When performing research and evaluating programs on the topic of maternal and child health—a field embedded in structural, racial, and gender-based inequities layered among social determinants of health— it is important to root the research in the context of the community. Traditionally, many public health initiatives employ a top-down approach to address public health issues rather than harnessing the lived experience of community members. Researchers must practice cultural humility and defer to the wisdom of community members to understand and effectively confront the challenges a population faces. The Department of Applied Research and Evaluation (DARE) at the National Institute for Children’s Health Quality (NICHQ) has been addressing this head on, with an explicit goal to embed equity at every level of research and evaluation, including recruitment, participation, and analysis methods.
Sudden Infant Death Syndrome (SIDS) Quick Facts

Approximately 3,400 babies in the U.S. die suddenly and unexpectedly every year while sleeping (Moon, 2021).

Research shows that Indigenous and Black infants have significantly higher sudden unexpected infant death (SUID) rates compared to white infants (Tanabe & Hauck, 2018).

Experts have found that breastfed/chestfed babies have a lower risk of Sudden Infant Death Syndrome (SIDS) and SUID and recommend breastfeeding/chestfeeding as a protective measure against SIDS and SUID.

During Spring 2021 DARE conducted a series of community listening sessions for the National Action Partnership to Promote Safe Sleep Improvement and Innovation Network (NAPPSS-IIN). The NAPPSS-IIN is funded by the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) to make safe infant sleep and breastfeeding a national norm. NAPPSS-IIN aims to do so by increasing infant caregiver adoption of breastfeeding/chestfeeding and safe infant sleep practices as recommended by the American Academy of Pediatrics (AAP) by empowering champions for these protective behaviors within systems serving systematically marginalized families at risk.

In support of NAPPSS-IIN, NICHQ provides technical assistance to states on integrating safe sleep and breastfeeding/chestfeeding promotion efforts; providing training and resources to systems and community groups, and helping families identify and overcome barriers in integrating safe sleep and breastfeeding/chestfeeding.

The purpose of these community listening sessions was to learn from the wisdom of community-based organizations and the people they serve. Listening session participants were asked about the resources and tools that help them promote safe sleep and breastfeeding/chestfeeding, and additional support needed to meet community safe sleep and breastfeeding/chestfeeding needs. While the analytic results are forthcoming, DARE is excited to share key lessons learned during NAPPSS-IIN community listening sessions.

What is Chestfeeding?

Chestfeeding is the process of feeding a child human milk from a person's chest. The term can be used by anyone, but often is used by transgender and nonbinary people when the words breastfeeding or nursing are not an ideal fit.

Read more about NICHQ's language evolution in this article by COO Heidi Brooks.

1. **Go in with a plan but build in flexibility.** During one of the NAPPSS-IIN community listening sessions, a participant asked the facilitator what they, the interviewer, could do to promote safe sleep and breastfeeding/chestfeeding. Rather than shying away from the question, the facilitator engaged the participant in an important conversation about the role
of public health organizations providing direction and leadership on the topic of safe sleep and breastfeeding/chestfeeding promotion. While developing a semi-structured interview guide before data collection is essential to frame the goals of any qualitative research activity, researchers should also prepare for flexibility by developing a range of broad prompts to facilitate discussion. Additionally, researchers should not be too concerned if participant discussion deviates from the initial plan, as authentically engaging with a community means that researchers must support participants in dictating the terms and content of their engagement. From an analytic perspective, to account for any interview flow changes across cases, researchers may use a combination of inductive and deductive coding techniques to allow the data to speak for themselves.

2. **Remember, disagreement can be good.** Hosting qualitative research activities with participants from diverse geographic locations and populations creates unique opportunities for discussion. When participants don’t agree, it is not a bad thing. Differences in opinions or varying perspectives are an opening to demonstrate how community-based approaches to public health issues are not one-size-fits-all and depend on social determinants. From a research perspective, disagreements in a research activity move the conversation along and lend nuance to findings on the topic at hand. For instance, during the NAPPSS-IIN community listening sessions, two participants expressed differing opinions on the use of media to promote safe sleep and breastfeeding/chestfeeding. Some participants said the spirited conversation motivated them to consider different messaging strategies or media (e.g., podcasts, videos) to promote safe sleep and breastfeeding/chestfeeding.

3. **Encourage participants to share their personal experiences as well as their professional ones.** Lived experience is just as valid as professional experience. For some, lived experience is what brought them to their professional career. For this reason, researchers should encourage participants to share both their personal and professional experiences on the topic of discussion while maintaining confidentiality. During one of the NAPPSS-IIN community listening sessions, a safe sleep professional said they had nothing to contribute to the discussion on breastfeeding/chestfeeding promotion, as it was not the purview of their job description. However, after listening to other participants discuss their work in breastfeeding/chestfeeding support, the same person chimed in with their personal experiences with breastfeeding/chestfeeding. This led to a crucial discussion on the role of policies and hospital coordination to support breastfeeding/chestfeeding adoption, which would not have occurred had the participant not felt empowered to share their personal story.
When conducting community-based public health research, researchers must practice cultural humility and defer to the wisdom inherent in lived experience of community members. This requires intentional flexibility and openness in research practices, as DARE learned from the community listening sessions for the NAPPSS-IIN project.

Sign up to receive an email when our full research findings on the opportunities and challenges community-based organizations face in promoting safe infant sleep and breastfeeding are available.

Learn more about NICHQ’s NAPPSS-IIN project and our dedication to making safe infant sleep and breastfeeding/chestfeeding the national norm.