested in the responses of the women when seeking healthcare – it is all about the inability to trust the descendents of those who have perpetrated such crimes of humanity. In the healthcare setting, health and social service providers need to respectfully listen to the stories of the women and understand their experiences without interruption, impatience, blame, stigma, bias or judgement. If providers can get beyond their own biased boundaries and if these simple, humanistic tasks can be achieved, it will be one step in the right direction for a new future in health and wellbeing for Indigenous peoples.



Note: Blood transfusions are excluded as an SMM indicator using ICD-10-CM/PCS in 2017. The Healthcare Cost and Utilization Project (HCUP) does not receive datea from Indian Health Service hospitals or tribally operated facilities. Although, over 75 percent of AI/AN deliveries occur outside of these facilities, Indian health facilities may refer more complex deliveries to other hospitals that would be included in HCUP. The 2016 AI/AM CMM rate was 81.6 SMM per 10,000 deliveries, which is approximately 30 percent lower than the 2017 SMM rate for all AI/AN hospital deliveries.

Source: Estimates provided by the Agency for Healthcare Research and Quality based on analysis of the Healthcare Cost and Utilization Project, State Inpatient Databases, 41 States and District of Columbia, 2017 (from all states with reliable race reporting data in 2017 except Minnesota, Montana, North Dakota, Nebraska, Utah, and West Virginia). *www.hcup-us.ahrg.gov/sidoverview.jsp*

Figure 4. **Similar to pregnancy-related mortality, AI/AN women are also more likely to experience SMM.**

> ***"The sign of ultimate oppression working is when the oppressor can take away his hands, stand back and say 'look at what they're doing to themselves.'"***
>
> - Jessica Gourneau, Ph.D.

The Intersectionality of the Social Determinants of Health

Complex personal, social, and structural conditions, sometimes referred to as social determinants of health (SDOH), have also been shown to impact racial and ethnic maternal health disparities. SDOH relates to the economic and social conditions in which people are born, live, work, play, worship, and age, which influence health and wellbeing (Figure 5). Research has found that poor health outcomes are more likely to occur for economically and socially disadvantaged groups. Women of color have a lower likelihood of having health insurance, receiving timely or any prenatal care, and, as mentioned above, are likely to deliver in hospitals that offer a lower quality of care. Indigenous women are also less likely to have access to paid parental leave and thus often must return to work sooner after delivery. Research suggests that exposure to stressful life events, such as financial distress, death of a loved one, domestic violence, and discrimination may contribute to poor maternal health outcomes, especially for Native women. Traumatic events may increase the risk of having a lower birth weight infant, risk of hemorrhage during labor and birth and postpartum depression. Birth trauma can result in blood pressure and heart rate elevation, imbalances of stress hormones, as well as telomere damage (caps at the end of chromosomes which plays a role on life expectancy). Chronic stress increases the risk of dangerous medical conditions during pregnancy, such as hypertension, which is most prevalent among Black and Native women, or even cardiovascular diseases. Native women are more likely to develop these pregnancy comorbidities at earlier ages, and their conditions are less likely to be controlled resulting in pregnancy complications or death.

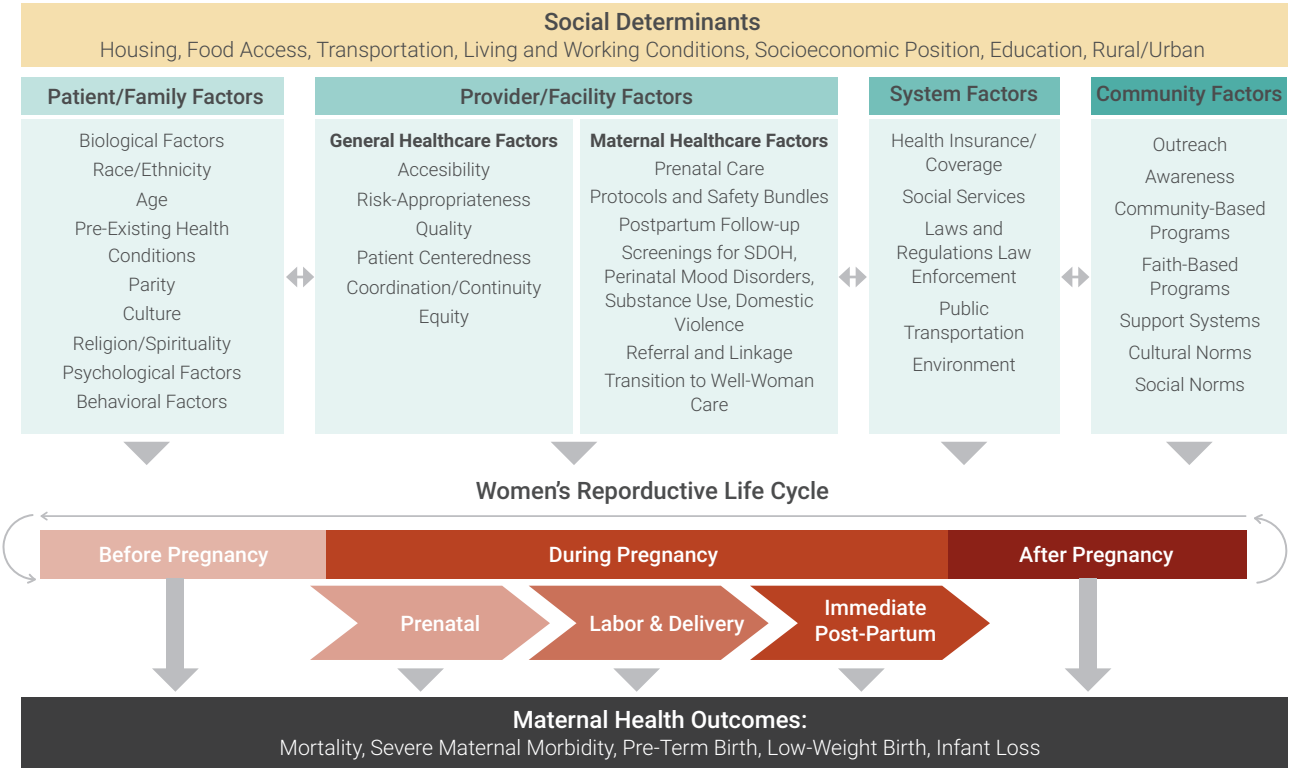


Figure 5. **Diagram of SDOH factors compounding ACES and affecting Maternal Mortality and Morbidity including Accessibility, retrieved from Lewandowski, et al., (2020).**

There are several dimensions of accessing care, including a woman's awareness of her pregnancy, her acceptance of the pregnancy, self-care behaviors, communication with family members, communication with her partner, social attitudes toward prenatal care, availability of prenatal care, receiving late or no prenatal care and her attitude toward health care providers. These factors can interact simultaneously to affect the maternal health outcomes of Native women, in addition to the difficulty of accessing insurance, struggling with both systemic and interpersonal discrimination and having underlying health challenges. These barriers can also present pre-existing challenges in health prior to conception, in ways that may jeopardize the health and well-being of future pregnancies.

