

Knowledge Itself Is Not Enough: Recognizing and Overcoming Social Barriers To Infant Safe Sleep Practices

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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.

At First Candle, we have been raising awareness about SIDS and other sleep-related infant deaths for years, and while we have seen progress, we have also come to realize that public education is very much a long-term proposition. We have also come to realize how much we ourselves learn in the process of working with others, and how our own awareness has been raised about what can be done better to help families engage in infant safe sleep practices.

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NHLBI, HRSA and the SIDS Alliance (now First Candle) in 1994.

Over the years, the recommendations have increased focus on requiring a supine sleep position on a firm surface, alone, with no extraneous bedding and no bed-sharing – what we call Room Share, Not Bed Share and Keep It Bare.

Between 1994, when Back to Sleep (now Safe to Sleep®) began, and 1999, the overall SIDS rate in the U.S. dropped by more than 50%. (2) However, since that time, the national SIDS rate has changed little. One explanation is that classification has broadened into sudden unexpected infant death (SUID), which includes SIDS and accidental suffocation and strangulation in bed (ASSB), and deaths that may previously have been considered SIDS are being otherwise identified.

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And, whereas the causes of SIDS are still unknown and SIDS is not preventable, the causes of ASSB are. So what particularly concerns us is that, according to the CDC, SUID remains the leading cause of death for babies one month to one year of age, re-

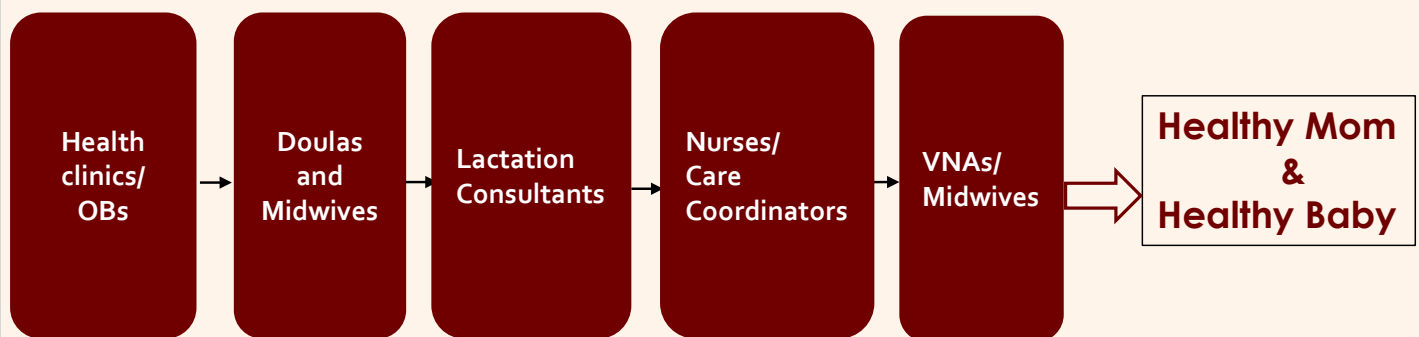


Message must come from everyone

Health care and education needs to start the day a woman realizes she's pregnant.

At each point, care providers have the opportunity to discuss maternal health, breastfeeding and safe sleep practices.

Changing from "It's not my job." to "It's my opportunity!"



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sulting in 3,600 infant deaths nationwide per year. What also concerns us is that even though ASSB can be prevented by following AAP Safe Sleep guidelines, there are barriers to compliance.

Through our work in the field, we have come to learn that this, in part, stems from implicit bias within the guidelines, which mandate a "one size fits all" approach regardless of cultural norms. This is critical, because the rate of SUID among black infants is three times higher than for whites, and for Hispanic babies, it is twice as high.

The AAP guidelines also recommend regular prenatal care for pregnant women, but there is increasing awareness that with regard to maternal health in communities of color, health inequities

result from structural racism in health care, lack of access to quality prenatal and postpartum care, and racial stress. These can contribute to low birth weight, pre-term birth, and birth complications, which are also infant death risk factors.

We saw that preaching the guidelines was not enough, so in 2017 we launched our Straight Talk for Infant Safe Sleep program, a train-the-professional education workshop targeted to a local community's health care providers, social service agencies, doulas, faith-based workers, childcare providers and nurses, which follows a collaborative and culturally sensitive approach.

The program, under which nurses can earn five CEU contact hours, recognizes that many factors influence a parent's safe

sleep decisions, including family and cultural norms, socio-economic factors, past experience, and the desire to bond or breast-feed (which is we recommend).

In our work across the country, we continue to learn from participants not only about the realities of bias they see but that providers themselves often do not have correct or complete Safe Sleep information. Straight Talk participants are surveyed at the start of the program, and we have found providers often discuss only back-sleeping and nothing else; less than half will have read the AAP guidelines and not be able to name more than two, and many are unaware breastfeeding can provide a protective mechanism against SIDS.

The Straight Talk course is therefore designed to provide:

- Clarity on SIDS and other sleep-related infant deaths;
- A thorough understanding of Safe Sleep recommendations and the reasons behind them;
- Recognition of implicit biases that diminish the value of Safe Sleep messages to families and strategies to overcome them.

We also look for and coach to develop a demonstrated ability to listen, learn, and engage in respectful dialogue with families regarding their beliefs and customs around safe sleep and breast-feeding.

In an environment that can be unfamiliar for newly expecting parents and full of new information about pre- and post-natal care, some of it potentially confusing – for example, nurses' infant sleep practices in hospital settings may differ from AAP guidelines – we must help providers not only clearly understand how to reduce preventable infant sleep-related deaths, but be able to convey this to parents and families in a desirable and achievable way.

References:

1. *SIDS and Other Sleep-Related Infant Deaths Updated 2016 Recommendations for a Safe Infant Sleeping Environment.*
2. <https://safetosleep.nichd.nih.gov/activities/SIDS/progress>

Disclosure: The author is the Director of Education and Bereavement Services of First Candle, Inc., a Connecticut not for profit 501c3 corporation.

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