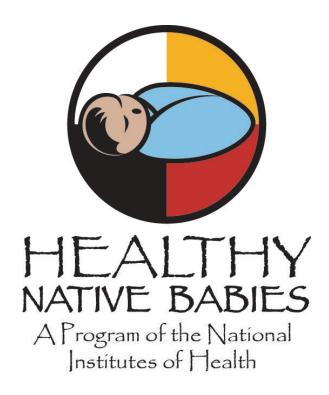
# Literature Review Summary



# Healthy Native Babies Project

January 2021

# Introduction

This report is intended to support the evaluation and redesign of the *Healthy Native Babies Project* (HNBP). It includes a brief outline of the burden of Sudden Unexpected Infant Deaths (SUID), including Sudden Infant Death Syndrome (SIDS); associated risk and protective factors among the American Indian and Alaska Native (AI/AN) population; and an overview of the promising practices that have been implemented by and with AI/AN people.

The HNBP was created to develop culturally appropriate SIDS risk reduction messages for AI/AN families, and to provide local support and training to health care providers and community health and outreach workers. The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health, met with AI/AN and federal partners in 2002 to address the high rates of SIDS in AI/AN communities, in response to the Aberdeen Area Infant Mortality Study. A work group formed to create an outreach initiative focused in the Northern Tier of the United States, which includes five Indian Health Service (IHS) Areas based in: Aberdeen, South Dakota; Anchorage, Alaska; Bemidji, Minnesota; Billings, Montana; and Portland, Oregon, where AI/AN SIDS rates were the highest. Members of this work group, and others, have continued the work, evolving the activities to meet current needs.

#### Methods

This report builds on previous literature searches by the HNBP, including studies on SIDS and SUID published between 2015 and January 2020.<sup>2</sup> As studies reporting AI/AN data are limited, publications outside of this date range were also included when more recent studies were not available. Multiple iterations of the primary search terms were used via PubMed MeSH (Medical Subject Headings), and within select Sudden Infant Death MeSH subheadings. For example, the search for literature on overall SUID and SIDS among AI/ANs combined either "sudden infant death," "SIDS," "Sudden Infant Death Syndrome," "Death, Sudden Infant," "Sudden Infant Death/epidemiology," "Sudden Infant Death/mortality," and "Sudden Infant Death/prevention and control," with "North American Indian," "American Indian," "Alaska Native," "inuits," "eskimo," "inuk," or "Native American." Other information included is from grey literature searches, and other relevant unpublished materials obtained by the HNBP.

# Rates of SUID and SIDS

SUIDs are infant deaths before one year of age that occur suddenly and unexpectedly, the cause of which is not immediately known before investigation, and include SIDS, accidental suffocation in a sleeping environment, and other deaths from unknown causes.<sup>3</sup> SIDS is the sudden death of an infant younger than one year of age that cannot be explained even after a full investigation that includes a complete autopsy, an examination of the death scene, and a review of the clinical history.<sup>4</sup>

In 1994, the NICHD in collaboration with other organizations launched Back to Sleep (renamed Safe to Sleep<sup>®</sup> in 2012), a public education campaign that promotes the American Academy of Pediatrics (AAP) safe infant sleep guidelines, including placing babies on their back to sleep. Since the initial launch, the overall SIDS rate in the U.S. has declined by more than 50%.<sup>5</sup> However, between 1995 and 2013, there was no significant change in non-Hispanic single race AI/AN SUID rates. During this period, SUID rates were consistently highest within the AI/AN population compared to other racial/ethnic groups in the U.S.<sup>6</sup> These disparities remain regardless of socioeconomic status, maternal age, birth weight, and prenatal care.

In 2017, the rate of SIDS among AI/AN infants (77 per 100,000 births) was more than double that of White infants (35 per 100,000).<sup>7</sup>

There is substantial regional variation in SIDS rates across the U.S. An examination of SIDS rates among the AI/AN population in states grouped by approximate IHS Areas during 2008-2017 shows the highest rates in the Alaska and Great Plains regions, followed by Portland, Billings, Bemidji and Oklahoma Areas (See Table 1).8 From 2006-2010, the infant mortality rate due to SIDS was significantly higher for AI/AN babies than for White babies in counties served by urban Indian health organizations nationwide (113 compared to 38 per 100,000 births). 9,10

Table 1: SIDS Rates Among AI/AN and White Infants, by Approximate Indian Health Service

IHS Area	States	AI/AN	White
		Rate per 100,000 Births	
HNBP Areas			
Alaska	Alaska	177	48
Bemidji	Michigan, Minnesota, and Wisconsin	114	30
Billings	Montana and Wyoming	116	60
Great Plains	Iowa, Nebraska, North Dakota, and South Dakota	177	56
Portland	Idaho, Oregon, and Washington	149	57
Other IHS Areas			
Albuquerque/Navajo/Tucson*	Arizona, Colorado, Nevada, New Mexico, and Utah	35	24
California	California	85	26
Nashville	Alabama, Arkansas, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Mississippi, Missouri, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Vermont, Virginia, and West Virginia	74	40
Oklahoma	Kansas and Oklahoma	114	61
Phoenix	Arizona, Nevada, and Utah	43	25

SIDS: Sudden Infant Death Syndrome; IHS: Indian Health Service; AI/AN: American Indian/Alaska Native Notes: ICD-10 Code: R95 (Sudden infant death syndrome - SIDS); Mother's Bridged Race: American Indian or Alaska Native and White<sup>11</sup>; \*Due to small numbers in select states, data were not available for these IHS Areas alone, therefore these were grouped as listed.