Rural Disparities and Access To Care

Compared to women living in urban areas, women living in rural areas such as in Tribal reservations may experience higher rates of delayed prenatal care initiation. Over the past two decades, many rural counties have lost their hospital-based obstetric services including the main IHS organization in Phoenix, Arizona. Less than half of women living in rural areas are within a 30- mile drive of a hospital with obstetric services. In these areas, women are more likely to have out-of-hospital births and to deliver in hospitals without obstetric units. It is important for facilities without obstetric units to be "OB Ready" in the event they need to perform an emergency delivery, and to have triage protocols in place when it is more appropriate to transfer expecting mothers to another facility with greater capacity.

One potential contributor to disparities in outcomes is shortages of maternal health care providers and services. Medically underserved areas and Health Professional Shortage Areas, which exist in all states in urban and rural areas identify geographic areas and populations with a lack of, and barriers to, access to health professionals and medical care services. These critical measures of access to care have been identified as markers of social determinants of health and associated with infant health outcomes.

The Scope of the Health Issue

- **Macro system.** Healthcare inequality has been linked to adverse maternal health in American Indian/Alaska Native (AI/AN) women. These healthcare disparities have been associated with a higher risk of short and long-term health conditions and mortality rates.
- **Microsystem.** Many Native women served by community clinics, private hospitals and even the Indian Health Service (IHS) system, are placed at a disadvantage with the lack or breakdown of communication from their service providers. It creates a barrier when attempting access to appropriate and needed maternal health education. Challenges in communication can contribute to the cycle of health and healthcare adversity.

Adverse Experiences in the Relationship with Healthcare Providers

Women of racially/ethnically diverse groups who present for prenatal care tend to have unique needs. Increasing rates of maternal mortality and severe maternal morbidity, especially among Indigenous women, have drawn attention to the inequality of care, especially in their prenatal and birth experiences. Native women are two to three times more likely to experience poor maternal and infant outcomes than Caucasian women in the United States (CDC, 2019). They experience a higher rate of hypertensive disorders and obstetrical hemorrhage (bleeding that occurs before, during or after childbirth) that is more than twice that of Caucasian women (Kozhimannil, et al., 2020). Native American women are especially at risk for the lack insufficient and/or ineffective prenatal health care. In these situations, there may be limited communication regarding for example, details on developing health conditions, side effects of medications, and warning signs with the necessary follow-up not always relayed by healthcare providers. These women are also at high-risk for reproductive and birth injustices, so traumatizing which may render them unable to communicate their rights or their needs at the time of the events. In addition, the COVID-19 pandemic has amplified the concerns over ineffective communication, because of women being confined to their homes exacerbating inequities in mothers' experiences; (Almeida et al., 2020), especially for those women in remote areas of reservations without IT access.

What does the data tell us about Native women in Arizona?

Arizona Data: Maternal Mortalities and Severe Maternal Morbidity review

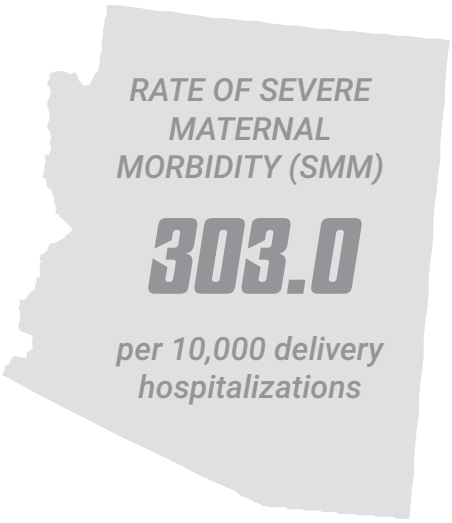
The *Arizona Department of Health* recently published a Maternal Mortalities and Severe Maternal Morbidity review report (Lewandowski et al., 2020). In brief, it was determined that during the year of 2019, there were 4,462 live births among AI/AN women living in Arizona.

» In 2016-2017, the pregnancy mortality ratio for Indigenous women living in Arizona was **128.3** deaths per 100,000 live births – **2.0X** the rate of Hispanic or Latina women.

The *AzDOH* Maternal Mortalities and Morbidity review shows a high level of death from addiction, overdose and domestic abuse.

100% of these deaths were considered preventable.

» In 2016-2019, the rate of Severe Maternal morbidity (SMM) for Indigenous women living in Arizona was **303.0** per 10,000 delivery hospitalizations or **3.6X** the rate of Non-Hispanic White women.



Severe Maternal Morbidity rates were highest among Indigenous women who experienced:

- Chronic hypertension or pre-existing diabetes
- Hypertensive disorders of pregnancy
- Inadequate or no prenatal care
- Preterm birth (prior to 37 weeks gestation).
- Cesarean section deliveries
- A history of prior cesarean section.

Data from the CDC: Infant Mortality and American Indians/Alaska Natives

- American Indian/Alaska Natives have twice the infant mortality rate as non-Hispanic whites.
- American Indian/Alaska Native infants are twice as likely as non-Hispanic white infants to die from sudden infant death syndrome (SIDS).
- American Indian/Alaska Native infants are 2.7 times more likely than non-Hispanic white infants to die from accidental deaths before the age of one year.
- In 2017, American Indian/Alaska Native mothers were 2.8 times as likely to receive late or no prenatal care as compared to non-Hispanic white mothers.

Personal Stories of Discrimination from the Women

- AIAN mothers are more likely than white women to experience discrimination, delays in care and to see a different provider each time they attempt to access prenatal care.
- In fact, 25 percent of AIAN women report experiencing discrimination when going to the doctor or a clinic.
- AIAN women often have long waits to see a health care provider for prenatal care, sometimes up to two hours for a 15-minute appointment.
- AIAN women receive a lower quality of care than white women, and care that is devoid of traditional cultural birth practices found in Indigenous communities.

