NICHQ National Institute for Children's Health Quality

Insights

Eliminating Sleep-Related Infant Deaths Starts by Identifying What Causes Them

Understanding what causes fetal, infant, and child deaths gives states and communities the information they need to identify focused, effective solutions. This makes infant mortality data—data that reveals the causes and contributors to death and system barriers—irreplaceable assets for any infant health improvement effort. And that makes the National Center for Fatality Review and Prevention (National CFRP) an essential partner.

The National CRFP, funded through a cooperative agreement through the Health Resources and Services Administration, Maternal and Child Health Bureau (HRSA MCHB), is the national resource and data center for Child Death Review (CDR) and Fetal Infant Mortality Review (FIMR) teams. These state and community teams conduct comprehensive and multidisciplinary reviews to better understand what's behind individual children and infant deaths. To support CDR and FIMR teams, the National CFRP provides technical assistance and training on data collection, manages a National Case Reporting System that combines all state and local data in one place and ensures data quality, and builds partnerships at the state and local level to review the findings and use data to improve systems and quality of care. Importantly, the National CFRP's assistance is extended to all state and community programs seeking to reduce infant and child mortality.

Multiple NICHQ teams, including those on the National Action Partnership to Promote Safe Sleep Improvement and Innovation Network (NAPSS-IIN) and the Safe Sleep Collaborative Improvement and Innovation Network (Safe Sleep CoIIN), have developed close partnerships with the National CFRP to better understand how and why babies are dying and what interventions they can test to improve outcomes.

Both NAPPSS-IIN and the Safe Sleep CoIIN are developing comprehensive solutions to help more families follow safe sleep guidelines. Each initiative is funded by the Health Resources and Services Administration, Maternal and Child Health Bureau.

"This is a powerful partnership for all our teams working to eliminate sleep-related infant deaths," says NICHQ Executive Project Director Pat Heinrich, RS, MSN, CLE. "Reducing inconsistencies in how deaths are coded, stratifying data by race and ethnicity, improving the quality of data collection–all of these efforts help states understand the variables that result in death and decide where to focus their improvement efforts."

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Fetal and Infant Mortality Review Program Manager Rosemary Fournier, RN, BSN, and National CFRP Director, Abby Collier, MS, have years of experience with using data as a catalyst for prevention. Here, they expand on how data that identifies the root cause of infant death can transform improvement efforts. We hope their summary inspires hospitals, communities, policy leaders, and state improvement efforts to make the most of this powerful partnership and better support systems-change.

Improvement Relies on Understanding the Root Cause of Infant Death

“Improvement efforts that strive to address the root cause of infant death are the most successful,” says Fournier. “If we only focus on what we think might help, our efforts are limited.”

Understanding the root cause relies on getting the full picture behind each death, continues Fournier. And this requires looking at both quantitative data, such as the medical cause of death and the specific care and services a family received, and qualitative data collected from maternal interviews with families. These interviews help review teams understand more about the context of the situation and the potential system-barriers the family may have faced, such as attending pediatric appointments or affording a safe crib.

To help teams identify root causes, the National CFRP adapted a Cause and Effect Diagram* for infant safe sleep. The diagram outlines the potential factors that result in babies sleeping in an unsafe environment (e.g., not having access to a crib, cultural implications, lack of knowledge from provider about safe sleep) and traces each factor to one of three potential solutions for improvement: caregiver education, health professional education, and providing/selling safe sleep environments.

Together, these data give teams a comprehensive understanding of the cause and contributors to death, which influences improvement efforts in multiple ways.

First, it helps *improve conversations with families* about safe sleep.

“We know from our data that most families are aware of the ABCs of safe sleep but there’s this disconnect in their knowledge of guidelines and their ability to practice them,” explains Collier. “Families want to do what’s best for their children and, in most cases, unsafe environments aren’t about a lack of knowledge but about some unresolved barrier, such as community violence or caregiver exhaustion or the myriad of variables that can happen in the first year of life.”

Understanding common root causes can equip home visitors and other health professionals to have deeper conversations with families about safe sleep—conversations that don’t just share knowledge but instead acknowledge systemic barriers and encourage shifting behavior. The National CFRP staff have frequently presented on translating review findings into action to help health professionals feel comfortable diving into these deeper conversations.

Second, understanding the root cause *reveals system failures* that contribute to sleep-related infant deaths. By systematically and objectively examining the events and circumstances that lead up to an infant death, review teams can see where systems (e.g., health

care, social services) are optimally supporting communities and where there are opportunities for improvement.

“We want to move away from thinking about this in terms of personal responsibility and instead focus on systems,” says Fournier. “In one community, we learned that mothers weren’t able to get their infants in for regular well-baby pediatric visits. They would then miss all those opportunities for the pediatrician to assess where the baby is sleeping and provide outreach and education. The big root cause was that the clinic hours were just terribly inconvenient, which we could solve by opening up evening hours and providing a Saturday clinic. Rather than just say, ‘oh these moms need to practice safe sleep,’ we identified a system solution.”

Importantly, identifying the root causes of infant deaths *requires and builds partnerships*—partnerships that ultimately become the key to addressing the issues teams uncover. Fatality review teams bring a host of partners to the table, including law enforcement, public health, child welfare, pathology, pediatrics, hospitals, community leaders, transportation, and the housing authority, to name just a few. Bringing professionals from across the community to regular meetings prompts deeper relationships between individuals who may have had very little prior connection. For example, says Collier, a police officer on a fatality review team knows to call the health department if he notices a family doesn’t have a crib, and feels comfortable reaching out because he knows they have a shared mission to help families access a safe sleep environment.

“These partnerships help us understand our work, communities and the families we serve in a more complete way,” says Collier. “And because of this, we can work together collaboratively to proactively solve problems that could adversely affect future families.”

From improving conversations with families to supporting partners that enhance systems, the National CFRP is an invaluable partner for NICHQ’s infant and children’s health improvement efforts. Learn more about our active projects here. And sign up for NICHQ News to access our latest resources, webinars, and Insights.

*The diagram is adapted from a causal diagram created by Ishikawa, Kaoru. Citation: Ishikawa, Kaoru (1968). Guide to Quality Control. Tokyo: JUSE