## Unpacking Racial Disparities Policy Initiative

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## Summary of Unanswered Questions Regarding Infant Mortality During Adult-Infant Bedsharing

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A group of experts gathered in Washington DC in spring 2014 to discuss unanswered questions regarding infant mortality during adult-infant bedsharing. The participants represented various perspectives on the debate about the extent to which bedsharing is a risk factor for sudden and unexpected infant death. (Learn more about this issue in The Illinois Report 2014 and a brief about the evidence base on the topic. This summary is based on the conversation, although it may or may not reflect the views of any individual participants.

One controversial issue is the American Academy of Pediatrics' recommendation that parents not share a bed with their infants. In-depth interviews and focus group studies suggest that new strategies may be needed in order to adapt public health messages and interventions about this issue for particular subgroups because some parents' personal and cultural experiences encourage bedsharing and given bedsharing can be used to comfort a sick infant or to protect the baby from crime in the neighborhood. Additionally, there is the challenge of recommending against bedsharing, on the one hand, while also promoting breastfeeding, on the other hand, since there is evidence that breastfeeding and bedsharing are positively correlated.

The spring 2014 meeting aimed to bring together scholars and other stakeholders with differing perspectives on these topics. Because this debate has sometimes been polarizing, the participants used

an adversarial collaboration model to constructively critique proposed research questions and research strategies, with the aim of identifying alternative hypotheses, approaches, and analyses that scholars and practitioners from each vantage point would find most compelling. Below we summarize some of the major research priorities that we drew from the conversation. But before we turn to these specific research questions, we first highlight a number of overarching challenges discussed at the meeting which make it difficult to conduct research on this topic.

One such overarching challenge is the inconsistencies and fluctuations in how sudden and unexpected infant deaths are classified. Official statistics suggest that recently there have been relatively low rates of the category used historically to define deaths as SIDS - Sudden Infant Death Syndrome - yet analysts recognize that classifications vary considerably depending on how death scenes are investigated and who evaluates the collected evidence. So the recently seen reductions may be more about classifications systems than changes in the underlying problem. A second challenge is that vital statistics data are often very slow to be released. Without up-to-date and reliable data on the phenomenon, securing the funding needed to conduct research on the topic is difficult. The relatively small number of cases of sudden and unexpected infant death, especially in any given locality or state, also makes it difficult to use some of the most rigorous scientific designs to study

## **About the Authors**

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Rachel Gordon is Professor of Sociology and Associate Director of the Institute of Government and Public Affairs at the University of Illinois at Chicago. the topic. For instance, fielding a contemporary case-control study was identified as a priority by meeting participants. Yet, a collaborative statewide and/or multi-site case-control study would be needed in order to have enough cases for statistical precision. Standardized scene investigation and classifications would also be necessary (such as those adopted by the <u>Sudden Unexpected Infant Death Case Registry</u>).

In addition to improved collection, reporting, and access to information about infant deaths, experts recommended a continuation and improvement of survey information about infant sleep practices, including more questions in the Pregnancy Risk Assessment Monitoring System (PRAMS) or other state surveys. Meeting participants suggested that information about parents' knowledge, attitudes and practices related to infant sleep might also be collected by state- or federally-funded home visits or during well-baby medical visits. The information from such surveys might be linked to other data. For instance, survey data can help scientists establish the rates of various risk and protective factors, like bedsharing, in different segments of the population, whereas vital statistics data can identify the rates of deaths in similar subgroups. Other state administrative data might also be linked with data sharing agreements or in data enclaves (e.g., the Census Research Data Centers, NCHS Research Data Center, or Center for State Child Welfare Data).

Meeting participants also discussed multi-pronged strategies to help prioritize research on sudden and unexpected infant death, identifying efforts needed to simultaneously reach out to funders, senior and junior scholars, and scientists in training. For instance, an overview report or guide covering "what you need to know about SIDS-related data" might be useful for scientists interested in working on the topic but unfamiliar with the nuances of data and definitions (e.g. how deaths are coded). Broadly documenting the ways in which infant sleep affects parent and child health might also encourage a broader array of scientists and funders to pursue the topic.