#### Data Limitations

Racial misclassification of AI/AN people in medical and vital records is a common barrier in epidemiologic studies on the population. <sup>12</sup> Racial misclassification consistently results in AI/AN people being classified as another race/ethnicity and underestimates the disease-related morbidity and mortality. <sup>13</sup> One study reported an estimated one-third of AI/AN children are not identified correctly as AI/AN in death records. <sup>14</sup> These limitations should be considered when reviewing rates of infant mortality for the AI/AN population.

# Biological Vulnerabilities for SIDS/SUID

The causes of many SUIDs may be discovered after an investigation. While the exact cause or causes of SIDS are not known, research has shown that babies who die of SIDS are born with one or more, often undetectable, abnormal biological or medical conditions, which may lead to unexpected responses to common stressors that occur during a baby's early life. <sup>15</sup> Specifically, recent research has shown the potential impact of infants' brain and genetic abnormalities, prematurity, and the influences of gender and the critical infant growth period on SIDS risk. These are each outlined briefly in this section, including data on the AI/AN population where available.

#### Brain and Genetic Abnormalities

The development and function of an infant's brain and nervous system play a role in SIDS risk. <sup>16</sup> The Aberdeen Area Infant Mortality Study, conducted among families from 10 Northern Plains Indian communities, suggested an intrinsic brainstem defect in SIDS cases in American Indians, and linked a specific brainstem neurochemical abnormality to prenatal exposure to maternal cigarette smoke. <sup>17</sup> Researchers also believe that genes may predispose infants to SIDS risk and act in combination with environmental risk factors that could result in SIDS. <sup>18</sup>

#### **Prematurity**

Being born prematurely has been shown to be a risk factor for SIDS. This is in part because preterm infants are not as able to regulate their breathing, heart rate, blood pressure, and body temperature as full-term infants. <sup>19,20</sup> Despite recent declines in overall rates, U.S. preterm births remain persistently high. <sup>21</sup> Approximately 10 per 1,000 live births are preterm, representing a large population of infants who are at increased vulnerability for SIDS. For AI/AN infants, the rate of preterm births is even higher at 11 per 1,000 live births. <sup>22</sup>

In an examination of mortality rates among infants born late preterm or early term between 2003–2005, rates of SIDS did not differ between non-Hispanic White and AI/AN babies.<sup>23</sup> In a study of SUID between 1995 and 2013, the AI/AN population had the highest SUID rates among preterm infants compared to all other races/ethnicities.<sup>24</sup>

#### Gender

Male infants account for over 60% of all SIDS cases, placing them at slightly higher risk than females.<sup>25</sup> The exact cause of the SIDS-gender association is unclear, however male infants appear to be more vulnerable than female infants to respiratory distress; and male infants may be more likely than female infants to have a gene that predisposes them to a condition causing a lack of oxygen to the brain.<sup>26</sup>

### Infant Age

The majority of babies who die of SIDS are in a 'critical growth period.' Before a baby reaches 6 months of age, there are periods of rapid growth and development that can cause an infant's system to be unstable. This may be why babies between one and four months are at highest risk of SIDS, and the majority (90%) of SIDS deaths occur before a baby reaches six months of age.<sup>27</sup> However, SIDS deaths can occur anytime during a baby's first year.<sup>28</sup>

# Triple-Risk Model

According to the Triple-Risk Model, SIDS is more likely in vulnerable infants with a preexisting abnormality.<sup>29,30</sup> The model states that SIDS may occur when three elements come together simultaneously:

- 1) The infant has an unknown or undetected biological or genetic problem that causes *vulnerability*;
- 2) The infant is affected by a *critical growth period* in its first year, which makes its body systems unstable for a limited time; and
- 3) The infant is exposed to one or more *environmental stressors* that it cannot overcome, because of the first two factors.

In short, an infant who is vulnerable and whose body systems are unstable, because of a critical growth period, may not be able to overcome environmental stressors. In further exploration of the persistent racial/ethnic disparities in SUID and SIDS, researchers may consider the possibility of an interplay between biological vulnerabilities related to factors such as metabolic or genetic abnormalities and environmental risk factors. <sup>31</sup> Known environmental factors are outlined in the next section.

