Peer Reviewed

First Candle: Building Approaches to Address Racial Disparities in Georgia Infant Mortality Rates

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Saving babies. Supporting families.

First Candle's efforts to support families during their most difficult times and provide new answers to help other families avoid the tragedy of the loss of their baby are without parallel.

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The SUID Gap in Georgia

Georgia is in a state of persistent 2-to-1 disparity in infant mortality rates (IMR) between Black and White populations, and Sudden Unexpected Infant Death (SUID) is part of that disparity. According to the CDC, the SUID rate in Georgia is 127.2/100,000 live births, the 11th highest in the country, and the 2020 Georgia Child Fatality Review Panel Annual Report acknowledges that "sleep-related deaths continue to be a disappointing issue" as the leading post-neonatal reviewable cause of death, accounting for nearly a third, and with 59.5% of SUID infant deaths being Black.

And yet the Back to Sleep campaign launched in 1994 through a coalition led by the National Institute of Child Health and Human Development (NICHD) made a difference in the state. By 2002, Georgia's SIDS death rate dropped 21%, but Black deaths were still higher. (1)

Central to the Back to Sleep (now Safe to Sleep) campaign has been the infant safe sleep guidelines put forth by the American Academy of Pediatrics (AAP) (supine positioning on a firm separate sleep surface with no extraneous bedding).

But, the 2020 fatality review panel also reported that unsafe sleep practices are a factor in Georgia; 64% of deceased infants were reported sleeping on an adult bed, and nine more in spaces including sofa chairs, twin bunk beds, mother's arms during breastfeeding.

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Georgia has a higher-than-national rate of unsafe sleep practices. In 2020, according to the CDC's Pregnancy Risk Assessment Monitoring System (PRAMS), 71.3% of respondents reported that "babies most often lay on back to sleep" vs. 79.5% for all PRAMS sites. In 2016, a Georgia hospital study found significant racial differences in safe sleep practices. Parents who identified as Black were less likely than parents who identified as White to know the recommended sleep position, less likely to place their infant supine, and significantly more likely to place their infant to sleep in an adult bed. Racial differences also remained when looking only at parents who received Medicaid; Medicaid parents who identified as Black were more likely to practice bedsharing than parents

who identified as White. (2)

Although the AAP guidelines have been in existence for some time, and there are evidence-based indications that compliance reduces SUID, the racial gap remains.

In addition to the guidelines, infant safe sleep has also become the focus of fairly recent federal actions, including rulings by the Consumer Product Safety Commission and federal legislation such as the 2022 enactment of the Safe Sleep for Babies Act, designed to foster infant safe sleep practices by banning inclined sleepers and crib bumper pads.

"Disparity stems from a broader context; in addition to sleep environments, the factors contributing to SIDS include inadequate prenatal care, low birth weight, and prematurity. Black mothers and infants have disproportionate rates of each of these risks due to elements including poorer care in racially isolated communities, denial of care, structural racism in the medical provider sector, poorer infant medical care, and postpartum mental health issues."

What is Adding to Georgia's SUID Disparity

Disparity stems from a broader context; in addition to sleep environments, the factors contributing to SIDS include inadequate prenatal care, low birth weight, and prematurity. Black mothers and infants have disproportionate rates of each of these risks due to elements including poorer care in racially isolated communities, denial of care, structural racism in the medical provider sector, poorer infant medical care, and postpartum mental health issues. These are abetted by the even more significant issues related to social determinants of health, such as lack of access to financial resources, safe housing, insurance, transportation, and employment. (3)

Listening In Order to Learn:

To examine contributing factors to the disparity and seek ways to mitigate them, First Candle has partnered with Healthy Mothers Healthy Babies Coalition of Georgia, funded by a three-year (2022-2025) grant from the U.S. Health and Human Services Office of Minority Health. The program focuses on the Atlanta Perinatal Region (APR), which includes the Atlanta Metro area and is the largest of the state's six perinatal regions in counties served (39), annual birth rate, and facilities offering childbirth or newborn care. The focus is primarily on Fulton, DeKalb, Gwinnett, and Clayton counties, but the whole region is eligible to participate.

The program's first phase used qualitative research to assess perceptions and attitudes among families, caregivers, and birth givers. The goal was to understand awareness, perception, and acceptance of the safe sleep guidelines and legislation, plus viewpoints on designing effective community-based outreach to reduce SUID rates.

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Focus groups were conducted among parents/birth givers/caregivers and providers, in addition to a birth giver survey and provider interviews.

