

Thursday, August 28, 2025

Promoting Safe Infant Sleep: Relying on Communities' Capabilities to Get the Word Out

nich

National Institute for
Children's Health Quality



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An Unimaginable Heartbreak

Every day, across the country, many families experience a death of an infant

- **Healthy babies should not die before their first birthday**

Despite decades of trying to reduce the number of sudden unexpected infant deaths (SUID), they still persist

- **Predominantly in historically marginalized communities**

Today's Agenda

- Why is Research Important?
- Exploring Biological Mechanisms
- When research is done with communities, not on them
 - Community-based approaches to infant safe sleep and breastfeeding promotion: a qualitative study
 - Engaging Diverse Stakeholders of Color to Reduce Black Infant Mortality: Lessons Learned
- The Future of SIDS Research

Why is Research Important?



Saving Lives

- SIDS remains one of the leading causes of death in infants under 1 year old. Each discovery about risk factors, protective factors, or potential biological mechanisms has the potential to prevent thousands of deaths each year.

Uncovering Biological Mechanisms

- Despite decades of study, the exact causes of SIDS are still not fully known. Research helps identify underlying vulnerabilities in infants, such as:
- Abnormalities in brainstem function that affect breathing and arousal.
- Genetic or physiological predispositions.
- Interactions with environmental risks (e.g., unsafe sleep positions, overheating, secondhand smoke).

Improving Public Health Guidance

Much of what we know about safe sleep—like placing babies on their backs, avoiding soft bedding, and room-sharing without bed-sharing—comes from SIDS research. Continued research ensures that public health recommendations are evidence-based and culturally responsive, reducing disparities in outcomes.



Improving Access and Outcomes for All Families

Black, American Indian/Alaska Native, and families with lower incomes experience higher rates of SIDS compared to other groups. Research helps identify systemic and structural factors that contribute to these differences—such as access to care, availability of resources, and culturally relevant education. These findings inform the development of strategies that expand access, promote fairness, and improve outcomes for all families.



Supporting Families and Communities

Every SIDS case represents not only the loss of a child but also profound trauma for families. Research into causes, prevention, and grief support provides families with answers, reduces stigma, and promotes healing.



Shaping Policy and Funding Priorities

Evidence from SIDS research informs policy decisions, hospital practices, and community-based programs. It also shapes how federal and philanthropic dollars are invested in maternal and child health.

TECHNICAL REPORT

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

Evidence Base for 2022 Updated Recommendations for a Safe Infant Sleeping Environment to Reduce the Risk of Sleep-Related Infant Deaths

Rachel Y. Moon, MD, FAAP;^a Rebecca F. Carlin, MD, FAAP;^b Ivan Hand, MD, FAAP;^c and THE TASK FORCE ON SUDDEN INFANT DEATH SYNDROME and THE COMMITTEE ON FETUS AND NEWBORN

Every year in the United States, approximately 3500 infants die of sleep-related infant deaths, including sudden infant death syndrome (SIDS) (*International Statistical Classification of Diseases and Related Health Problems 10th Revision* [ICD-10] R95), ill-defined deaths (ICD-10 R99), and accidental suffocation and strangulation in bed (ICD-10 W75). After a substantial decline in sleep-related deaths in the 1990s, the overall death rate attributable to sleep-related infant deaths have remained stagnant since 2000, and disparities persist. The triple risk model proposes that SIDS occurs when an infant with intrinsic vulnerability (often manifested by impaired arousal, cardiorespiratory, and/or autonomic responses) undergoes an exogenous trigger event (eg, exposure to an unsafe sleeping environment) during a critical developmental period. The American Academy of Pediatrics recommends a safe sleep environment to reduce the risk of all sleep-related deaths. This includes supine positioning; use of a firm, noninclined sleep surface; room sharing without bed sharing; and avoidance of soft bedding and overheating. Additional recommendations for SIDS risk reduction include human milk feeding; avoidance of exposure to nicotine, alcohol, marijuana, opioids, and illicit drugs; routine immunization; and use of a pacifier. New recommendations are presented regarding noninclined sleep surfaces, short-term emergency sleep locations, use of cardboard boxes as a sleep location, bed sharing, substance use, home cardiorespiratory monitors, and tummy time. In addition, additional information to assist parents, physicians, and nonphysician clinicians in assessing the risk of specific bed-sharing situations is included. The recommendations and strength of evidence for each recommendation are published in the accompanying policy statement, which is included in this issue.