# **Environmental Factors**

In an effort to reduce the risk of infant sleep-related deaths, the AAP identifies factors in the infant sleep environment—the third component in the Triple-Risk Model and the only modifiable factor—in "SIDS and Other Sleep-Related Infant Deaths: Updated 2016 Recommendations for a Safe Infant Sleeping Environment" (See Sidebar).<sup>32</sup>

This section briefly outlines selected SUID and SIDS environmental factors, including data on AI/AN communities where available, in order to highlight factors that could have important implications for SIDS risk reduction policies and practices for the AI/AN population. While race has been repeatedly identified in research studies as a risk factor for SIDS, race is a social category, not a biological factor. <sup>33</sup> Rather, racial disparities in SIDS and other sleep-related causes of infant death can be understood as related to a wide range of social inequities stemming from a history of systemic racism that continues to perpetuate

# AAP Recommendations for a Safe Infant Sleeping Environment

- Back to sleep for every sleep.
- Use a firm sleep surface.
- Breastfeeding is recommended.
- Room-sharing with the infant on a separate sleep surface is recommended.
- Keep soft objects and loose bedding away from the infant's sleep area.
- Consider offering a pacifier at naptime and bedtime.
- Avoid smoke exposure during pregnancy and after birth.
- Avoid alcohol and illicit drug use during pregnancy and after birth.
- Avoid overheating.
- Pregnant women should seek and obtain regular prenatal care.
- Infants should be immunized in accordance with AAP and CDC recommendations.
- Do not use home cardiorespiratory monitors as a strategy to reduce the risk of SIDS.
- Health care providers, staff in newborn nurseries and NICUs, and childcare providers should endorse and model the SIDS risk reduction recommendations from hirth.
- Media and manufacturers should follow safe sleep guidelines in their messaging and advertising.
- Continue the "Safe to Sleep" campaign, focusing on ways to reduce the risk of all sleep-related infant deaths, including SIDS, suffocation, and other unintentional deaths.
- Pediatricians and other primary care providers should actively participate in this campaign.

intergenerational trauma. <sup>34,35,36,37</sup> Social inequities directly contribute to negative birth outcomes, including lower birth weight and preterm birth, which, in turn, influence the physiological risks of SUID and SIDS as previously described. Factors linked to these social inequities, such as maternal smoking, absent or limited breastfeeding duration, and lack of prenatal care or quality prenatal care, also influence racial disparities in SUID and SIDS. <sup>38</sup> It is critical to consider the social and cultural context across generations and within individual lifetimes when examining the underlying causes of racial disparities in birth outcomes. <sup>39,40,41,42</sup> This section outlines relevant social and cultural context for SIDS among the AI/AN population within public health literature, in addition to the environmental factors addressed in the AAP recommendations.

# Infant Sleep Environment

Individual-level factors specific to an infant's sleep environment shown to increase the risk for SUID and SIDS may be more common in AI/AN communities and put AI/AN infants at even higher risk. 43,44,45 These risk factors include bed sharing and use of soft sleep surfaces, and soft objects and loose bedding in the infant's sleep area. 46 Related risk factors specific to SIDS include stomach or side sleeping during naps and at night, and overheating. 47

Research suggests that among certain populations, including AI/ANs, where and with whom babies sleep is a matter of long-held values, beliefs, and cultural practices.<sup>48</sup> Among many AI/AN communities it has been a common practice and a historical norm for infants to sleep in the same room as their parents or to bed share. The reasons why a mother or other infant caregiver may choose to sleep with the infant, despite the recommendation against it, include the following:

- Cultural norm—it is a traditional practice.
- Personal choice—it is the right choice for the family.
- Convenience for feeding—it may be easier for breastfeeding.
- Bonding—it may provide a more 'connected' feeling.
- Safety—to monitor the baby for SIDS risks or dangers like vermin, kidnapping, or stray gunfire.
- Specific situation—there may be an inability to be at home for naps or night-time sleep.
- *Economic necessity*—there may be limited resources to buy a crib, or makeshift sleeping locations may be used when living in an overcrowded living arrangement.

In focus groups including AI mothers and other caregivers from two reservations in Michigan, decisions about infant sleep location and position were focused on perceptions of what would make their infant most comfortable (such as sleeping longer) and safe, and what would be easiest for the parents. <sup>49</sup> While parents were aware of safe sleep recommendations, they lacked awareness of the underlying rationale. Parents were receptive to safe sleep education from providers; and they also shared frustration that health care providers did not explain the rationale behind safe sleep messages and did not address individual concerns, such as infant choking or infant comfort. These findings suggest that education about safe sleep recommendations needs to include both detailed explanations about the reasons behind the recommendations, and utilize a conversations-based approach that takes into account each family's needs, beliefs, and the context of their lives. <sup>50,51</sup>

Further, AI/ANs may be less likely to receive critical recommendations about safe sleep environments from health care providers. In a study of 2016 Pregnancy Assistance Monitoring System (PRAMS) data in 29 states, compared to non-Hispanic White mothers, non-Hispanic AI/AN mothers had lower reports of

receiving advice regarding safe sleep environments, including placing an infant to sleep in a crib, bassinet, or pack and play; and placing an infant's crib or bed in the mother's room.<sup>52</sup>

