Acknowledging Root Causes and Understanding Lessons Learned to Address Sleep-Related Infant Death Among American Indian and Alaska Native Populations

HEALTHY
NATIVE BABIES
A Program of the National
Institutes of Health

Healthy Native Babies Project

April 2022

Contents

Introduction 1
Methods 1
Results 1
- Awareness of safe infant sleep 1
- Challenges to practicing safe infant sleep 2
  - *Impact of COVID-19* 3
- Cultural and traditional strengths 4
- Communication approaches 5
  - *Healthy Native Babies Project materials* 6
- Lessons for working with Native families 7
- Supporting educators and care providers 8
- Addressing root causes of SIDS risk 9

Summary 10

Acknowledgements: We are grateful for the time and expertise the participants committed to this project and to the work they do every day to support Native communities.

Suggested citation: Rutman, S., King Bowes, K., Simkins, G., Helvey, K., Tanner, L., Zephier, M. *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (2021). *Healthy Native Babies Project: Acknowledging Root Causes and Understanding Lessons Learned to Address Sleep-Related Infant Death Among American Indian and Alaska Native Populations*. U.S. Department of Health and Human Services, National Institutes of Health.

Introduction

American Indian and Alaska Native (AI/AN) people have the highest Sudden Infant Death Syndrome (SIDS) rates of any racial/ethnic group nationwide.[1] SIDS is part of a broader category of infant death called Sudden Unexpected Infant Death (SUID) that includes both known causes and unknown causes, most of which are categorized by the Centers for Disease Control and Prevention as SIDS, accidental strangulation, and suffocation in bed and those of unknown causes.[2]

The *Healthy Native Babies Project* (HNBP) offers community-informed training to local providers and community health and outreach workers on reducing the risk for SIDS and other sleep-related causes of infant death using approaches specific to AI/AN cultures.[3] The HNBP also gathers updated information to understand communities' current challenges and strengths in addressing safe infant sleep. The information will be used to develop and fine-tune materials and activities, including training classes and technical assistance to share with Native communities and others that serve them.

Methods

HNBP team members conducted semi-structured in-depth key informant interviews between July 2020 and May 2021 with 16 individuals representing eight Indian Health Service (IHS) geographic regions. Participants included a diverse range of representatives working to address safe infant sleep in AI/AN communities, including program directors, healthcare and service providers, a spiritual elder, and health educators. Individuals were based at tribal organizations, hospitals, the IHS, urban Indian programs, and university and state-based agencies that serve AI/AN populations.

Interviewers used semi-structured data collection guides focused on: level of awareness of SIDS; community strengths for supporting safe infant sleep, including traditional and cultural practices; the challenges that communities face when addressing safe infant sleep, including the recent impact of the COVID-19 pandemic; and recommendations for ongoing efforts. Prior to data collection, interviewers discussed the project purpose and explained the confidential and voluntary nature of participation to the participants. Interviews lasted approximately 1 hour. Content analysis and structural and emerging coding of qualitative data involved extracting and sorting information into themes using Microsoft Excel.

Results

Analyses showed consistent themes across participants related to safe infant sleep level of awareness, challenges, lessons learned from working with communities, and recommended activities to support families, except where noted.

Awareness of safe infant sleep

Participants were asked about their perceptions of awareness of safe infant sleep overall in their communities and service populations, and about the disparity in SIDS deaths between Native and non-Native populations. One participant specifically said they did not believe there was awareness of the

[1] Rutman, S., King Bowes, K., Simkins, G., Helvey, K., Tanner, L. *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (2021). *Healthy Native Babies Project: Literature Review Summary.* U.S. Department of Health and Human Services, National Institutes of Health.

[2] *Eunice Kennedy Shriver* National Institute of Child Health and Human Development. Accessed March 31, 2022. https://safetosleep.nichd.nih.gov/safesleepbasics/SIDS/Common

[3] For more information regarding The *Healthy Native Babies Project* and resources, please visit: https://safetosleep.nichd.nih.gov/resources/caregivers/healthynative

increased SIDS rates among AI/AN communities. Most participants believed their communities know about safe infant sleep generally, with a couple noting direct experiences, such as, *"Sadly, often people know someone who has experienced a SIDS death."*

Many participants described reasons that awareness of SIDS is not sufficient to prevent risk.