abstract

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Drs Moon, Carlin, and Hand approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Exploring Biological Mechanism



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August 28, 2025

**“Their stories are so powerful”:
Community-based approaches to infant safe sleep
and breastfeeding promotion**

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Parent Project: NAPPSS-IIN

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National Action Partnership to Promote Safe Sleep Improvement and Innovation Network (NAPPSS-IIN)

- **Project aim:** Increase infant caregiver adoption of safe infant sleep and breastfeeding practices as recommended by the American Academy of Pediatrics (AAP) by empowering champions for these protective behaviors within systems that serve families at risk.
- **Collaborative aim:** Work with community-level organizations to increase the proportion of infants who:
 - are placed to sleep **on their backs** in a **safe sleep environment** that follows the AAP recommendations,
 - are **ever breastfed**, and
 - continue to breastfeed at **six months**,
 - while addressing disparities in these outcomes by **geography** and **race/ethnicity**.



Community Listening Session Methods

Concept

- To inform the project's development, NAPPSS-IIN hosted a series of community listening sessions to better understand the experiences of community-level organizations and providers in promoting safe sleep and breastfeeding
- **Research questions**
 - What areas do community-level organizations need **support** to meet their community's needs around safe sleep and breastfeeding?
 - What **tools** or **resources** could assist community-level organizations in improving their work to promote safe sleep and breastfeeding among their client populations?

Published in *BMC Public Health*

Research article | [Open Access](#) | [Published: 07 March 2023](#)

Community-based approaches to infant safe sleep and breastfeeding promotion: a qualitative study

[Meera Menon](#), [Rebecca Huber](#) , [Dana D. West](#), [Stacy Scott](#), [Rebecca B. Russell](#) & [Scott D. Berns](#)

BMC Public Health **23**, Article number: 437 (2023) | [Cite this article](#)

2219 Accesses | 5 Altmetric | [Metrics](#)

Abstract

Background

In the U.S., sudden unexpected infant deaths (SUID) due to accidental suffocation and strangulation in bed (ASSB) are increasing, with disparities by race/ethnicity. While breastfeeding is a protective factor against infant mortality, racial/ethnic disparities are present in its uptake, and motivations to breastfeed are also often coupled with non-recommended infant sleep practices that are associated with infant sleep deaths. Combining infant safe sleep (ISS) and breastfeeding promotion on the community level presents opportunities to address racial/ethnic disparities and associated socioeconomic, cultural, and psychosocial influences.

READ THE
PUBLICATION



<http://bit.ly/44ivPJU>

Design and Methods

- Hermeneutic phenomenology with thematic analysis
- Four focus groups (n=18) conducted in March 2021
- Analysis was conducted by a team of two analysts (Pooled $K > 0.80$)
- Key themes were identified and discussed iteratively by a team of three



Community Listening Session Results



Theme 1: Education and Dissemination

Education and Dissemination

Education Challenges

- Absence of effective teaching guidance
- Ignoring guidelines



Education and Dissemination

Education Opportunities

- Guidance on messaging and tone
- Education standards



Education and Dissemination



Dissemination Challenges

“[We need] tools for **open, candid conversations** to talk with families about this intersection between breastfeeding and safe sleep. We see that they're often [taught] separate **and parents experience them together**...And so I would like...to have conversations that are less prescriptive, less, "Abstinence only, you should do this," on both breastfeeding and safe sleep and more **nuanced**. Be able to get down into the **realities** without being so...
Preachy, I guess.”