*Sleep Position*. In a Centers for Disease Control and Prevention (CDC) examination of PRAMS data from 2009-2015 in 15 states, non-supine (not on the back) sleep positioning decreased significantly among most racial/ethnic groups, except among AI/AN respondents.<sup>53</sup> In 2016 PRAMS data, the proportion of non-Hispanic AI/AN mothers reporting placing their infants on their back to sleep was similar to that of non-Hispanic White mothers (82% and 84%, respectively).<sup>54</sup> Select studies have not seen significant associations between sleep position or bed sharing and SIDS among AI/AN samples.<sup>55,56</sup> Findings such as these suggest that the relationship between SIDS and sleep position among AI/AN infants is more complex than previously acknowledged.

Bed Sharing, Soft Objects, and Loose Bedding. In a CDC examination of PRAMS data from 2009-2015 in 15 states, bed sharing prevalence was higher among AI/AN respondents compared with non-Hispanic Whites. <sup>57</sup> In a 2016 study of PRAMS data, non-Hispanic AI/AN mothers reported lower use of separate approved sleep surfaces compared with non-Hispanic White mothers, and notably higher rates of sleeping on a couch or armchair compared to overall rates. <sup>58</sup> In the same study, non-Hispanic AI/AN mothers were least likely to avoid soft bedding compared with non-Hispanic White mothers, and had higher rates of their infants sleeping with a blanket compared to overall rates. <sup>59</sup>

Overheating. In the 2002 Aberdeen Area Infant Mortality Study, researchers found that an AI baby's risk for SIDS and other sleep-related causes of infant death was higher if the infant was wearing two or more layers of clothing. <sup>60</sup> During 1995-2013, the proportion of SUID during the winter months decreased for all races/ethnicities except for AI/ANs, whereas the proportion during the summer months increased for non-Hispanic Whites, non-Hispanic Blacks, and Hispanics, but did not change among AI/AN infants. This indicates that recommendations against seasonal over bundling and overheating infants had inconsistent success across racial/ethnic groups, and shows the importance of developing culturally appropriate outreach and education strategies. <sup>61</sup>

# Commercial Tobacco Use

Smoking commercial tobacco may affect the development of the nervous system, and the infant's brain stem in areas involved with arousal, heart and breathing functions, sleep, and body movement control. 62 Pregnant women who smoke commercial tobacco are also at higher risk for pregnancy loss, preterm labor and birth, and having a low birth weight infant. Preterm birth and low birth weight are risk factors for SIDS; the risk of SIDS goes up as a baby's birth weight and gestational age go down. 63 Risk of SUID more than doubles with any maternal commercial tobacco smoking during pregnancy; risk goes up in relation to the average number of daily cigarettes during pregnancy; and any reduction in the number of cigarettes smoked is associated with a small decrease in risk. 64

Overall the AI/AN population has the highest prevalence of smoking commercial tobacco for both men and women compared to any other population group in the U.S., although smoking rates can vary considerably from one Tribe to another. According to the CDC, 26% of AI/AN women smoke commercial tobacco during their pregnancy—the highest rate of any racial/ethnic group, with rates much higher among pregnant women in certain AI/AN Tribes. In a recent study including participants from two reservations in South and North Dakota, referred to as the Safe Passage Study, the risk is increased for smoking commercial tobacco when the exposure continues after the first trimester, or with continuous exposure as compared to those not exposed or who quit early (around the end of the first trimester).

However, pregnant AI/AN women are less likely to receive clinician facilitated smoking cessation interventions during prenatal care, highlighting the need for implicit bias training and education for providers of AI/AN patients. <sup>68,69</sup> Further, there is a long history of commercial tobacco companies targeting AI/AN communities through extensive promotions, sponsorships, and advertising campaigns. <sup>70</sup>

### Maternal Drinking

Maternal drinking during pregnancy increases an infant's risk for SIDS and other sleep-related causes of infant death. This is true particularly for AI/AN infants, based on the Aberdeen Area Infant Mortality Study which found that:<sup>71</sup>

- Binge drinking (five or more drinks at one time) during the mother's first three months of pregnancy increased the risk of SIDS eight times that of infants whose mothers did not drink.
- Any alcohol use during the three months before a woman became pregnant and during the first three months of pregnancy increased the risk of SIDS six times that of infants whose mothers did not drink during the same periods.

In the Safe Passage Study, the risk of SIDS was as much as eight times higher for continuous drinkers compared to those that did not drink.<sup>72</sup> The risk was increased when drinking continued after the first trimester, or with continuous drinking during pregnancy compared to those that did not drink or who quit early (around the end of the first trimester). In this study, there was no significant association between any post-natal drinking or smoking between mothers of SIDS infants and mothers of infants alive at one-year.