> *They definitely know about [SIDS], but that doesn't mean they necessarily think co-sleeping is risky. There is a [perceived] protective factor in keeping baby close to you. I think all moms feel that way, and Native families too.*
>
> *Even though they may know, they may not really buy into it.*
>
> *No one thinks in the middle of the night they are going to roll over on their babies or pin them in the crack between the mattress and the wall, but it happens, it does happen.*

Participants also described gaps in awareness, "*There is a lot of messaging around back sleeping, and a good response to that, but we are seeing blankets and other things in the bed."* Similarly, another participant described local survey data with a high proportion of AI/AN participants reporting they place their infants to sleep on their backs, and much lower proportions that have firm sleep surfaces and sleep environments without soft objects or loose bedding.

Challenges to practicing safe infant sleep

When asked what makes it difficult for families to practice safe infant sleep, one participant summarized the most common issues as follows:

> *There are challenges in the built environment. Living in multigenerational families. Living in homes where there is substandard housing. Babies may not have a place to sleep safely. Parents may struggle living with elders [when they try to] insist on, or demand smoke-free environments. [Parents may struggle regarding] other spiritual and cultural beliefs about baby and mother being together [in bed]. We are also encouraging breastfeeding, which may complicate safe sleep issues, as mothers bring babies to bed with them to nurse.*

Within these challenges, overwhelmingly the most common was a **lack of money and space** for a separate sleep surface, including housing insecurity. This also related to multiple other safe infant sleep risks, such as overheating.

> *In some of our housing situations, there is not adequate heat in the wintertime, and babies might be overheated by what they are dressed in for sleep.*

Barriers to healthcare was the second most common challenge described, including lack of access to care, limited time during visits to address safe infant sleep comprehensively, lack of continuity of care with transfers between systems and providers, and a lack of health literacy among those seeking care.

Another issue within healthcare described by a few participants was **cultural insensitivity** and **racial incongruence between healthcare providers and patients** leading to lack of uptake of recommendations.

It really depends on the providers they are working with. There are amazing providers having those conversations and promoting decision-making on the part of the parents, and then there are others that are very culturally insensitive… and especially when you have providers that are older that are working in Indian clinics and IHS clinics that have been doing this for 30 years.

Other frequently noted challenges were perceived incompatibility between **breastfeeding** and safe infant sleep, and the **influence of family members**, especially grandmothers. The challenge of family influence was also described as related to housing insecurity.

Breastfeeding reduces [SIDS] risk, but it's easy to get a good latch and then fall asleep with baby in bed, which increases risk.

Elders are very much respected in our culture. Even though we know safe sleep recommendations have changed over the years, grandma might still think it's good to have babies sleep on their stomachs.

A handful of participants also described a perceived incompatibility between some **traditional spiritual and cultural beliefs**, like physical connection during sleep for mothers and babies, and mainstream safe sleep practices. A couple of these participants shared that safe infant sleep is a sensitive topic with one explaining that some tribal cultures are told not to talk about death.

Two participants described a **lack of societal support for families** as a challenge to practicing safe infant sleep, with one explaining this as follows:

It's a really different picture to practice safe sleep, for example if you have to get up five times per night, if you have paid maternity leave for a year. That is really different than if you have to get up, and get the kid to daycare by 7 a.m., so you can get to work, otherwise you'll lose your job and you won't be able to pay your rent.

Other noted challenges to families practicing safe infant sleep were **media** and **second-hand smoke**.

Pinterest and all of that makes the cribs really pretty and all of the bumpers, toys, and blankets.

Most the time when I'm talking to my patients, they have relatives that smoke, and they are not going to stop.

Impact of COVID-19

Interview participants were asked how they think the COVID-19 pandemic may have impacted the practice of safe infant sleep in their communities. The most common response was **barriers to perinatal care**, with one healthcare representative stating their organization was closed due to COVID-19, and others describing fewer visits, and fewer opportunities to discuss safe sleep with response to COVID-19 taking precedence. Multiple participants specifically noted the barrier to providing home visits due to COVID-19.