Education and Dissemination

Dissemination Opportunities

- Nighttime decision making
- Translated materials



Theme 2: Relationship Building and Support

Relationship Building and Support

Client-Provider Relationship Building

- Individualized attention
- Provider follow through
- Virtual





Relationship Building and Support

Peer-to-Peer Connections

- Support groups
- Events
- Connections to external specialists/organizations
- Referrals

Relationship Building and Support



Peer-to-Peer Connections

“I've also learned to just **maintain connections** with mothers and families that I have served or been a doula for in the past because they can **tell their stories** to clients that I'm serving now and I think that stories are so, so, so, so **powerful.**”



Theme 3:

Working with individuals' personal circumstances and considerations

Personal Circumstances and Considerations

Capacity

- Overwhelm
- Trusting own intuition



Personal Circumstances and Considerations

Social Determinants

- Opioid use
- Poverty
- Mental health
- Language barriers



Personal Circumstances and Considerations



Social Determinants

“[Safe sleep promotion makes] **assumptions** that [the client] has a crib or room for a crib. [But,] we **don’t always know** their living circumstances and how that impacts what they’re able to do.”

Personal Circumstances and Considerations



Generational Barriers

“**Things have changed** a lot since our clients’ mothers and grandmothers were having babies. [Extended family members will say]...you’ve got to give both [formula and breastmilk] because the baby is not [eating] enough, or, you put the baby on their stomach to sleep because that's what we did. We educate our moms, but then there's kind of **that missing piece** – how does it get from the mom, to the grandma, and the auntie and the older generation who **did things differently?**”



Theme 4: Tools and Systems



Tools and Systems ...

- Material resources for patients
- Media portrayal of safe sleep and breastfeeding
- Policy
- Work environment

Limitations

- Focus groups conducted virtually over Zoom
- Did not examine responses based on demographics of providers/community-based organization
- Demographics of communities not considered as part of the analysis
- Broadly categorized community-based organizations and providers (both policy-level focused, individual-level focused, etc.)
- Perspective of providers only



Thank you!

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**Engaging Diverse
Stakeholders of Color to
Reduce Black Infant
Mortality: Lessons Learned**