#### Concurrent Commercial Tobacco and Alcohol Use

The Safe Passage Study further found that infants prenatally exposed to both alcohol and cigarettes beyond the first trimester have a substantially higher risk of SIDS compared to those unexposed, exposed to alcohol or cigarettes alone, or when the mother reported quitting in early pregnancy.<sup>73</sup> These results held even after researchers took into account other known risk factors for SIDS, like lower socioeconomic status and lower education levels, which suggests that the findings may be more broadly relevant.

# Breastfeeding

Breastfeeding is associated with a reduced risk of SIDS.<sup>74</sup> In national data from 2015, 18% of AI/AN infants were exclusively breastfed for their first six months. Compared to other races/ethnicities, AI/ANs have the second lowest rates of breastfeeding initiation (76%), and the third lowest rates of breastfeeding duration at six months (55%) and 12 months (31%).<sup>75</sup> An analysis of New Mexico PRAMS data showed AI women were less likely to report breastfeeding in the hospital than other racial/ethnic groups, and less likely to say they were encouraged to breastfeed on demand than other groups.<sup>76</sup> A study in Montana reported on the challenges to breastfeeding among AI/AN communities related to community stressors, such as a lack of health care infrastructure limiting prenatal breastfeeding counseling, historical trauma, and substance use.<sup>77</sup> Recommendations include strengthening family and intergenerational relationships, such as by involvement of grandmothers and health care professionals to support breastfeeding and address identified stressors.

A study including Tribal communities in the Pacific Northwest reported the need for enhanced education about the timing and methods for the introduction of solid foods, strengthening social networks to support healthy infant feeding choices, and expanding the perceived value of breastfeeding to include broader health benefits, particularly in the context of childhood obesity. Study authors also noted the diversity of customs and beliefs across Tribal communities, highlighting the importance of designing interventions

with communities. Many Tribes and urban Indian communities are encouraging breastfeeding by focusing on its cultural role, and promoting policy changes to support breastfeeding in hospitals, workplaces, and communities. <sup>79,80,81</sup>

Some breastfeeding advocacy groups encourage bed sharing to promote breastfeeding, and promote that bed sharing is safe among infants who are breastfed (a protective factor for SIDS) and infants whose mothers do not smoke, drink alcohol, or use illicit substances. However, the issue of infant safe sleep in the context of breastfeeding while bed sharing is debated. 82 The 2016 AAP guidelines describe that infants who are brought into the bed for feeding or comforting should be returned to their own crib or bassinet when the parent is ready to return to sleep. 83 Parents and other caregivers should be especially vigilant as to their wakefulness when feeding infants on couches or armchairs, as sleeping on couches and armchairs creates a high risk of infant death, including SIDS. 84

#### Health Care Access

AAP guidelines for SIDS risk reduction highlight substantial epidemiologic evidence linking a lower risk of SIDS for infants whose mothers obtain regular prenatal care.<sup>85</sup> Lack of prenatal care means fewer opportunities for education and support related to safe infant care practices, commercial tobacco smoking cessation, and breastfeeding. In 2017, compared to non-Hispanic White mothers, a lower proportion of AI/AN mothers received prenatal care in the first trimester (63% vs. 82%), and a higher proportion received late or no prenatal care (13% vs. 5%).<sup>86</sup> AI/AN women experience barriers specifically related to prenatal care, including lack of access and continuity of care, and lower quality of care.<sup>87</sup>

The U.S. government's unique responsibility to provide the AI/AN population with medical care is based in established treaties and laws, however high proportions of AI/AN people lack access to health care, increasing their risk for poor health outcomes. <sup>88,89,90</sup> In a study of 2009 PRAMS data from 29 states, AI/AN women had lower odds of stable health insurance coverage than unstable coverage around the time of pregnancy, and higher odds of reporting Medicaid coverage than private insurance at delivery compared to White women. <sup>91</sup> In a study of National Health Interview Survey (NHIS) data before the Patient Protection and Affordable Care Act was implemented, a striking proportion of AI/ANs in the study did not have health insurance and many cited costs as the reason. <sup>92</sup>

In the same study, compared to non-Hispanic Whites, AI/ANs in urban areas had 20% higher odds of reporting not receiving health care due to cost, and 70% higher odds of reporting a lack of a usual place to go when sick. Other barriers to care reported in this study, including wait times in the doctor's office and on the phone, and limited office hours, highlight the capacity challenges faced by clinics serving urban AI/AN communities and other groups in urban areas. 93,94 Persistent documented barriers to care for AI/AN people also include: cultural differences creating problems with provider communication, discrimination (whether intentional or not), perceptions of bias and mistrust, lack of confidence in ability to get health care, dissatisfaction with care, and differences in beliefs and attitudes about health care. 95,96,97,98,99 Culturally appropriate prenatal care is critical to improve outcomes among the AI/AN population. 100,101

