

## Insights

# 3 Lessons from Centering Community Voices: Safe Sleep and Breastfeeding Using a Quality Improvement Framework

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Quality improvement (QI) work is driven by an interest in implementing changes that lead to improvements. In breastfeeding and safe sleep work, this can be challenging. It can be difficult to fully and accurately understand the source of maternal and child health inequities. Ultimately, professionals do not yet have a clear idea of which strategies work best, particularly for families who are Black, Indigenous, and people of color (BIPOC). The National Action Partnership to Promote Safe Sleep Improvement in Innovation Network (NAPPSS-IIN) project has confronted these challenges and found that community-based participatory quality improvement might hold the answer. As NAPPSS-IIN concludes its fifth year of breastfeeding and safe sleep work, three key lessons have emerged about the value of community voice in breastfeeding and safe sleep quality improvement.

The [National Action Partnership to Promote Safe Sleep Improvement in Innovation Network \(NAPPSS-IIN\)](#) is a collaborative effort to make infant safe sleep and breastfeeding/chestfeeding the national norm by aligning members of the healthcare system and members of the community

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and empowering them to effectively promote these protective behaviors within systems that serve Black and Native families. Funded by the Health Resources and Services Administration (HRSA) Maternal Child Health Bureau (MCHB), NICHQ led this initiative from 2017-2022.

Sudden Infant Death Syndrome (SIDS) accounts for a large proportion of Sudden Unexpected Infant Death (SUID) in the United States. SUID is a public health concern across population groups, but significant inequities impact American Indian/Alaska Native and non-Hispanic Black families. Efforts to reduce infant mortality among these groups start with an attempt to understand the drivers of the inequities. Professionals in the field, like Dr. Lori Feldman-Winter, say that the current understanding of sources of inequity relies on conjecture.

“We can hypothesize that it is because of structural and interpersonal racism, implicit biases, occupational differences, inability to get paid leave, the physical environment, or inability to access necessary resources,” Dr. Feldman-Winter said. “It could be all of those things.” Methodological QI initiatives must confront the reality that current research has not successfully tested these hypotheses in a way that conclusively explains the source of disparate maternal and child health outcomes.”

Lori Feldman-Winter, MD, MPH, is a pediatrician and Professor at Cooper Medical School of Rowan University. Dr. Feldman-Winter has an established career in adolescent medicine and is recognized internationally as a breastfeeding expert. She has worked extensively with the American Academy of Pediatrics to lead their efforts around breastfeeding promotion and Sudden Infant Death Syndrome (SIDS) prevention. Dr. Feldman-Winter is one of the faculty co-chairs on the NAPPSS-IIN project.

The goal is to prevent infant mortality and eliminate racial disparities, but an unclear understanding of the sources of inequity makes implementing effective change uniquely challenging. Many hospital systems are making an effort to improve their culture and mitigate the impact of interpersonal racism and implicit bias on patient health outcomes. Across the country, culturally congruent peer support networks have demonstrated incredible success. However, access to necessary peer support is variable and limited for many caregivers. Efforts on the policy level seek to provide socio-economic support and paid leave to new parents, and numerous initiatives across the country are working to improve maternal and child health outcomes to ultimately close the gap in SIDS. The challenge is that research has been unable to methodologically propose a theory-based solution, test it, and demonstrate success in closing the gap. Quality improvement teams must test changes they believe will lead to improvement based on limited previous research.

The NAPPSS-IIN project was organized into three cohorts of intervention. Cohort A focused on hospital sites (postpartum) while Cohort B focused on hospital and prenatal sites (prenatal). Cohort C represents a major shift in project methodology. For Cohort C, the project focus shifted to increasing adherence to safe sleep and breastfeeding recommendations in community settings. The decision to move beyond hospital settings and into community settings aimed to save infant lives by reaching children and caregivers where they live and grow while confronting the realities of systemic racism.

When talking about Cohort C of the project, Dr. Feldman-Winter said, “From the very first

meeting, it was apparent that we had to confront racism. To start, we wanted people of color to represent all parts of the project and lead the way moving forward. We started with project leadership – a woman of color became the project leader and that was the start of a renewed effort to break down barriers and achieve meaningful inclusion.”

This equity-focused structure allowed Cohort C to connect with the communities that needed to be reached and hear their voices in an empowering way.