- Urban Indian Health Institute, Seattle Indian Health Board (2016)

Communication barriers

A qualitative study was performed and interviews with Indigenous women in the Northern Plains uncovered several communication barriers within their prenatal health care. Many of the 58 American Indian women who were interviewed reported various communication difficulties with the clinicians at the IHS. Native mothers were more likely than Caucasian women to experience discrimination, delays in care and to see a different provider each time they attempt to access prenatal care. In fact, 25 percent of the women reported experiencing discrimination when going to the doctor or a clinic (RWJF, 2017). Some of these communication barriers included clinicians who seemed too busy to ask or respond to patient-related questions, feeling that the clinician did not care about the patient or her reasons for seeking care, and an overall lack of trust of clinicians, especially white clinicians. This lack of trust of IHS providers often resulted from negative experiences during pregnancy and delivery. When asked about her prenatal health care experiences, one Native woman in this sample stated, "He [the doctor] said that I was going to have a C-section … [but] he wrote in my chart that I was supposed to have a natural birth. So, I was in labor for 4 days before they did anything and then they brought in a specialist." Another woman stated, "They knew things that were wrong but never informed me until my son was born and they said they knew ahead of time but I was never told." A lack of female health care providers may also prevent some women from presenting all of their health needs which in turn, can affect the quality of their interactions (Halbert et al., 2006).

It is stories like these regarding substandard experiences that detour many women from seeking care during pregnancy. Native women have felt discouraged from seeking prenatal care because they might have heard negative stories about poor prenatal care and labor experiences from other women and immediately distrusted the provider or health care system as a whole (Hanson, 2012).

Not all women had negative experiences affected by communication barriers, with several stating they had "good" experiences, "I made it to all of my prenatal visits, I knew there was a lot more information that I wanted to know but I didn't ask for it, I don't know if they had it anyways, it was never offered."

Additionally, high turnover rates of clinicians and understaffing within their primary healthcare system, the Indian Health Service (IHS) causes expectant mothers to see different providers at each visit, and visits are conducted under time constraints, making it difficult to build the patient-clinician relationships, let alone ask for health information. Barriers to care in general were related to the relationship between a patient and her clinician, including a patient not having a provider who has personalized knowledge of the patient and their health beliefs and who shows respect and listens to the patient (Sofaer & Firminger, 2005). Unfortunately, these barriers may still present despite the use of IT services as seen in Telehealth situations.

Health-related Education and Awareness

The attainment of health knowledge is a process which can influence and be influenced by the basic social determinants of health, one in particular is the inability to access the internet due to constrained resources. There is an extensive body of research that consistently demonstrates a positive correlation between educational attainment and health status indicators, such as life expectancy, obesity, morbidity from acute and chronic diseases, and health behaviors. In addition, educational attainment may have an intergenerational effect, in which the degree of maternal education conveyed and effectively received, has been associated to children's health and well-being.

Feeling Safe to Access Health Information

The perception of safety is also a key factor in the ability to access health-related knowledge. Violence and stigma are two barriers of many that will impede Native women from reaching out to seek information on health during physical visits with their providers. Stigma is also considered a SDOH and manifests in three ways:

Community
- encountered among family, friends, workplace and in faith places.

Institutional
- noted in healthcare, clinics, school, Universities, and legal system.

Internalized
- felt within oneself.

The perception of safety is also important for mental health. Perceived danger and the fear of violence or the sudden onset of a trigger, can induce stress, anxiety, PTSD and feelings of insecurity—all of which compromise the woman's ability to reach out and seek help for safety, forgoing the pursuit of education or healthcare. The woman may be held hostage in her own home by either the perpetrator or by her perceived sense of danger. Furthermore, feelings of being stigmatized especially within close communities, can also undermine the woman's efforts to seek health information, especially seen in cases of sexual assault.

Improving access to health education through the use of technology especially when accessed within a safe place, supports the woman's right to health-related knowledge whenever she chooses and however she chooses to use it. It involves passing on high-quality health information that initiates clear communication regardless of socioeconomic or cultural background. If her attempt to seek information from the internet is interrupted by a suddenly threatening experience, she can immediately disengage. The pursuit of maternal health knowledge using technology is one vital conduit to combat healthcare inequality and support positive health outcomes.

> ***Birth justice" refers to the right to give birth with whom, where, when, and how a person chooses."***
>
> Ross & Solinger, 2017

The Recurrent Problem of Obstetric Violence

Another area of concern where there may be a breakdown or lack of communication, is during labor and birth. Obstetric violence is a violation of a woman's space, privacy and rights to dignity, bodily respect and autonomy and for many, a recurrent trauma. Unfortunately, many healthcare providers have not been privy or mandated to take training on recognizing, understanding and managing implicit bias which can lead them to continue inflicting these abuses on Native women. Some providers have poor quality relationship skills and make health decisions based on their perspective of the race and ethnicity of the woman. On the other hand, there are providers who just perform their jobs in ways to expedite the tasks at hand so they can move on to the next patient. They may also lack knowledge on effective communication or just choose not to converse with the woman nor consider taking the time to explain the process of the intervention. These scenarios can lower the self-esteem of the women, making them feel like "I'm not good enough," thus creating another barrier for them. Nevertheless, women of color have been subjected at some point in their lives, to these heinous acts during the childbearing years and beyond. Common violations during women's health visits, pregnancy and/or birth may include being ignored during the woman's time of need, loss of autonomy, yelled at and/or verbally abused, physically abused, threatened, and/or minimized. An example of implicit bias is when a provider decides on a woman's eligibility for an intervention like pain relief during labor based on her perceived race, ethnicity and gender. For example, not providing an epidural for an Asian woman because "Asians are known to be stoic and can handle the pain." Other violations that Native woman may experience include unauthorized exams by unknown providers, being told that, "If you don't have a Cesarean section, your baby might die," or having a medical audience during exams and/or procedures without a thorough explanation for the purpose of the exam and without obtaining verbal consent first (NASEM, 2020).

Native American women who are subjected to these practices during pregnancy and birth can be triggered and retraumatized, especially if they have endured a history of PTSD - an experience referred to as **complex perinatal trauma.** During these acts of abuse, a woman may dissociate (appearing like she is day dreaming; which may be accompanied by eyelid fluttering), experience fear, terror or helplessness. Some women will freeze and be unable to speak or express their emotions; others may have heightened apprehension of being injured or dying during delivery and may behave erratically and/or excessively. Pregnancy and birth trauma can also provoke postpartum anxiety and depression, which can negatively alter the level of cortisol (the body's stress hormone) reducing milk production and delaying breastfeeding success (Rodriguez, 2017). Social and emotional dysregulation in children, may also be a consequence of maternal PTSD during labor and birth (Kim et al., 2014).