#### Social and Cultural Context

It is critical to understand the social and cultural context in which AI/AN people live and raise their families to effectively support SUID and SIDS risk reduction policies and practices. Historical oppression and trauma, ongoing systemic racism, and resilience through culture are key aspects of this context for AI/AN people. <sup>102</sup>

Historical Oppression and Trauma. Historical oppression and current experiences of trauma affect SIDS risk. <sup>103</sup> For AI/AN people, historical trauma includes multiple layers of individual, group, and intergenerational traumatic experiences that have undermined the social and cultural fabric that once supported vibrant and intact AI/AN families. Such oppression encompasses historical land dispossession, forced removal, assimilative boarding schools or relocation policies, prohibition of spiritual practices, and environmental degradation. <sup>104</sup> Historical trauma from colonialism and federal policies resulting in cultural genocide have a continuing negative impact on AI/AN families, passing from generation to generation. <sup>105</sup> Development and evaluation of healing intervention models, grounded in Indigenous worldviews and led by AI/AN people, are needed in efforts to address these traumas. <sup>106,107</sup>

Systemic Racism. Systemic racism is a root cause of adverse health outcomes among AI /AN people and is embedded in policies and funding for housing, health care, education, and employment, which determine opportunities, risks, and resources impacting the capacity of AI/AN families to create a safe infant sleep environment. <sup>108,109</sup> For example, homelessness and unstable housing are a serious problem for AI/AN families in both urban and rural areas of the U.S. <sup>110</sup> Approximately 10% of mothers of AI/AN infants in California were homeless or did not have a regular place to sleep at night during their pregnancy, nearly three times the rate for the state overall; and more than 10% reported having to move during their pregnancy due to problems paying the rent or mortgage. <sup>111</sup> Nearly 20% of mothers of AI/AN infants in the same California study reported that either they or their partner experienced job loss or a reduction in hours or pay while they were pregnant. <sup>112</sup>

However, racial health disparities persist regardless of socioeconomic status and upstream social factors. <sup>113</sup> Cultural racism, which labels as inferior the values, language, imagery, symbols and assumptions of selected racial groups, manifests through negative stigma, stereotypes, and conscious or unconscious bias within institutions and norms. <sup>114</sup> These negative racial stereotypes (e.g., being lazy, unintelligent, or violent, and having unhealthy habits) against AI/AN people have been reported in national studies and can impact the quality of clinical care among other key resources. <sup>115</sup> The lack of positive, multidimensional representations of AI/AN people within society also contributes to cultural racism, and is being reclaimed in part through the infusion of accurate and contemporary representations of and by AI/AN people. <sup>116</sup>

The psychosocial stressor of racial discrimination is also a significant risk factor for adverse birth outcomes. <sup>117</sup> In a recent California study, 20% of mothers of AI/AN infants reported worrying about racism somewhat or very often across their lifetime, compared to only 14% of mothers overall. <sup>118</sup> Further, exposure to stressful life circumstances over the course of a woman's life is thought to impact birth outcomes, such as low birth weight and prematurity, which are tied to SIDS risk. <sup>119</sup> In a study of PRAMS data in 19 states, more than one in three AI/AN women reported experiencing traumatic stressors just before or during pregnancy; the highest percentage across all other racial/ethnic groups. <sup>120</sup>

For AI/AN people in urban areas, a loss of connection to Tribal social networks can result in lack of social support, high stress, and diminished cultural ties. <sup>121,122</sup> A 2016 study reported on findings from discussions with AI/AN parents in four urban areas, in which parents highlighted community patterns such as alcohol and tobacco use, adolescent parenting, and violence as challenges to creating a safe environment for their infants. Other specific barriers to infant health and safety practices were a lack of money, housing, transportation, and childcare; as well as social isolation and stress, especially for adolescent parents. <sup>123</sup>

Culture as Medicine. Despite experiencing historical and current oppression, AI/AN families, communities, cultures, and governments have always had inherent assets that promote healing and wellbeing. These include drawing strength from place of origin, connection with the natural world, traditional practices, cultural identity, language and symbols, kinship ties, spirituality and religion, ceremonies, community activities, and humor. 124,125 One model of Native women's health describes how cultural factors such as community, traditional healing practices, and Native identity function as buffers against stressors. 126 Connection with Native identity and culture serves as a vital protective factor, which could intervene against increased risk for SUID and SIDS within AI/AN communities. 127,128,129,130,131 AI/AN parents in four urban areas identified facilitators for keeping their infants healthy and safe, and breaking unhealthy patterns. They described a strong Native identity; Native-specific resources, such as those offered at urban Indian health organizations; control over their own environment, such as determining who they allow around their infant, and having consistent housing; shared values among caregivers; and social support. 132,133 These findings on the value of urban Indian health organizations to urban dwelling AI/AN people have also been reported in other studies. 134 The strength and resilience of AI/AN people should be emphasized in efforts to promote health and wellbeing, acknowledging that the answers to challenges are known within AIAN communities. 135

# **Promising Practices**

Persistent high rates of SUID and SIDS among the AI/AN population likely means risk reduction and other outreach campaigns for the general population are not reaching AI/AN communities, are not addressing the most critical factors, or are not being presented in a way that would reduce the risk or disparities experienced by this group. A version of the social-ecological model presented by the National Action Partnership to Promote Safe Sleep is used to outline this section, in which findings from reviews of evidence on safe sleep interventions are described, highlighting studies including data on the AI/AN population where available. Illustrative examples of efforts to address SIDS and other sleep-related causes of infant death among the AI/AN population are provided, with the goal of considering promising practices and lessons learned.