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ENGAGING THE DIVINE 9 TO IMPROVE INFANT HEALTH

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KBEN

Kansas Birth
Equity Network

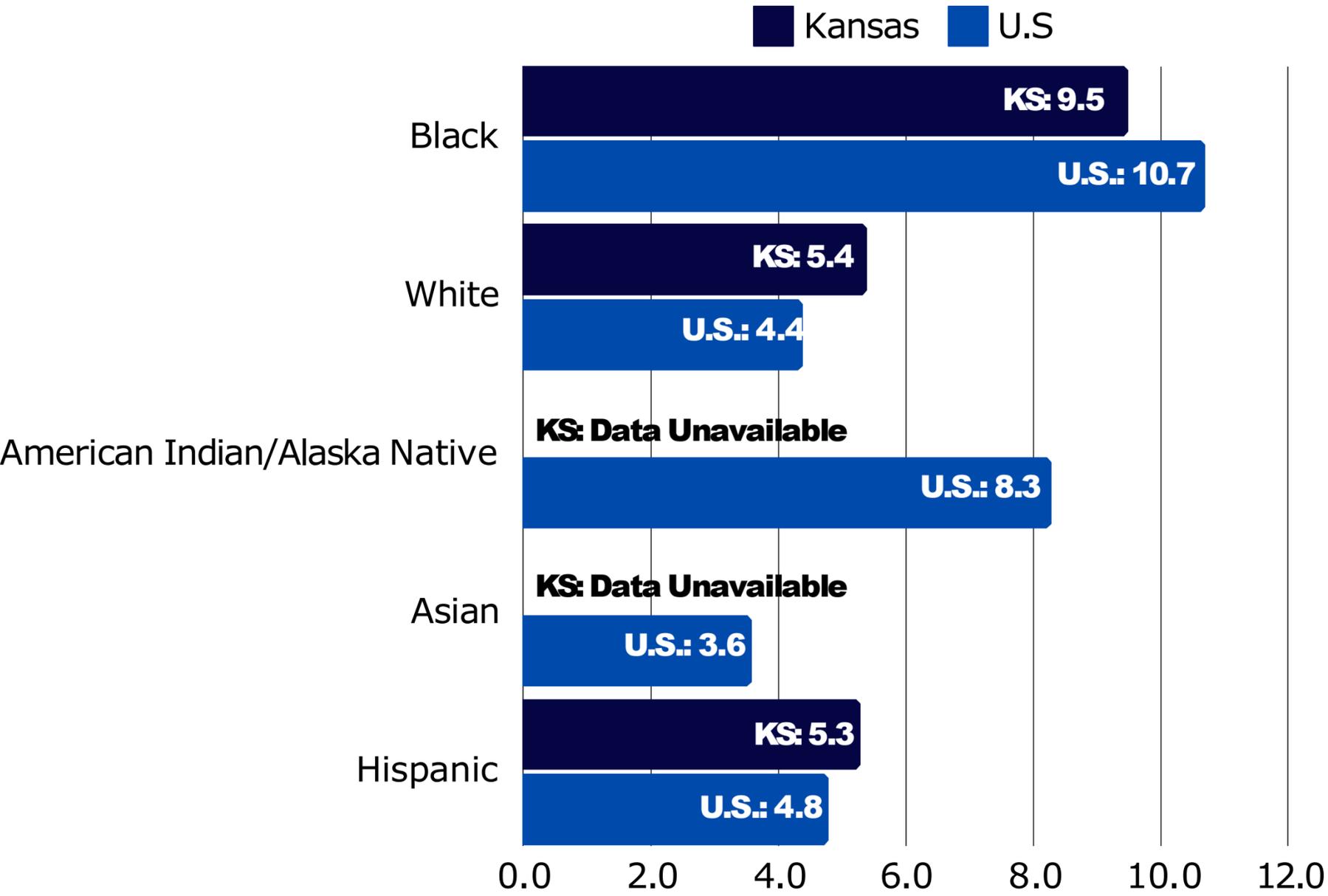


Roadmap to Address Black Infant Mortality

Understanding, engaging, and impacting through community-led strategies

- 1 Understanding the urgency of Black infant mortality disparities
- 2 Engaging the Divine 9 in the K-SBHI initiative
- 3 Impact strategies: frameworks, engagement, and Celebrate Day 366
- 4 Path forward: sustaining collaboration for birth equity

Infant Mortality: Kansas



Deaths per 1,000 live births

In Kansas, Black infants are 1.8 times more likely to die than white infants.



INFANT MORTALITY DISPARITIES

The disparity between Black and White infant deaths today is greater than it was under antebellum slavery.

FACTS

In 2023, Black infants die at 3 times higher than that of White infants.

2023

1850

In 1850, enslaved infants died before 1 year of age at a rate 1.6 times higher than that of White infants