Obstetrical violence is unwarranted and unacceptable and should be reported and addressed appropriately. If a woman is approached for anything that makes her feel uncomfortable, she has the right to open the lines of communication, speak up and say NO or STOP. She also has the right to file a formal complaint about her experience and have the institution respond to her in a timely fashion.

Studies have shown that women of color are at higher risk of exposure to a lifetime of discrimination which can potentially lead to chronic stress or "weathering." As these daily stressors build up, the cells in the body start to age at a faster rate which in turn, will elevate one's vulnerability to chronic conditions like diabetes and hypertension. The higher stress levels associated with racism and discrimination is hypothesized to degrade the reproductive health of women of color, making it more difficult for those women to achieve a healthy state in preparation for pregnancy (NASEM, 2020). It is imperative that Native women take a stand to break this cycle of abuse to improve their chances of having a healthy pregnancy, birth and baby.

Empowering Self-Determination of Health in Indigenous Women

by Fostering Critical Health Literacy

When considering a plan of action to address maternal inequities in the American Indian/Alaska Native communities, the whole gamut of root causes that are precipitating the effects on the mother/baby/family/community quad should be considered to guide plans of action. It is evident that the SDOH, the history, the abuses and coping mechanisms, the racism, the soul wounds/adverse physical health and healthcare and the epigenetic impact on future generations will need to embody a movement, not only from a multidisciplinary collaboration but also to be driven by multi-theoretical and multi-scientific perspectives. The following will provide examples of the frameworks used to guide action.

The Critical Health Literacy (CHL) framework (NASEM, 2021)

A study by Liang & Brach (2017), showed that during the period from 2011 to 2014, rates of health literate care increased slowly but steadily. However, almost one-third of the population seeing health care providers had found that instructions given by their health care provider were not easy to understand and over two-thirds did not have their understanding of instructions they received verified using the Teach-Back method. Failure to adopt health literacy universal precautions in the face of the high prevalence of limited health literacy may perpetuate adverse health outcomes that are costly to society.

Lack of clear communication in healthcare has been barrier to improved health status especially in Native women. Women with certain chronic health conditions like diabetes prior to pregnancy and limited health literacy is associated with worse glycemic control, thus increasing the risks for complications in pregnancy. Lack of healthcare communication is demonstrated in a number of ways such as (Center for Rural Health):

- In conversations with health care professionals
- On prescriptions and over-the-counter medication bottles
- Appointment slips
- Informed consents
- Discharge instructions
- Health education/promotion materials
- Insurance/Medicare applications and correspondence
- Other medical and health information

Women Collaborating with Health Researchers for the Community

The National Academies of Science, Engineering and Medicine (NASEM, 2021), explored the application of the **Critical Health Literacy** framework enlisting in the assistance of the Duwamish Tribe of Seattle, Washington and facilitated by *Linn Gould* (Just Health Action, JHA) to achieve health equity. Sykes, et al., (2013 F) finalized the definition of "Critical Health Literacy," as "a distinct set of characteristics of advanced personal skills, health knowledge, information skills, effective interaction between service providers and users, informed decision-making and empowerment including political action as key features of critical health literacy. The potential consequences identified are improving health outcomes, creating more effective use of health services and reducing inequalities in health thus demonstrating the relevance of this concept to public health and health promotion." Gould states says that empowerment cannot be achieved unless critical health literacy is developed and action is taken on the social determinants of health (SDOH). Empowerment is part of the process and the outcome. Ms. Gould worked with the Duwamish to examine the SDOH and its root causes through storytelling within the community. She facilitated **Community-based Participatory Framework** (CBPF) so that the Tribal members maintain ownership of the data, the research findings and outcomes and be able to bring this information back to the community. She focuses on 3 components of the framework to encourage community members to build skills, capacity and act as change agents within the **Community-Academic partnerships** using:

Functional literacy	**translating research information into clear and culturally sensitive language.**
Interactive literacy	**Tribal members act on and share the information.**
Critical literacy	**the researchers and Tribal community work together to achieve community-level change (LaVeaux et al., 2018).**

Gabriel Maldonado is the CEO and Founder of **TruEvolution**, a community-based organization that advocates for health equity and racial justice to advance the quality of life and human dignity of LGBTQ+ people. He has focused much of his work on stigma. Maldonado offered eight suggestions to implement health literacy in health agencies and institutions (Appendix 2).

Critical health literacy can also be used to build resiliency. It is essential that both researchers and Tribal members jointly engage in interventions that empower and build the infrastructure of Tribal communities that support health inequities and especially, maternal and women's health inequalities.

Women Collaborating with the Clinician

Agency for Research and Healthcare Quality (AHRP) Share Approach (ARHP, 2021)

Initially, the health literacy field was just for those had has poor literacy skills. It has since evolved to include others who also face challenges when trying to access healthcare and education, to understand health information and for those who wish to navigate the healthcare system and learn about research,. Acknowledging that the healthcare system is overly complex, healthcare organizations have started to take responsibility to ensure that everyone, especially people of color and elders, are able to find, understand, and use health information and services.

Addressing health literacy is a vital priority. Most recently, ***Healthy People 2030***, which establishes national objectives for health improvement, has included "attaining health literacy to improve the health and well-being of all" as one of its five overarching goals. Healthy People 2030 also adopted two definitions that together constitute health literacy.

a. Personal Health Literacy

is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others. The following is a program and an organization in support of empowering Native women for the betterment of health and well-being.

» Ask Me 3

Designed by health literacy experts, Ask Me 3 is intended to help patients become more active members of their health care team, and provide a critical platform to improve communications between patients, families, and health care professionals (See Figure 6).

Figure 6. **Ask Me 3. Retrieved from *www.ihi.org/askme3***

You will need to create a free account to access the brochures.

» **Body and Soul Sovereignty, United (BASS, U)** – See description on page 4.

b. Organizational Health Literacy

is the degree to which clinicians and organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others (See Figure 7). The following is one evidenced-based example of a toolkit to improve the relationship between the woman and her provider by opening the lines of communication.