What They Said:

Birth Givers: (Survey: N=111; 87% Black,49% currently pregnant, 59% aged 26-35. Focus group: N=12, all Black, half 26-35, half 36-45, 75% pregnant). Most were aware of the guidelines, but barriers to compliance, even if respondents acknowledge the risks, include fear, fatigue, convenience, baby fussiness or health, no space, no support, or being a single mom. There was some surprise at the recommended pacifier use. Most were unfamiliar with the Safe Sleep for Babies Act, and most think it will have little impact on them as they do not use the items. A few acknowledged having products now prohibited. There is a sense of conflicting messaging when they see the promotion of potentially unsafe products by reputable programs and organizations. They would be interested in safe sleep events and see a need for holistic content around broader maternal and emotional health issues, with hands-on in-person demonstrations, clear messaging, visual aids, story sharing, and access to free resources and activities for children.

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"Full transparency, I know the guidelines as far as how she is supposed to sleep, but… every once in a while, if I am laying down and breastfeeding… sometimes we do fall asleep in bed. Then, of course, I transition her to her bassinet, but it's not always 100%." – Birthgiver.

Dads: (N=18): This includes support partners of Black birthing people. They see ways to support their partners in safe sleep and a need to inform a broader range of caregivers about safe sleep, including grandparents and daycare staff, updating practices handed down over generations. There was a strong willingness to attend community events and connect with other dads for in-person interaction.

Our mothers and daddies and grandparents, they need to be retaught some of this stuff. That a lot of stuff could be good, but a lot of stuff that they learned or that they passed down was really out of survival. How much of that was detrimental?... A lot got to be corrected." --- Dad

"They felt a need for more hospital-based conversations around safe sleep and supported sharing safe sleep information, including handouts and referrals. They recognized the prevalence and potential risks of co-sleeping, particularly among Black families, but also the need to meet families where they are and to use safe sleep messaging that does not instill fear."

Doulas: (N= 7, all serving Black families in the APR.) They see families affected by SIDS or sleep-related infant death and the risks posed by sleep deprivation while trying to manage breastfeeding and separate sleeping spaces. They felt a need for more hospital-based conversations around safe sleep and supported sharing safe sleep information, including handouts and referrals. They recognized the prevalence and potential risks of co-sleeping, particularly among Black families, but also the need to meet families where they are and to use safe sleep messaging that does not instill fear. Parents may be unaware of the Safe Sleep for Babies Act since banned items continue to be sold.

"When I constantly hear a lot of Black families specifically, this is them talking about co-sleeping, it's like the best thing they could ever have done for themselves." - Doula.

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Providers: (N=6). Professions included lactation consultants, nurses, pediatricians, community health workers, and family practitioners with experience working in Black communities. Providers covered the practices around infant safe sleep, including guidelines, education, and application by families and caregivers. They share the guidelines with their clients and patients in settings that include hospitals, where they are also aware of a need for clarification when NICU sleep practices have to be different. Other insights included:

- The earlier the pregnancy is, the better it is for starting the conversation about infant-safe sleep and incorporating it into prenatal care.
- Infant-safe sleep practices are affected by cultural practices and beliefs, including generational advice and traditional adherence, and families may be navigating between these and evidence-based practices.
- Breastfeeding can also be challenging to compliance. It requires close contact and, due to fatigue, can result in the parent falling asleep during feeding. Providers suggested realistic approaches to parents in finding practical answers.
- Providers often must meet families where they are, with realistic solutions when the guidelines are not being followed.
- Infant sleep product bans may have little impact on low-income families, who may not be purchasing these items due to cost. Nonetheless, providers need clear communication about the accepted uses and the risks of infant products.
- Safe sleep events should be diverse and culturally sensitive in their approach. Trust should also be built through relatable and trusted community members. Messaging should also be disseminated through community settings and provide positive reinforcement vs. judgmental language.

"Because there's so much distrust in the community for doctors and hospitals and healthcare in general… having other community members that people see as a source of knowledge out there in the community saying this is what we need to do and why, and this is what I did with my baby or this… didn't work out so well and I don't what that to happen to you, we need those stories in the community." - Provider

Emerging themes:

Threads running through the responses include:

- There is a need to understand real-world circumstances, the lived realities of families and caregivers, and the realization that families may be working toward the best solutions they can and would benefit from practical advice and support. "Meet families where they are" with people they can trust.
- The effects of overarching policies such as the AAP guidelines, CPSC rulings, and legislative bans may vary depending on family circumstances, awareness, and relevance. Banned product actions may also be of variable value due to inconsistencies between legislation and market availability.
- Breastfeeding remains a key issue, as it is recommended in the guidelines and elsewhere for infant health and maternal benefit, but it creates challenges to maintaining infant-safe

sleep guidelines and dealing with fatigue.

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Next Steps:

The three-year program is a multi-method effort that includes:

- Examining policies and laws and their potential effects on infant mortality rates
- creation of a community-based multi-sector team as an integral part of strategic direction and long-term infrastructure in outreach
- Establishing sustainable outreach programs to the target populations in the Atlanta Perinatal Region may influence models for use in other parts of the country.

These initiatives are underway in various stages, and First Candle looks forward to pursuing and reporting the results.

References:

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About First Candle

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,500 infant deaths nationwide per year.