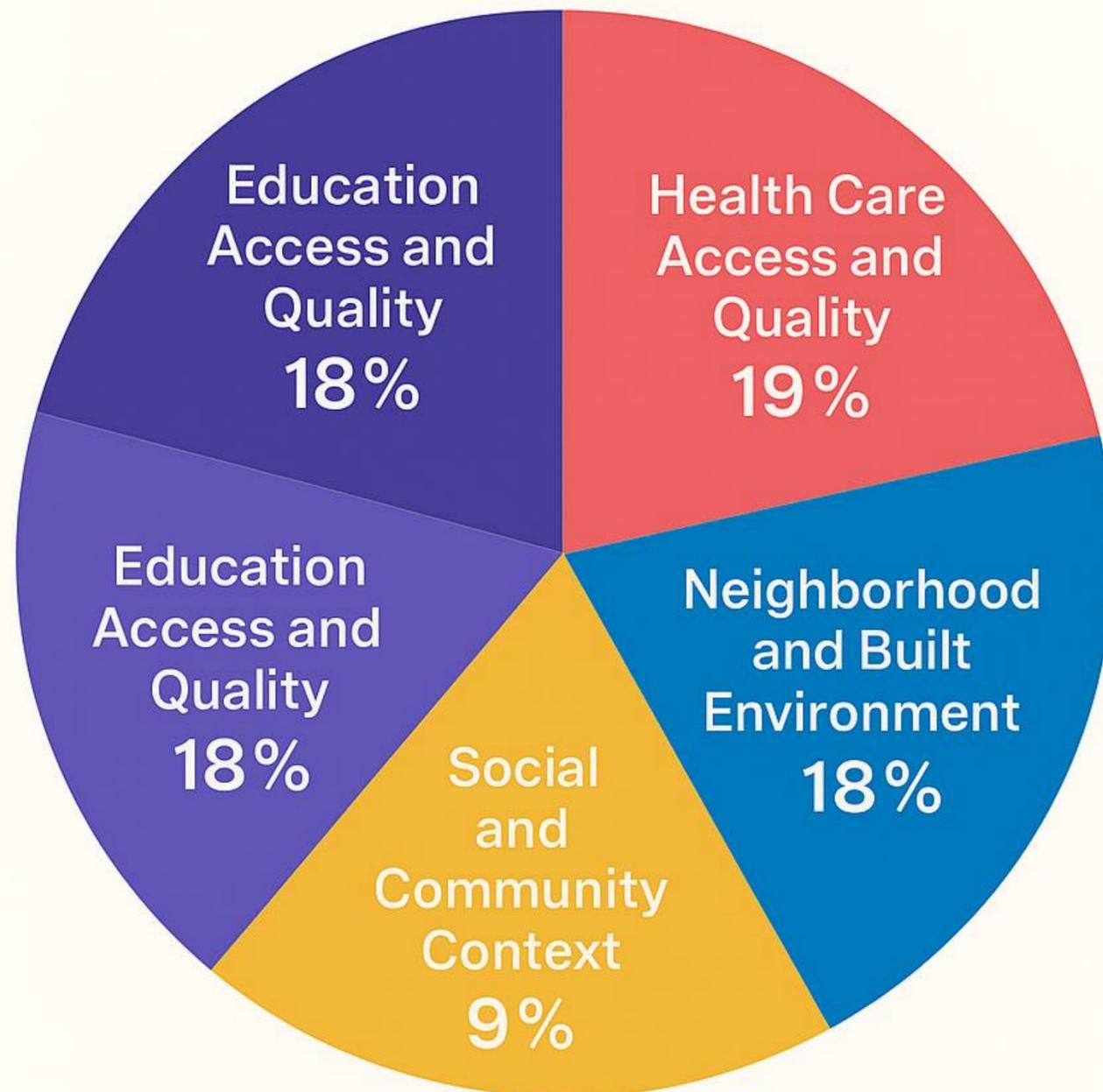
It was estimated that Infant mortality stole the futures of 87 kindergarten classes in 2015.