» **The Share Approach**

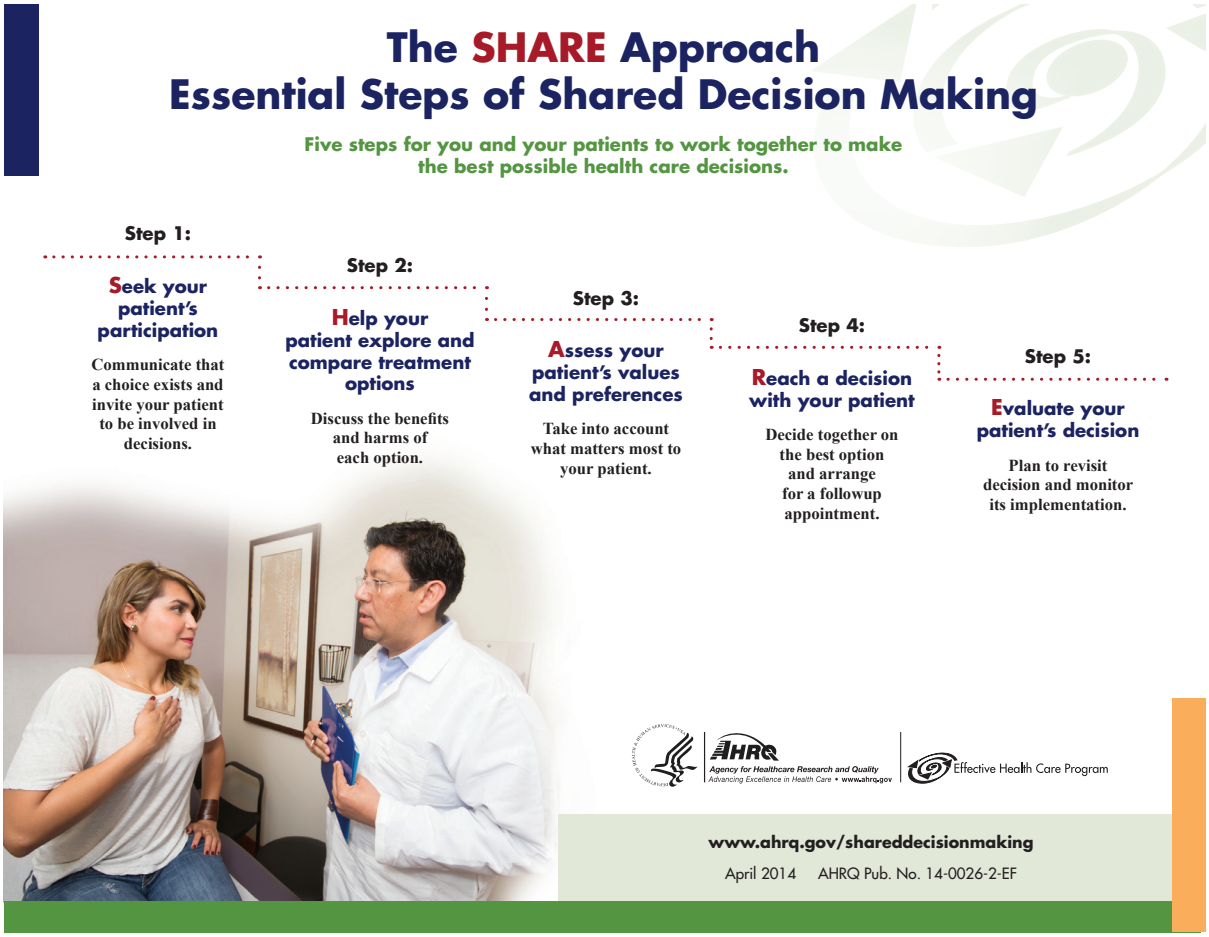


Figure 7. **AHRP - The Share Approach. Retrieved from *https://www.ahrq.gov/health-literacy/index.html*.**

Promoting Effective Client-Provider Relationships

The Birth Justice framework

Birth Justice exists when Indigenous women are empowered during pregnancy, labor, childbirth and postpartum to make healthy decisions for themselves and their babies. Birth Justice is part of a wider movement against reproductive oppression. It aims to dismantle the inequalities of race, gender, socioeconomic status and sexuality that lead to negative birth experiences, especially for women of color, low-income women, and survivors of violence and soul wounds.

A prime example is in the work of the Tewa Women United organization who utilizes a holistic perspective in Reproductive and Birth justice. They believe that every woman has the right to a birthing experience that promotes autonomy, dignity, respect, and empowerment for mother, child, and family. They incorporate the issues of gender justice, birth justice, environmental justice, economic justice, healthy sexuality and body sovereignty, advocacy and healing for survivors of sexual violence, to form a comprehensive approach to building beloved communities and ending violence against Indigenous women, girls, and Mother Earth (***https://tewawomenunited.org/***).

One crucial aspect of birth justice is the need to promote more effective client-provider relationships during pregnancy, birth and postpartum. Native women, at any given time during the perinatal period, have the right to open communication with the provider regarding the state of their health and the course of their healthcare. It mandates disclosure of all existing and potential risks, benefits, and alternatives in healthcare decisions and options. Clarity should be established from the onset regarding the necessity of providers to listen to, hear and acknowledge the needs that Indigenous women may have regarding maternal health, not to be ignored, minimized, stigmatized, or stereotyped. Furthermore, Native women have the right to be free from any form of "obstetrical

violence" and be able to communicate this to the provider without stigma, or any other form of judgement. Obstetric violence includes loss of autonomy, being yelled at and/or verbally abused, physical abused, threatened, or minimized. This also includes unauthorized exams by unknown providers or having a medical audience with exams and/or procedures. Obstetrical violence is unwarranted and unacceptable and should be reported and addressed appropriately.

There is a copy of the complete document on our website for your review and/or download, titled, **The Native Woman's Bill of Rights for Pregnancy, Labor and Birth**.

Recognizing Implicit bias and Being Culturally and Trauma-sensitive: A Call to Action for Effective Provider Training

It is well established that healthcare providers like many others members of society, have ingrained implicit biases which have been associated with lower quality patient-provider communication, especially with regard to Native women. These prejudicial attitudes and beliefs are activated spontaneously, unconsciously, and shaped by stereotypes taught to them earlier in life, even as early as 3-5 years of age and often resulting in inequitable behaviors toward underserved populations.

The Joint Commission (Jointcommission.org, 2021) is the nation's oldest and largest standards-setting and accrediting body in health care. The organization released its issue of Quick Safety 23 to discuss the impact of implicit bias on patient safety. What makes implicit bias "frightening" in health and health care is that the result is "unthinking discrimination" of which caregivers are not aware. Apart from discrimination, there is also the potential for blatant acts of disrespect and abuse that occur in the maternity care of Native women. Although, implicit bias is not just limited to race, it is "racism, not race" that leads to healthcare inequities and adverse health. The quality of care may be affected through implicit bias or poor cross-cultural communication. Aside from Joint Commission's recommendations to examine the processes of hospital organizations, administration, policy and protocols, they also provide guidelines for clinicians as shown below:

Actions that health care providers can take to combat implicit bias, include,

- Having a basic understanding of the cultures from which your patients come.
- Avoiding stereotyping your patients; individuate them.
- Understanding and respecting the magnitude of unconscious bias.
- Ineffective provider – client relationships challenged by communication barriers leading to negative patient experiences, potentially inducing triggers from past trauma. Recognizing situations that magnify stereotyping and bias.
- Knowing the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the ***National CLAS Standards***).
- Performing "teach back (e.g., the National Patient Safety Foundation's "Ask Me 3®" educational program).
- Consistently practicing "evidenced-based medicine" – not taking shortcuts. Learn about the AIM Maternal Health bundles – see ***www.MCPapforMoms.org***.