[Home visitors] can look at the infant's sleeping space, and they can make suggestions, and they cannot do that now.

There were also examples provided about the **benefits of technology** for healthcare and education, such as increased access to visits for those with transportation issues, as well as the use of YouTube videos demonstrating how to use portable cribs. However, these benefits were not universal, with lack of access to internet or equipment also posing common barriers for some communities.

Several participants said that the **COVID-19 pandemic exacerbated housing issues**, which caused challenges creating a safe infant sleep environment. A lack of resources including food insecurity were also described as leading to **increased stress**, with one participant noting, "*These [COVID-19] restrictions may cause people to be lax with regards to safe sleep behaviors.*" The issue of space due to crowded housing was also described as related to increased exposure to environmental commercial tobacco smoke and domestic abuse, which was noted as not specific to Native communities.

Cultural and traditional strengths

When asked about traditional and cultural practices to support practicing safe infant sleep, the most common response was the **strength of the extended family**, "*Many family members take an active role in helping to raise these children. Really, the community helps raise them.*" The traditional belief that **children are sacred** was also a frequent response.

> *We are raising the next generation of our tribe, of our clan, of our people. That value is inherent in traditional Native culture, and may have been lost through colonization, through the impact of trauma on our communities… this generation of babies are the leaders of tomorrow, and the keepers, and the helpers for elders that we so revere.*

Incorporating traditional and cultural practices was also described by a few participants as a way to build on a strengths-based approach to health education.

> *We have far more strengths in our communities, within our cultures, within our languages, and within our ceremonies—we have far more strengths than we have barriers or challenges; and to draw on those is really important and connect those to whatever we are trying to affect change in, is really important.*

Participants shared traditional practices and teachings as opportunities to incorporate education about safe infant sleep, including beading, baby wrapping, dancing, breastfeeding, pow wows where star quilts are gifted, sacred tobacco, and traditionally living substance free.

When specifically asked about the role of **cradleboards** in their communities, most noted a high level of interest in and use of cradleboards with a few sharing less awareness, including about whether local tribes traditionally used them or whether they are recommended as safe. One participant expressed the desire for a statement at the national level that they could include in their local policies, "*to say that cradleboard use is considered safe or as it relates to Indian population. I think that part has been missing.*"

Two participants commented on **traditional parenting practices** as cultural strengths for practicing safe infant sleep.

> *I think like a lot of the teachings that we have as [tribal] people affect parenting style, affect parenting efficacy and connections between families, and I really believe that those are the types of things that support safe sleep and safe sleep environments.*

One participant noted the diversity across communities and individuals in connection to traditional and cultural practices, highlighting the importance of tailoring efforts to the communities being served.

> *I think it's really dependent on family dynamics and family situations. In some areas we still have a lot of [tribal people] that are traditional and then we have other families that didn't grow up with that teaching, don't have that teaching. It's going to be a wide range, and it's really dependent on the communities that you serve.*

Communication approaches

When asked about recommended communication methods to support Native families in practicing safe infant sleep, participants addressed a range of approaches, including audiences, timing, settings, and materials. Several participants noted the need to consider **fathers and multigenerational families** in communication and education efforts.

> *We really need to be creative in including the father. Everything's 'mom, mom, mom,' and fathers need to understand that they have a responsibility too. Including that father perspective, I think, would be helpful.*

> *There are many people caring for an infant. It is really important that the education extend beyond the mom and the dad; bring in grandma, grandpa, aunties, uncles, the whole extended family.*

Multiple participants recommended the best **timing for education** as during the prenatal period; or if that connection is not made, then before the family leaves the hospital or birthing place, and highlighted opportunities for birth workers to include safe sleep education.