LEADING CAUSES

Race/Ethnicity	Overall Infant Mortality (per 1,000)	SIDs/SUIDs Rate (per 100,000)	SIDs/SUIDs Risk vs White Infants
Non-Hispanic Black	10.9	~244.0 (2022)	~3× higher
Non-Hispanic White	4.5	~83.2	Reference baseline
Hispanic	4.9	~61.6	Lower than Black & White

- **For Black Infants vs. White Infants:**
 - **Low Birthweight / Preterm-Related:** 3.6× higher
 - **Sudden Infant Death Syndrome (SIDS/SUID):** 3.2× higher
 - **Maternal Complications:** 3.2× higher
 - **Accidents (unintentional injuries):** 2.4× higher
 - **Congenital Malformations:** 1.4× higher

Social Determinants of Health for Black infants



**SOCIAL
DETERMINANTS
OF HEALTH
IMPACT**

Who We Are

Our Root: Community

- Collaboration with Divine Nine Chapters in Wichita, KS
 - Kansas Sisters and Brothers for Healthy Infants
 - Raise awareness
 - Develop solutions
 - Celebrate Black Families: Celebrate Day 366

Today:

- Community-Centered Network
- Members across Kansas & KC Metro
- Diverse Members: birth workers, clinicians, parents, community members, & more!
- Center the experiences of Black families
- Create space for collaboration
- Celebrate Black Babies & Families
- Develop solutions that improve the health of Black families



Addressing Black Infant Mortality Disparities

Urgent need for community-driven health solutions



Persistent Infant Disparities
Black Infants Die Twice As Often



Clinical Limits Recognized
Care Alone Insufficient



Social Health Factors
Environment Shapes Outcomes



Community-Led Action
K-SBHI Fosters Engagement

K-SBHI Framework Integrating Theory of Change and Collective Impact

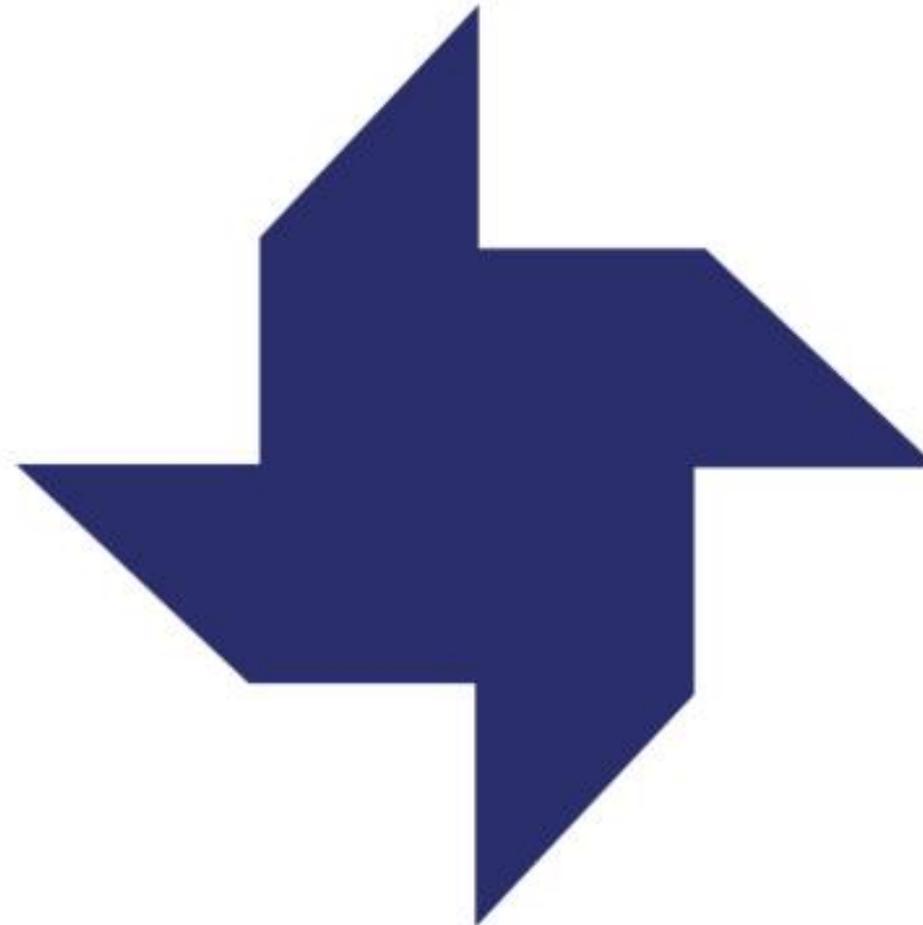
Theory-driven, multi-sector collaboration improving Black infant health outcomes

Theory of Change directs planning to reduce social determinants of Black infant mortality

It specifies intended outcomes, important contextual factors, and clear pathways to address social determinants impacting Black infant mortality, supporting effective intervention design (Weiss, 1995; Makowiecka et al., 2019).