- Consider the Integration of BH into PC of women – provides co-located services, warm handoff, immediate mental health care based on evidence-based screening tools (EPDS, M3 Checklist tool from LabCorp is another option, ***https://files.labcorp.com/labcorp-d8/2019-09/L15034-0417-3.pdf***.
- Using techniques to de-bias patient care, which include training, intergroup contact, perspective-taking, emotional expression, and counter-stereotypical examples.
- Need for a universal and equitable evidence-based standard of care, mandated in polices and protocols for all providers to follow without deviation, except when needed to individualize care based on patient's health risk and condition.
- Ineffective dissemination of gender-related maternal health education.
- Lack of provider accountability to provide equitable care to Native women - need to confer with authoritative licensing agencies to include these educational mandates especially in licensing of new providers.
- Understanding the responsibility of being trauma-informed and willingness to implement sensitive practices in the care of women (Refer to the Handbook on Sensitive Practice for Healthcare Practitioners: Lessons from Adult Survivors of Childhood Sexual Abuse, ***https://cdho.org/docs/default-source/pdfs/reference/sensitivepractice.pdf?sfvrsn=6***

The **Health Literacy Review** written by the Center for Rural Health, offered recommendations for healthcare providers on how to communicate with Native elders. However, these suggestions can also apply to other patient populations including Native women during their pregnancy.

The recommendations were adapted and listed as follows:

1. **Plan what you are going to say.** Logical order and one step at a time.
2. **Define new health care terms.** Explain any and all acronyms.
3. **Verify understanding.** Restate and rephrase in a way that the patient understands, but it isn't condescending.
4. **Establish an environment conducive to discussion.** Select a quiet place where one can sit near the woman. Speak clearly allowing time for her to process the information.
5. **Organize your message.** Omit extraneous information and repeat the most important information.
6. **Adjust to the needs of the patient.** Be respectful of the need for silence always watching, listening, and reading the patient. Choose your words carefully!
7. **Encourage active participation in appointments.** Ask the patient to write down concerns or make lists. Be sensitive that many patients will be reluctant to ask questions of people in authority. Encourage family participation.
8. **Pay attention to non-verbal Communication.** Try to make sure the patient encounter is welcoming and respectful.

The following are suggestions from the **Native elders** themselves to the providers:

1. **Provide more time for the woman.** Pregnant women need more time than the normal office appointment allows because you are caring for two people. Allow time for interaction.
2. **Help women formulate their questions.** Put yourself in their shoes, what would you want to know about your health and the health of your baby?
3. **Be positive.** Native healers are positive and support the notion that a remedy will work, often times non-native providers indicate that the woman should try the remedy, if it doesn't work come back. That may be contrary to the culture.
4. **Definitions and the anatomy.** Not everyone understands the human anatomy, use patient friendly terms, if possible.
5. **Deal with biases.** Fear of going to doctors, not wanting to hear the results, denial, anger, fatalism, etc.
6. **Understand the probability of comorbidity, economic, and transportation problems.** Perhaps the woman needs to care for other children or can only access transportation on certain days. Be attentive to non-verbal communication. Notice silence, gestures, posture, etc. It may be considered rude to make eye contact.

To address racial/ ethnic inequities in the quality of care, attention is needed to ensure first of all, that healthcare providers resemble the ethnic composition of the population of childbearing women such as certified nurse-midwives, obstetricians, community health workers, doulas, maternity nurses, nurse practitioners, physicians' assistants, public health nurses, family medicine physicians, and pediatricians with the goal of increasing its diversity, distribution, and size. Such efforts are important to provide culturally concordant care, foster trust in providers who will communicate on a level that is equitable and meets their psychosomatic needs, and ultimately, achieves optimal birth outcomes. Unfortunately, this is not the case within the Indian Health Services (IHS). To strengthen the diversity of the workforce, investments are needed to enable and support prospective maternal care providers from historically underrepresented groups to enroll in qualified education programs. Greater opportunities for interprofessional education, collaboration, and research across all birth settings are also critical to improving quality of care.

Additional strategies for achieving an equitable workforce which include

- Creating pipeline recruitment programs beginning in high school and establishing professional and career pathways through such ancillary roles as community health workers;
- Casting a wider net for recruitment and reducing both barriers to application and biases in selection criteria;
- Increasing opportunities for mentoring and peer support;
- Fostering inclusive professional organization practices;
- Requiring training in implicit bias for faculty and students; and
- Providing preferential selection for applicants with the potential to address unmet population needs (Sandall et al., 2018).

Trauma-Informed Practices in the Care of Indigenous Women

Trauma-informed care is known as "a strengths-based service delivery approach that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes physical, psychological, and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment (SAMHSA, 2018)." Experiencing trauma can alter individual biology and behavior over the life course; these changes have an impact on interpersonal and intergenerational relationships. Trauma's mode of transmission is most often through adverse power dynamics. For many, this power differential may include Native women at the mercy of non-Indigenous healthcare providers during labor and birth. Inequitable power differentials are root causes of trauma and the mode of transmission of trauma (Committee on Community-Based Solutions, 2017). Historical and current societal structures and policies that create and perpetuate these inequitable power differentials drive health and healthcare disparities. In addition, cultural humility, which stands in contrast to cultural competence, calls for each of us to commit to life-long learning about our own identities so that we can better understand our own complex cultural identities and aspects of power and privilege (or lack thereof) in society. The practice of cultural humility, then, asks us to use our self-awareness and respect for others' self-determined, always evolving cultural identities to interact in ways that recognize, minimize, and mitigate these power differentials.