## Influencers and Organizations

Focus group participants, including AI mothers and other caregivers, in Michigan described various items as being influential on mothers' decisions about infant sleep environment, e.g., safe sleep materials and speaking with staff from hospitals, and home visiting programs such as Healthy Start. <sup>136</sup> Furthermore, participants described family and friends with experience with infants as influential for young mothers. Fathers were also described as influential in decisions about sleep location, particularly related to not bed sharing.

A 2017 review of evidence on safe sleep position interventions showed that those implemented at the caregiver, health care provider, and hospital levels (where there were not already quality improvement initiatives), as well as national campaigns, appear to be most effective in increasing exclusive back sleep position in infants. Authors of the 2017 review also recommended that future evaluations assess the effectiveness of evidence-informed interventions by race/ethnicity due to substantial variation in adherence to safe sleep recommendations among racial and ethnic subgroups. Health communication campaigns have the greatest, most lasting impact when conducted in conjunction with health and social service systems that provide access to essential services while reinforcing educational messages. 138

### **Community**

A systematic review of prenatal and infant-toddler health promotion programs in the Canadian Indigenous population examined potential underlying program mechanisms that could explain positive program outcomes. <sup>139</sup> The study found that programs that built in local Indigenous community investment and thus achieved a sense of local community program ownership, and subsequent sustained local program participation, were successful in positively impacting a diverse range of prenatal and child health outcomes across a range of Indigenous populations and settings. Specifically, the following criteria were examined within the review, and defined as Indigenous community investment-ownership-activation:

- Prioritization and validation of community-based experiential knowledge;
- Integrated commitment to community development/capacity building;
- Local cultural grounding;
- Using social networks and community opinion leaders to endorse/promote program;
- Focus on sustainability of the program; and/or
- Building on existing community structures/infrastructures.

A similar review of programs within the AI/AN population in the U.S. was conducted using the same search strategies and criteria as the review in the Canadian Indigenous population. <sup>140</sup> Likewise, programs focused on reduction of risk factors relevant for SIDS, that included at least two elements of Indigenous community investment-ownership-activation reported positive results.

A review of national health communication campaigns for the AI/AN population highlighted the importance of incorporating AI/AN cultural concepts and practices in a way that features the strengths of the community. <sup>141,142</sup> An emphasis on strength-based concepts, such as political and cultural sovereignty, self-determination, and spirituality, is an effective way to counteract the historical trauma and cultural degradation that impact AI/AN communities. <sup>143</sup> While differences among communities exist, AI/AN values and beliefs can still be incorporated effectively into programs through practices common across many Tribes, such as oral teachings and learning by observing and through experience. <sup>144</sup>

# Policy and Society

A review of peer-reviewed literature on safe sleep interventions between 1990 and 2015 strongly emphasized the importance of multi-pronged, consistent messaging across multiple levels tailored for target populations. <sup>145</sup> Authors of a study that compared selected world populations by SUID and SIDS rates, and selected risk factors, noted that recommendations for social policy makers should accompany recommendations to individual caregivers and health care providers to have an impact on underlying societal risk factors for SUID and SIDS. <sup>146,147</sup> In other words, programs should not expect individuals to address the burdens placed on them by history and an inequitable social structure. The context, which affects individuals and communities' ability to implement positive change, needs to be addressed in any culturally relevant SUID and SIDS risk reduction effort. <sup>148</sup>

### Sample Programs

Select efforts to address SUID, SIDS, and infant health among AI/AN communities are outlined here with the goal of considering potential promising practices.

> The federally endorsed Family Spirit Home Visiting Program by the Johns Hopkins Center for American Indian Health, in partnership with the White Mountain Apache, San Carlos Apache, and Navajo Tribal communities, has shown significant positive impacts on parenting knowledge,

parental locus of control, depressive symptoms, externalizing problems, and use of illegal drugs and marijuana. A secondary analysis of this model, which assessed parental competence, maternal emotional and behavioral health outcomes, and child emotional and behavioral health outcomes among young Native American mothers and their children, reported that unstable housing, parity, and low educational attainment were moderators of intervention effectiveness, highlighting the need to tailor intervention content to meet families' most salient needs. 150