During the NAPPSS-IIN project, community-based participatory quality improvement has emerged as an innovative way to address these concerns in breastfeeding and safe sleep QI work. This inventive and non-traditional approach to quality improvement applies key principles from community-based participatory research to empower communities to lead QI efforts. Often, QI projects involving the community entail the community coming to the project team to receive key documents related to the change process. The NAPPSS-IIN project took a unique approach, starting with community members and allowing the community to express their needs and propose solutions before proceeding with QI methodology. The project team found that breastfeeding and safe sleep support in Black and Indigenous communities requires vulnerability and humility on the part of the project team. By restructuring the quality improvement process to be authentically community-based, NAPPSS-IIN was able to gain invaluable insight into the drivers of health inequities and desired solutions.

### **Lesson 1: Communities understand their own needs in ways that only they can.**

“In QI, we often ask ourselves, ‘What changes can we make that will result in an improvement?’ But we also need to be asking, ‘How can we be better listeners?’ When you are wondering why something is happening the way it is, sometimes it is best to just ask. Just ask and listen,” Dr. Feldman-Winter said.

To reshape their understanding of community needs, NAPPSS-IIN turned to the community. Listening sessions created a safe space for community members to express their needs. In contrast to relying on inconclusive evidence or speculation, the NAPPSS-IIN project team shifted their strategy to one of humility and intent listening. The results were invaluable. For physicians like Dr. Feldman-Winter, the community listening sessions offered a novel opportunity to hear the unfiltered opinions and experiences of different individuals regarding breastfeeding and safe sleep. By listening to community experiences, members of the project team came to better understand how to develop meaningful and effective interventions that support and empower birthing people.

For example, during a community listening session, community members discussed the realities of parenting and human milk feeding as an adolescent birthing person.

“I wouldn't want to make an adolescent feel like they have to breastfeed. As we heard from community members, adolescent parents have so much else going on,” Dr. Feldman-Winter said. By providing community members with opportunities to identify and discuss the challenges they face with human milk feeding and safe sleep, members of the NAPPSS-IIN team gained a novel perspective on how to provide information to birthing people and families in ways that are

empowering and center the desires of the birthing person.

## **Lesson 2: Communities provide unique insight into developing public health solutions.**

Community listening sessions also offered community members an opportunity to explain from their own perspective what can be done to meet their needs. In earlier cohorts of the NAPPSS-IIN project, the project team prepared change documents, implemented them as planned, and saw expected improvements. This process follows standard QI methodology. In many successful QI plans, teams start with strong evidence, implement change accordingly, and observe the outcomes they theorized. This was not the case in Cohort C of the NAPPSS-IIN project. By starting with the community in Cohort C, the project team abstained from developing key documents and proceeding with traditional QI methodology. Instead, the project team prioritized empowering the community, allowing the community to shape the development of the key change documents. By listening to community voices, the NAPPSS-IIN received insight into breastfeeding and safe sleep solutions that went beyond the collective expertise of public health and medical experts.

## **Lesson 3: Community involvement in quality improvement work should start on Day One of the project.**

Community-based participatory quality improvement requires immense introspection and humility from everyone involved.

“After Cohorts A and B, we got to a point where, with breastfeeding and safe sleep messaging, we knew we had to be open, vulnerable, and humble, allowing the community to lead,” Feldman-Winter said. The nature of breastfeeding and safe sleep work allows for community voices to speak to the needs that exist – and how to meet those needs – in a way that is unsuccessfully explained by other forms of research. “It kept resonating with me, saying, ‘We are the experts. We are the faculty. We will create the documents and get feedback after the fact,’ is not the best way to inspire change. Why not have folks from the community come to the table and help with the QI process from Day One?”

There is much to gain from meeting with community members and positioning them as leaders in the work before the QI process completely begins. To effectively involve community members in quality improvement, they should be positioned as knowledgeable experts and leaders from the beginning.

The information and insight gained by Cohort C of the NAPPSS-IIN project significantly impacted the project’s trajectory, and the project is far from complete. Community-based participatory quality improvement is expected to bring about exciting and powerful change. The NAPPSS-IIN project involves top experts and changemakers from across the nation. By acknowledging the community as critical experts of their own experience, NAPPSS-IIN is positioned to transform breastfeeding and safe sleep quality improvement.