Integrated approach combines theory-driven evaluation with multi-sector collaboration

This fusion enhances sustainability by linking evidence-based strategies with cross-sector engagement, aiming for lasting community impact on Black infant health disparities.



Collective Impact Model promotes coordinated community action with shared agendas

This model emphasizes alignment and collaboration among diverse community stakeholders to solve complex social problems through a unified, mutually reinforcing approach (Kania & Kramer, 2011).

KU researchers and Divine 9 co-developed shared goals and trust across sectors

The partnership fostered a common agenda, shared measurement systems, and mutual activities, building trust to mobilize actors in public health, healthcare, community services, and public awareness.

Divine 9 Fraternities and Sororities Leading Infant

Key chapters driving community engagement and health initiatives

Organizatiior	Chapter	Role
Alpha Phi Alpha Fraternity, Inc.	Eta Beta Lambda Chapter	Leadership and community engagement
Alpha Kappa Alpha Sorority, Inc.	Beta Kappa Omega Chapter	Planning and maternal-child health programming
Delta Sigma Theta Sorority, Inc.	Wichita Alumnae Chapter	Community awareness and outreach
Kappa Alpha Psi Fraternity, Inc.	Wichita Alumni Chapter	Safe sleep and fatherhood initiatives
Sigma Gamma Rho Sorority, Inc.	Gamma Chi Sigma Alumnae Chapter	Resource coordination and education
Zeta Phi Beta Sorority, Inc.	Sigma Zeta Chapter	Community services and event support

Steps to Build the K-SBHI Initiative

From formation to impactful community engagement

KU researchers initiated outreach to Divine 9 leaders

KU researchers sent interest letters to seven local Divine 9 fraternity and sorority presidents, inviting collaboration to address infant mortality disparities in Sedgwick County.

Resource mobilization supported event

K-SBHI members secured funding and in-kind support to cover event logistics, incentives, and marketing efforts effectively.

Community assessment guided event

Assessment identified gaps in awareness and educational needs, shaping the content and outreach strategies for Celebrate Day 366.



Kickoff meeting secured chapter commitment

A kickoff meeting presented data on disparities and health determinants; six chapters attended and pledged their support for the initiative's goals.

Monthly meetings foster planning and trust

Regular monthly committee meetings allowed representatives to plan collective impact activities and build mutual trust among members.

Celebrate Day 366 created to raise awareness

An annual event, Celebrate Day 366, was proposed to educate families and celebrate Black infants' first birthdays, increasing community awareness.

Celebrate Day 366: Empowering Black Families

Annual event raising infant health awareness and community support



Purpose centers on community education and empowerment

Focuses on infant mortality, social determinants, and supporting Black families through shared agendas and knowledge.



Diverse activities promote health and family engagement

Includes sessions on safe sleep, prenatal care, co-parenting, health fairs, screenings, and Black infant birthday celebrations.



Significant event growth through strategic outreach

Attendance rose 128% in the second year due to enhanced marketing via radio, newspapers, flyers, and church collaborations.



Adapted event format during COVID-19 to maintain impact

Shifted to virtual panels addressing birth equity, Black parenthood, and COVID-19's effects on pregnancy in 2020-2021.