> *I think a lot of education should be provided by [obstetricians (OBs)] to give the moms time to think about it, look it up for themselves and create plans before baby ever comes.*

> *We could be utilizing individuals that work with moms, that do birth work, our birth workers [like midwives, doulas and groups who support women in prenatal and postpartum periods]. Those groups could be really solid places where we could talk more about harm reduction and supporting families in that way.*

Home visits were recommended by several participants as an opportunity for consistent and reinforced education on safe infant sleep, with a few specifically noting, "*The education and buy-in has to happen at the community health aide level.*" One participant recommended leveraging widespread programs, such as the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) to distribute safe infant sleep information to Native families. **Community events and support groups** were also suggested by a few participants as opportunities for outreach with safe sleep messages.

> *When families are connected to community, and to other people in the same phase of life, that can support each other, those are places where safe sleep messaging and harm reduction could really be happening.*

Regarding materials that would support Native families in practicing safe infant sleep, a few participants described using the Johns Hopkins Center for American Indian Health's *Family Spirit* home-visiting curriculum, which is evidence based and culturally tailored, and includes a section on safe infant sleep.[4] However, they also described the need for more in-depth information to supplement materials currently in the field. Specific recommended educational materials included **culturally relevant handouts and flyers**, which can be used as conversation starters.

Overall, **visuals** such as graphics, images, and pictograms, as well as stories and videos, were mentioned frequently as more valuable than written materials, specifically for elders and to support a range of literacy levels. Videos were also noted as desirable for *"young people regardless of their literacy rate."* The need for **safe sleep products**, such as sleep sacks and low-cost and portable cribs, was also indicated by several participants.

Healthy Native Babies Project materials

We asked for those who were familiar with the *HNBP* materials to offer their thoughts, and participants overall shared a positive response.

> *I have always heard good feedback from our home visitors about that Healthy Native Babies curriculum.*

> *It is wonderful and has great educational videos.*

Specifically, participants described the fact that the materials are **culturally specific** as key to their unique value.

> *It is really the only source of Native images, and colors, and graphics that I can think of.... So just having the material fills a big void.*

> *I love that [HNBP] is presented using visuals that people in our region can relate to. And that's different [from other safe sleep programs].*

A few participants also commented on the utility of having **customizable** materials.

> *Just having a set of things that could be customized—pictures of Native moms and babies, poster templates, PowerPoint templates—having editable materials saved us hours and hours of work…. Every community is different, every setting is different. Being able to customize it, and tailor it, and incorporate it into other things is really nice.*

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[4] Johns Hopkins Center for American Indian Health's Family Spirit home-visiting program https://caih.jhu.edu/programs/family-spirit/. Accessed September 24, 2021.

The primary recommendation was for HNBP hard copy **materials to be updated**.

> *Some of the [HNBP] flyers and the bumper stickers that are included in the kits maybe should be updated to be more modern in their look.*
>
> *I know it was pretty old stuff, and I had to get rid of it because it was more than 5 years old.*

This feedback also illustrates the need for **more outreach** about the more recent materials that are available, which was also shared by participants.

> *…making other programs more aware of HNBP curriculum and materials.*
>
> *…to have them in each community would be helpful.*

Lessons for working with Native families

When asked about the lessons they have learned in working on safe infant sleep in Native communities, the most common response was the need for **community partnership**.

> *In a tribal community, you cannot come in and preach at people. You cannot talk at people about safe sleep. You have to have their buy-in, and that comes through relationship, through understanding, through respect, through acceptance.*
>
> *Spending time building relationships with community stakeholders, building that trust and then letting those stakeholders run the show is helpful.*
>
> *You have to have that intimate knowledge, both of the community and the individual, in order to be successful.*

Related to community partnership, was the theme of **sustainability** described by a couple of participants as the time needed to build trust with individual families and communities, as well as to evolve maladaptive generational patterns, and to improve systems of care to better serve Native communities.

The second most common lesson learned was about the need for **culturally specific care**.