Survivors of trauma may be "triggered", consciously or unconsciously, by situations they encounter in the healthcare setting especially during episodes of obstetric violence. Traumatic memories, provoked by healthcare encounters, may make medical care intolerable to a patient and contribute to worsened health outcomes (Raja et al., 2014). Exposure to one traumatic event increases the vulnerability of individuals and communities to future trauma. Because trauma is pervasive and associated with many chronic illnesses and high-risk behaviors, it is essential that all healthcare providers assume that all patients have histories of trauma and thus, should automatically be treated with trauma-informed sensitivity. Disclosure of trauma should never be a required element to receive complete and competent care.

The Practical Application of Trauma-Informed principles

The 4 C's Paradigm (Machtinger, 2018)

1 Calm

Pay attention to how you are feeling when you are caring for the woman. Breathe deeply and calm yourself to model and promote calmness for her, yourself, and your co-workers. Re-design healthcare environments, policies, and practices to reduce chaos and promote calmness, preferably using traditional symbolism – ask the women what they prefer to see, let the women be your cultural informants.

2 Contain

Limit trauma history detail to maintain emotional and physical safety. Provide education, resources, and referrals to trauma-specific care without requiring disclosure of trauma. If, for whatever reason a disclosure is needed, one way to obtain clues to the time of onset of traumatic events without explicitly inquiring about these events is to ask the age of onset of poor mental health and substance use. When a patient reveals that they began using alcohol or other drugs at a very young age, this is virtually pathognomonic for trauma and adversity. Other questions of concern to consider when providing trauma-informed care to women:

- *"How many times does a patient have to re-tell their trauma story to get the help they need in our system?"*
- *"How much information about sensitive trauma history details should be documented in the electronic health record and who should have access to this information?"*
- *"How can we provide information and access to trauma-specific services without requiring our patients to disclose trauma history details?"*
- *"How can we partner with the many other professionals serving our patients (lawyers, case managers, school administrators, advocates, police, etc.) in ways that don't re-traumatize our patients or staff?", and*
- *"How can our staff share experiences and information with one another in ways that don't traumatize one another?"*

However, it is best to normalize fear of returning to the healthcare setting if the triggering of a trauma response occurs; invite the patient to share what changes would make visits more tolerable and healing.

3 Care

Practice self-care and self-compassion while caring for others. Practice cultural humility. Normalize and de-stigmatize trauma symptoms and harmful coping behaviors (as common sequelae of trauma).

4 Cope

Emphasize coping skills, positive relationships, and interventions that build resilience. Document a "Coping Strategies" list instead of only "Problem Lists" and include patient's own words of wisdom and good self-advice in the "after-visit" summary. Improve identification and treatment of mental health, substance use, and other sequelae of trauma.

An Indigenous Feminist Perspective

Native women have been faced with multiple and overlapping forms of historic discrimination that exposed them to human rights violations in every aspect of their daily lives, from their civil and political rights and their right of access to justice, to their economic, social and cultural rights and their right to live free from violence. Indigenous women may encounter different obstacles, such as the unique geographic and economic challenges to gain access to health and education and limited access to social programs and services especially within rural communities. In addition, the political, social and economic marginalization of Native women contribute to persistent structural discrimination positioning them particularly susceptible to different acts of abuse. The onset of violence begun with its generalized and widespread use during the colonial period as a form of establishing power and maintaining order. Such brutality is also apparent in the afterlife of colonialism, typically seen in current day victims of domestic and sexual abuse, MMIWC, and survivors of sex trafficking. The lingering of political domination in the bodies of Indigenous women and infants, contribute to the maternal and infant mortality and morbidity. Decolonial work around gender positions itself as a pathway to greater equality for health. Although Native women have been subjected to discrimination and violations of their bodies and souls, they have played a crucial role in the history of the struggle for the self-determination of their rights as women.

In the provision of maternal and women's healthcare, it is vital to understand the underlying gender-related principles that may dictate how well the provision of care was received, how effectively health literacy was achieved and how successful were the healthcare outcomes (See Appendix A).

> ***"Indigenous feminism is an intersectional theory and practice of feminism that focuses on decolonization, Indigenous sovereignty, and human rights for Indigenous women and their families. Imagine how much better this work will be when Indigenous matriarchs have autonomy, agency, and power once again. Not power over men or others, but transformative power, which grows from respect for self and equality with others, in all their diversity of identity, experience, and ability.***
>
> ***This is the crux of Indigenous feminism."***
>
> - Jihan Gearon, Indigenous Feminist

Expert Opinions

» According to ***Nicolle L. Gonzales***, Navajo Nurse-Midwife, Founder and Executive Director of **Changing Woman Initiative** from New Mexico, when performing a literature review regarding the experiences of Native women, reported, "There is no current research dedicated to understanding the lived experiences that Native American women have to demonstrate what it's like for them to access care through the colonial settler medical system.In fact, it's probably not hard to believe, but for the first time in history, on February 12, 2019, a congressional briefing was held on Native American Maternal health in Washington D.C. Indigenous women leaders working to address maternal health disparities in the areas of missing and murdered indigenous women, reproductive rights, and access to healthcare participated. They spoke as key advisors to share their perspectives. After the hearing, it was clear that despite policy changes and medical technological advances over the past decade, the needs of Native American women still aren't being adequately addressed. This begs the question of "why." Why isn't there research dedicated to explaining Native American's lived experiences around birth, motherhood, and around reproductive choices?" Furthermore, "As more Native American women step into their power and demand for better birthing and women's health options in their communities, more and more invisible barriers are unveiled."

*Nicolle Gonzales, is a certified Nurse-Midwife and founder of the **Changing Woman Initiative**, a New Mexico-based organization to advance indigenous women's reproductive rights. She focuses on birth equity for Native American women and has served as the founding board president and vice board president of two new birth centers in New Mexico. She is a writer and an advocate for indigenous birth, midwifery, reproductive justice, and indigenous feminism. Retrieved from AspenInstitute.org.*

» Brianna Theobold, an assistant Professor from the University of Rochester, who is the author of Reproduction on the Reservation: Pregnancy, Childbirth, and Colonialism in the Long Twentieth Century (Critical Indigeneities) in 2019, commented to Time.com, "From the establishment of the first government hospitals, Native women—as nurses and other staff, as members of tribal health committees, and as activists—have struggled to ensure that these institutions met patients' needs. But non-Native hospital staff's openness to Native healing practices has varied over time and by institution, and reservation hospitals have been consistently underfunded. In recent years, some hospitals have reduced or eliminated obstetric services, forcing women to drive up to two hours to give birth. Drive time, as public health researchers emphasize, directly affects outcomes. This history matters. It matters because it continues to affect Native maternal and infant health outcomes. It matters because today Native American women continue a rich legacy of advocating for the health and well-being of their communities. This history matters because knowledge of historical injustices can be a crucial ingredient in working toward a more just future."