- Another home visiting model being implemented among the AI/AN population includes the Southcentral Foundation's **Nutaqsiivik Program**. Using the Nurse-Family Partnership model, the program provides prenatal, neonatal, and post-partum care, including home visits, and previously reported a decrease in deaths through its program.<sup>151</sup>
- ➤ The **Safe Sleep, Sweet Dreams** program in the IHS Aberdeen Area implemented community-based, home visiting education for SIDS risk reduction and in 2007 reported between 5% and 74% knowledge gains in nine risk areas. <sup>152</sup> Authors noted that education delivered by hospital or visiting programs staff was well accepted, inexpensive, and produced significant and meaningful improvements in knowledge; but also noted the need for examination of follow-up behaviors, not assessed in this study.
- A decrease in the Alaska Native fetal-infant mortality rate in 2010 and 2011, especially in rural areas, was reported to have been due in part to statewide efforts related to preventing postneonatal sleep-associated deaths, including the *Healthy Native Babies Project* (HNBP) trainings, which took place in two rural areas with the highest SIDS rates in the state at that time. <sup>153</sup> Also in Alaska, *Healthy Alaska Babies* is an infant safe sleep "train the trainer" workshop for health care, public health, and social services workers which adapted the HNBP materials for their local context. <sup>154</sup>
- Another example of an adaptation of the HNBP materials is the **Inter-Tribal Council of Michigan's Infant Safe Sleep Resource Site** for parents, providers, and Tribal home visitors. The resources include a video to educate parents about safe sleep guidelines; a free, online video course for Indigenous women caring for newborns; and a toolkit to educate Tribal leaders about the importance of infant safe sleep, including action items for the promotion of infant safe sleep in Tribal policy development, strategic planning, and community education. <sup>155</sup>
- The 1,000 Grandmothers: Infant Safe Sleep Project was developed by the International Association for Indigenous Aging (IA2) and the Michigan Public Health Institute, funded by the CDC in four AI Tribes, and adapted from the HNBP materials. The IA2 project team developed collaborative relationships with selected elder Tribal participants—especially grandmothers—to conduct focused mentoring and education for young mothers. The pilot project was implemented in geographically and culturally diverse Tribes, i.e., the Turtle Mountain Band of Chippewa Indians in North Dakota; the Eastern Band of Cherokee Indians in North Carolina; the Hannahville Indian Community (Potawatomie); and the Sault Ste. Marie Tribe of Chippewa Indians. Pre- and post-interviews and quantitative assessments indicate that educational strategies were effective. 156 Project presentations also shared practical lessons learned.
- ➤ The Coming of the Blessing Initiative, begun in 1998 by the women of Wind River Indian Reservation and later supported by the March of Dimes, aims to address disparities in birth outcomes for AI/AN families using a perinatal education booklet and adaptation of a perinatal

education curriculum called Becoming a Mom. The booklet project expanded to include support for educators on any reservation to provide culturally appropriate prenatal education, a photo exhibit celebrating AI/AN families and babies, and a culturally appropriate AI/AN appendix to the curriculum. Reservations in North Dakota, Wyoming, New Mexico, Nevada, Arizona, Alaska, and Montana have participated in Coming of the Blessing trainings.<sup>157</sup>

- Native Generations is a nationwide campaign addressing high rates of infant mortality among AI/ANs in urban areas. The campaign promotes infant mortality protective factors, such as increased use of Native-specific resources (including health care, support services, and programs), and connection to Native identity, culture, and community. The materials include an 11-minute video, and guides and flyers for sharing the video hosted on a dedicated webpage. Pilot survey data indicate the video may help increase awareness and connection. 158
- The **Bedtime Basics for Babies** program, a large, free crib and education program, reported a change in knowledge and practices of safe infant sleep in a large proportion of participants. However, there was no change in intention to place infants on their back for sleep among AI mothers in Washington. The Bedtime Basics program is no longer active, but **Cribs for Kids** is another program that provides cribs for mothers who cannot afford them, and educates mothers about the dangers of unsafe-sleep environments. The
- Native populations around the world may have originated the concept of Back to Sleep with their traditional use of the **cradleboard**, **the Wahakura**, **or other culturally appropriate sleep surfaces**. <sup>161,162</sup> In the United States, the specific design of a cradleboard differs from Tribe to Tribe, but is essentially a handmade, framed, flat basket or board. Native teachings about cradleboards say they keep the baby safe in a distinct location, help with the child's skeletal development, strengthen neck muscles, and provide an opportunity for the infant to be visually and emotionally stimulated by his or her environment and family.

Many Tribes and urban Indian community centers offer classes on how to make and use cradleboards. Cradleboard classes provide safe sleep education, a safer sleep product, and social support for expectant families. The classes and support also help AI/AN mothers connect with their culture, which may be protective against infant mortality. <sup>163</sup>

In Washington State, the **Native American Women's Dialog on Infant Mortality** (NAWDIM), offers cradleboard classes in and around Seattle. NAWDIM is a collective of community members, social service and medical providers, and allies. Cradleboard class attendees spend the day constructing cradleboards from preassembled components, building community with other families, and learning about nutrition, breastfeeding, and the best ways to keep their baby safe during sleep. <sup>164</sup>

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