Strengthening Community Trust in Infant Health

Key lessons on communication, engagement, and sustainability

- **Building trust through shared agendas and communication**
Establishing trust among diverse stakeholders required consistent communication and a unified agenda to align goals effectively.
- **Enhancing community awareness with tailored outreach**
Low initial attendance highlighted the need for targeted messaging and outreach tailored to the Black community's interests and values.
- **Fostering reciprocity via active researcher involvement**
KU researchers participated in fraternity and sorority service activities, promoting mutual support and community ownership of initiatives.
- **Utilizing multi-channel marketing for improved engagement**
Campaigns through churches, radio, and social media significantly increased event reach and participation within the community.

Measurable Outcomes in Divine 9 Engagement

Attendance growth, awareness, and stakeholder impact

39 attendees

Initial Celebrate Day 366 turnout

First event attracted 39 participants including 34 Divine 9 members.

128 attendees

Attendance growth year-over-year

Second annual event saw 128 attendees due to better marketing.

6 chapters

Fraternity and sorority involvement

Six Divine 9 chapters actively committed to community service.

Multiple panels

Expanded virtual event topics

Panels covered birth equity, Black parenthood, and COVID-19 effects.

Grant funding

Community foundation support

Funding covered facilities, marketing, and staffing expenses.

**Sustained
collaboration**

Ongoing KU and Divine 9 partnership

Reciprocal engagement fostered trust and long-term cooperation.

THE SUIDS EVIDENCE SUPPORTING THIS APPROACH

01

Black infants have 2x the mortality rate of White infants in Kansas.

02

Nationally, a disproportionate number of SUIDs occur among Black, Indigenous, and Hispanic infants, often linked to inequities in health education, socioeconomic factors, and access to care.

03

Trusted messengers and peer-led interventions consistently outperform generic public health campaigns in these communities.

CONCLUSIONS

-
- The Divine 9 and K-BEN partnership demonstrates a transformative approach to public health—one that replaces one-size-fits-all messages with culturally embedded, community-driven interventions.
 - By leveraging historic trust, amplifying community voices, and funding grassroots organizations, this model directly addresses the underlying causes of SUID and broader infant mortality disparities.

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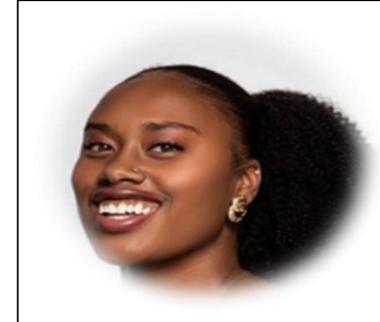
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Thank You!



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The Future of SIDS Research





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**What's Next?
The National
Community
Partnership to
Promote Safe
Sleep
Initiative**



The NCPPSS aspires to.....

- **Center Community Expertise:** Elevate the lived experience of families, doulas, elders, and community leaders as central to shaping messaging, policy, and support systems.
- **Promote Culturally Aligned Practices:** Collaborate with leaders to co-develop safe sleep practices that respect family traditions while prioritizing infant safety.

The NCPPSS aspires to.....

- **Create a National Learning Network:** Foster continuous peer exchange between community-based organizations, public health experts, and researchers committed to infant mortality prevention.
- **Rebuild Trust and Infrastructure:** Address the erosion of trust caused by one-size-fits-all campaigns and restrictive funding policies by investing in grassroots solutions and unrestricted support.

A New Era in Infant Survival: Recognizing the True Value of Community-Centered Initiatives,”

- **Webinar #3** - The third and final webinar in the series, “**A New Era in Infant Survival: Recognizing the True Value of Community-Centered Initiatives,**” will focus on the importance of community involvement and its power to drive improved health outcomes, increased awareness of infant care practices, and stronger social networks that advocate for birthing families and infant health.
- *Attendees will have the opportunity to participate in an interactive session to share best practices and receive guidance from infant safe sleep experts and educators, leaving them ready to take action.*

Share Your Feedback

Scan the QR code to take our short survey about your interest in the National Community Partnership to Promote Safe Sleep Initiative.





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