Across all of the research questions discussed at the meeting, we also identified the need for scholars to attend to variation by socio-economic status, race-ethnicity and culture. Doing so is important because infant death rates vary by demographic characteristics, with lower-income, Black families being most likely to experience a baby's death suddenly and unexpectedly. Such attention is also important because cross-cultural and anthropological research suggests that infant sleep practices, including bedsharing, may vary in different contexts and cultures. Experts also recognized the need to holistically consider all of the caregivers who are responsible for babies' sleep (including not only mothers but also fathers, grandparents, and other relatives as well as babysitters or child care providers) and to consider all sleep contexts (including shared sleep surfaces, such as chairs or couches, in addition to beds; and, independent sleep environments, such as infant carriers and bouncy seats, in addition to cribs and bassinets). Although in some

of the research questions listed below we explicitly called for attention to variation by socio-economic status, raceethnicity and culture, we have the need for such attention implicitly in mind for all research questions.

## **Research Questions**

We organized the research questions into three groups: (1) Research on Bedsharing Practices and Risks, (2) Research on Individual and Community/Societal Interventions, and (3) Historical and Archival Research.

Research on Bedsharing Practices and Risks

- What is the contemporary risk of infant mortality associated with bedsharing in the United States, including among higher educated, White, suburban families?
- To what extent do rates of sudden and unexpected infant death change when county coroners and medical examiners turn over? Does this association vary based on characteristics of the local community and/ or the coroner/examiner? Is it possible to adjust for such variation when studying trends and correlates of sudden and unexpected infant death?
- Which risk factors for sudden and unexpected infant death have the greatest effects, through both direct and indirect pathways (e.g., smoking cessation by expectant mothers may both increase the baby's birth weight and reduce mortality risks after birth)? Which safe sleep practices are easiest for parents to implement (e.g., changing the baby's sleep position versus stopping smoking)?
- When observing parental routine sleep practices (at home or in a sleep laboratory), how is bedsharing behavior similar or different for different subgroups of parents (breastfeeding or not? more or less educated? Black, White or Latino?). Under what circumstances do parents bring infants to bed? How often do mothers fall asleep when they bring the baby into bed to feed or for comfort? How often do bedsharers overlay on their infants, and is the frequency different across subgroups (e.g., for mothers, fathers or other bedsharing adults? by socio-economic status, race-ethnicity or other factors like alertness, stress, or alcohol use?). How do parents use sleep environment products, such as bassinets, side sleepers, and in-bed sleep spaces, and how does use vary across subgroups (e.g., for breastfeeding versus formula-feeding mothers)?
- How do safe sleep routines differ at home and in child care (assessed by parents'/caregivers' reports and/or by observation in home/child care or a sleep laboratory)? Do parents' and caregivers' stress levels differ when managing sleep of the same infant? Does the infant's stress level differ when his or her sleep is managed by parents and other caregivers?

- What components of individual interventions are most effective (e.g., are interventions that give parents cribs or other infant sleep spaces more effective when combined with education about safe sleep practices)? Does effectiveness vary across a range of outcomes (e.g., parents' knowledge and beliefs about safe sleep practices? their report of the infant sleep practices that they use? their observed practices at home or in a sleep lab? their own and their babies' stress levels, as reported by the parents or measured at home or in a sleep lab)?
- Are similar or different educational/training interventions and public health campaigns effective with relatives (e.g., fathers, grandparents) and child care staff (e.g., neighborhood child care homes, licensed family child care providers, child care center teachers) as with mothers?
- To what extent do interventions related to breastfeeding and bedsharing support or conflict with one another? Can lactation supports assist with promoting safe sleep practices (and vice versa)? Are lactation consultants differentially available depending on community demographic characteristics (e.g., as mapped with GIS)? Even if available, are lactation consultants easy for new mothers to access (including through home visits) and do new mothers know about them?
- How do parents interpret public health materials and campaigns, both cognitively and emotionally? To what extent do some types of materials or campaigns produce stress in parents without altering their attitudes or behaviors?

- How are expectations and routines surrounding infant sleep portrayed on television and in social media (e.g., a "good baby" sleeps through the night)? To what extent are portrayals of sleep environments consistent with safe sleep recommendations, including those from the American Academy of Pediatrics (AAP)? To what extent have portrayals shifted across historical time?
- What are historical and current practices for the commercial marketing of infant sleep products and for assuring consumer product safety related to them? To what extent are products required to be evaluated before being marketed to expectant and new parents, especially cribs and sleepers? How are harmful products identified and taken off the market? How do parents interpret product marketing?