Brianna Theobald is an assistant professor of history at the University of Rochester and the author of "Reproduction on the Reservation: Pregnancy, Childbirth, and Colonialism in the Long Twentieth Century." Writing in the on Sunday, she discusses the legacies of racial hierarchies—and how structures of power have fostered dehumanization, exploitation, and abuse. Retrieved from Time.com.

Appendix A

Addressing the Needs of Native Women and Girls

When addressing biases, racism and discrimination, we must also consider the underlying needs of Native women and girls, especially in their challenges when accessing education in health. The following guiding statements were derived from the **Substance Abuse Mental Health Service Administration (SAMHSA)** and should be considered when planning and implementing programs for healthcare improvement:

1. Native women and girls, are more frequently vulnerable to violence and trauma, and this vulnerability must be addressed in prevention efforts as well as other mental health and substance abuse services. Trauma-informed environments based on **respect, and dignity** are essential for them to **feel safe** in seeking access to care. Women should always be offered the choice of a preferred gender in healthcare providers.

2. Trauma can have a strong and long-lasting effect on the development and on the experiences of women and girls. It can affect a woman's or girl's world view, including her social-emotional responses, her **view of herself, and her ability to trust others.** Past trauma can influence current skills, experiences, and feelings. It can have an impact on every area of a girl's or woman's life, including parenting, relationships, work, and **self-advocacy.**

3. To identify and **respond to trauma disclosures and reactions appropriately** and with cultural sensitivity.

4. **Relationships are critical** to the emotional development of women and girls and also play a significant role in both the development of, and recovery from, mental health and substance use conditions/disorders. Thus, competencies for working with Indian women and girls must address the relational-cultural context of their functioning especially in light of patient - provider relationships. Additionally, when caring for women with substance use disorders, anything written in the chart will be flagged and may be used punitively, thus almost ensuring that the woman will not be able to discuss these issues with her provider. The use of urine drug screens without the woman's consent is also a form of abuse.

5. The number of incarcerated women grows annually. The prevalence of mental health and/or substance use conditions/disorders among these women is high, and their involvement in the criminal justice system further increases their risk. Staff serving women involved in legal systems must consider the special needs of woman and girl offenders especially regarding **access to prenatal care** during pregnancy and postpartum (e.g., separation from family, employment barriers, institutionalization, and additional trauma).

6. Women with mental health and/or substance use conditions/disorders are more highly stigmatized and stereotyped. This may create **barriers to accessing services**, which can prevent or impede recovery. Women in recovery may also be at greater risk of being blamed or judged because of their disorders. They may also face negative sexual stereotypes or criticism of their parenting ability.

7. To **establish trust and rapport with women and girls during prenatal care** and discuss their roles, values, symptoms, experiences, priorities, and service needs.

8. To implement approaches that **empower women and girls** to take action in their own lives.

9. To work effectively with women and girls who are still developing their identities and who are in the process of discovering and **articulating** their preferences, interests, and goals.

10. To **establish therapeutic alliances t**hrough development of trust and rapport, as well as to demonstrate empathy, caring, and appropriate boundaries.

11. To create and contribute to a **safe prevention or treatment environment** that encourages connection, empo werment, and mutuality, and minimizes coercion.

12. To coordinate and collaborate with health/medical and **other service providers** regarding issues specific to pregnancy.

13. To **support pregnant women to remain engaged in services,** and to counter stigma and judgment that pregnant women may experience in the community by using strength-based approaches to create a safe, supportive environment.

14. To screen for the continuum of maternal and postpartum emotions and disorders such as anxiety, depression, and psychosis, and take appropriate action when needed and **without stigma.**

15. To communicate effectively and in a **safe, unbiased, and supportive** way while working with women and girls, particularly with regard to reproductive health, pregnancy, and parenting decisions.

16. To assist women and girls to **communicate effectively with health care providers** (e.g., preparing a list of questions, listening, taking notes, asking for written information, and disclosing sensitive personal information).

17. Value women and girls as **active participants in their health and wellness,** and recognize that they are capable of setting their own priorities and identifying steps toward change.

18. Recognize one's **personal biases** (e.g., concerning race, ethnicity, gender, socioeconomic status, language, ability, education, and citizenship status) and consider how these biases may affect, expand, or limit attitudes or approaches to serving Native women and girls.

19. **Be motivated to take care of oneself and model a healthy lifestyle for women and girls.**

20. There is meaning behind the proverb, "It takes a village to raise a child." This is true regarding the health needs of Native women and babies. It will take a woman's support system such as her partner, relatives and Tribal community to support her healing, her recovery and her resilience.

Appendix B

Implementing Health Literacy in Health Agencies and Institutions

Presented by Gabriel Maldonado

Functional Health Literacy Interventions

- **Health literacy.** "If I know what it's called, then I can tell you." Maldonado stated that agencies should consider whether their materials, on a basic level, are comprehensible by the population for which they were created.
- **Monolingual materials.** "If I can read it, then I can engage with it." Maldonado emphasized the importance of fully translating all materials into languages besides English.
- **Non-shame-based language, engagement, or policies** (e.g., empathy-driven case management services, protocols, and response plans). When an interaction denies a piece of an individual's identity or induces shame, Maldonado said, any useful health information that might have been included in the messaging is undermined. Shame can be triggering for clients, he said, and shuts down opportunities for learning.
- **Multichannel communication tools.** "If I can reach you then I feel connected and supported." Some individuals may have limited access to some communication tools (e.g., Internet access). As such, it is beneficial to communicate health information through multiple media.
- **Integrated behavioral health services.** "Every day my mind needs maintenance and my soul needs healing." By integrating behavioral health services into care, health agencies can both increase access to this important type of care, and use the opportunity to improve health literacy about the intersections between mental and physical health.
- **Comprehensive prevention and care services.** "If I can go to one place then I can do it all." By co-locating services, health agencies can both increase access to holistic care and improve health literacy about the connection between prevention and care.

Interactive Health Literacy Interventions

- **Peer support/navigators.** "If they speak my language and know my story, we can move faster." Once a community member has reached functional health literacy, they can serve as peer support/navi¬gators and share health information with others. Maldonado stressed the importance of the messengers in building functional health literacy in a community. He noted that having community members as messengers can accelerate an intervention, due to the shared language and cultural context with the intended audience.

Critical Health Literacy Interventions

- **Health systems literacy.** "If I can understand it, then I can navigate it" When individuals understand the stigma in health systems, and have built resiliency, they are better able to take actions to reduce stigma in those systems.

SOURCE: Maldonado presentation, January 27,2021.

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