> *The systems of care that we have are not necessarily built for us.*
>
> *There are over 500 tribes in the U.S., and they all have things that are very unique to them. It makes it challenging, but [Native] people want that connection, and people outside of Native community-work and cultures may not understand at all how important that is.*

One provider explained this issue from their perspective as follows:

> *An initiative like this really needs to be led by cultural leaders. When it's coming from someone like me who is not Alaska Native—when I say let's get a bassinet and put the baby there—it can be taken as me saying the cultural practice is inadequate. It can come across as me challenging*

> *generational ways; it can come across as condescending and almost a form of cultural oppression.*

Patient-centered care that is **focused on risk-reduction**[5] and that is **strengths based** was described by several participants as an essential approach to safe sleep promotion with Native communities. Patient-centered care is defined as when, "an individual's specific health needs and desired health outcomes are the driving force behind all health care decisions and quality measurements. Patients are partners with their healthcare providers, and providers treat patients not only from a clinical perspective, but also from an emotional, mental, spiritual, social, and financial perspective."[6]

> *My lessons learned really are lessons about the importance of a harm reduction approach. Not everyone will be able to meet all of the requirements that constitute a safe sleep environment. It is important to meet people where they are.*

> *Making sure you can ask questions and have conversations without making people feel shame; make sure you're focusing on the strengths of a family and culture and making it more of a partnership than us just telling people what to do.*

Several participants highlighted the importance of **addressing the material needs** of families along with providing education.

> *People need access to resources. It's not helpful to tell people they need a crib but have no way to help them get one.*

> *I feel caring for the mom postpartum—the mom, dad, and family—so that they feel supported, a community around them that supports them, so they can focus on the baby and themselves [in the postpartum period]; I KNOW that impacts safe sleep.*

Supporting educators and care providers

Several participants commented on the need to support healthcare and social service providers and health educators to **address the often-complicated infant sleep risk environment**.

> *I would love to have a toolkit - tools and resources - for harm-reduction strategies for talking with families, and what that messaging looks like within the context of educating a family or a community.*

> *Finding balance around messages related to breastfeeding and co-sleeping is the area that is most ambiguous. They don't know what the alternatives are. It is the hardest to provide definitive information for families, it is more about helping them find what works for them.*

[5] Altfeld, S., Peacock, N., Rowe, H. L., Massino, J., Garland, C., Smith, S., & Wishart, M. (2017). Moving Beyond "Abstinence-Only" Messaging to Reduce Sleep-Related Infant Deaths. The Journal of Pediatrics, 189, 207–212. https://doi.org/10.1016/j.jpeds.2017.06.069.
[6] What Is Patient-Centered Care? NEJM Catalyst. January 1, 2017. https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0559. Accessed September 24, 2021.

> *Anything that can help young parents speak to elders, and anything that can help us as a community—health workers, and health educators, distributors of [safe sleep] information community wide—anything that can help us address those issues that may occur with grandparents or elders would be helpful.*

A few participants talked about the need for **cultural sensitivity training** for non-Native providers to help address cultural barriers for families accessing services and engaging with traditional practices. Participants also spoke about the need to foster **collaborations across providers and organizations**, such as creating a forum for sharing lessons learned and ideas for mutual support, providing ongoing professional development, and promoting continuity of care.

A handful of participants brought up the need for **investment in data monitoring and data quality improvement**, including the importance of infant death review boards and the desire to provide local-level data to tell a more complete picture for individual communities.

> *There is a role [on infant death review boards] for advocacy and safe sleep issues. We review death certificates to see if they are accurately labeled regarding SUID and SIDS.*
>
> *We try to monitor as best we can. We have recording challenges, cases are misreported, we don't often know all the cases that happen.*
>
> *National data are not translatable to the local-level responses. We need mechanisms for monitoring not just incidences, but risk factors and conditions that lead to that. And that gets me back to all the policy issues. We need to broaden what we think of as safe sleep work.*

Addressing root causes of SIDS risk

Throughout the interviews, participants highlighted the need to address the root causes of SIDS risk factors experienced by AI/AN communities, including moving beyond individual-level interventions to incorporate policy-level interventions and taking a **holistic approach to safe infant sleep**.

> *We need to shift from focusing on only trying to influence the behavior of mothers and parents, to taking a really serious look at our policies around maternity leave. What happens at the hospital? What happens post-discharge? What kinds of support are we providing to the mothers? Not what THEY are doing, or not doing, but what the system, and what we as a society are doing.*
>
> *We have to look at things in the context of all these other variables that also need to be addressed. How do we weave these together to create one story, rather than tackling one thing and then dropping it and moving on to the next thing?*

Participants emphasized the **impact of historical and ongoing policies** of genocide and colonization of Native peoples on SIDS risk factors, barriers to successful intervention, and response by tribal leaders.

> *Most of us, our fathers, mothers, grandfathers, grandmothers were raised during the boarding school era, and they were indoctrinated where might was right. You couple that with what*

> *happened to our people during Wounded Knee in '73, leading to the violence and destruction that our families endure today, including the breakdown of the family unit...*

> *It's really important to be aware the legacy of child protection acts and practices, and how much it has traumatized people. And all that trauma carries on today, and it really affects how "helpers" coming into the community are seen if it is anything to do with children. People are really afraid of having their kids removed.*

> *There are bigger picture needs that need to be approached as well. What we are doing in the Child Protection Services and tribal court systems are not working. We need to advocate for our leaders to address the systemic needs of people and integrate culturally appropriate interventions.*

One participant talked about the current opportunity to **address racism and inequities** and the impact on safe infant sleep and birth outcomes.

> *How racism and birth inequities are affecting [disparities in health and safe infant sleep] is something I hope everyone's thinking about right now because it trickles down to all of these outcomes and disparities we have.*

A few participants described the importance of **Native community leaders guiding policy** agendas to address safe infant sleep. There was also a comment about the need for **national leadership and advocacy** about the risk of SIDS and other sleep-related causes of infant death in AI/AN communities overall, as well as a specific need to address the unsafe sleep practices seen in images and marketing of cribs and bedding merchandise.

> *The communities are not completely in line with the [national] policy makers' recommendations. Native people need to be involved at the very beginning, in interpreting the data, and translating it into livable contexts.*

> *A lot of folks do not consider SIDS as big of an issue as they used to. You just don't hear about it as often. I wonder too about public health funding. You don't see as many campaigns, there are not as many billboards, and not as many materials are available. We had the HNBP Toolkit, but I haven't really seen anything else.*

Summary

Consistent themes emerged in interviews with a diverse range of experts on addressing the high rates of SIDS among AI/AN communities. The most common challenges to safe infant sleep shared by participants were housing insecurity creating the lack of separate sleep spaces, and barriers to healthcare. Both issues were also described as recently exacerbated by the impact of the COVID-19 pandemic.

Recommended individual-level approaches to safe infant sleep among AI/AN communities included patient-centered, risk reduction, and strengths-based models of education and care, while addressing families' living conditions and material needs. Participants highlighted the importance of early and consistent education for fathers and extended family with birth workers and home visitors, and the value of collaborations across providers and organizations in these efforts. Participants also noted the need for

cultural sensitivity training for healthcare and social service providers to help address barriers for families accessing services and engaging with traditional practices.

Building on the strength of embedded community support systems, participants described traditional practices and teachings as opportunities to incorporate education about safe infant sleep. Recommendations specific to communications included the success of visuals, stories, and videos, and the need for customizable and culturally specific safe sleep materials. They shared the importance of continuing to update and make HNBP materials available as the only known AI/AN culturally specific safe infant sleep materials.

Participants underscored the need to address the root causes of SIDS risk factors experienced by AI/AN communities, including taking a holistic approach to safe infant sleep by prioritizing funding for policy-level interventions in addition to individual-level approaches. A frequent theme was the need for AI/AN community partners to acknowledge the impact of historical and ongoing policies of colonization and genocide on SIDS risk factors and barriers to intervention among AI/AN communities. The current national public consciousness around racism was recommended as an important opportunity to address the impact of systemic racism on safe infant sleep and birth outcomes among AI/AN communities.

These findings can be shared broadly with health educators, healthcare and social service providers, and AI/AN communities to support recommended approaches to SIDS risk reduction. Community leaders, funders, and policymakers can use these findings to advocate for and fund policies that address systemic risk factors for SIDS and other sleep-related causes of infant death in AI/AN communities.