

Eunice Kennedy Shriver National Institute of Child Health and Human Development

**Healthy Native Babies Project
Safe to Sleep In-Person Focus Groups**

**FACILITATOR'S GUIDE
120-Minute Focus Group with Mothers**

BACKGROUND INFORMATION AND SELF-INTRODUCTIONS

Introduction: Good afternoon/good evening. My name is _____ and I am the facilitator for today's focus group discussion. I am a member of a national team that is conducting community-based assessment of a safe infant sleep program. The main purpose of our discussion today is to inform the next phase of the *Healthy Native Babies Project*. It is part of the safe infant sleep campaign being implemented by the Eunice Kennedy Shriver National Institute of Child Health and Human Development at the National Institutes of Health.

All of you at this meeting are mothers. Because you each have unique experiences as mothers, feel free to agree and disagree with each other about any of the topics we will be discussing. Although I am an independent consultant for the *Healthy Native Babies Project*, I will not be offended by anything you say. Thank you, in advance, for being straightforward with your comments.

We have a very limited amount of time together—our discussion will end at about X:XX p.m. When discussing topics, please do your best to speak one at a time, and please allow each other to get more or less equal “air time.”

Permission: I am audio-recording our discussion. I am interested in what is said, not who said it. We will only use first names during the discussion. In the final summary report, individual names, tribes, or organizations will never be connected to any comment you make during the discussion. Information you provide will not be disclosed to anyone but the investigators conducting the study, except as otherwise required by law. Does anyone have any questions about this or the consent form they completed? Do I have everyone's permission to proceed?

Self-introductions: I am now going to go around the table. Please introduce yourself using the name you would like me to use during the discussion, and tell what ages your infants are, or if you are not the mother, what ages the infants are that you care for. Please briefly tell us what one thing that has been the most pleasurable about caring for your baby. Also please state whether you have attended a *Healthy Native Babies* workshop, or are a member of the *Healthy Native Babies* Advisory Group.

Public reporting burden for this collection of information is estimated to average 120 minutes, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0643). Do not return the completed form to this address.

NOTE TO FACILITATOR ON GETTING THE FOCUS GROUP STARTED

The **goal** of this focus group, or Talking Circle, is to generate information about our audiences' knowledge, attitudes, beliefs and behaviors related to certain topics, including (but not limited to) SUID, SIDS, safe infant sleep, maternal and infant health in general, and practices related to seeking or providing health information. The **target audience** for this focus group is mothers.

How this guide is organized

The Facilitator's Guide includes the following:

- **Domains:** main discussion topics
 - **Lead questions:** the first question you will ask the participants in each domain
 - **Primary questions:** highest priority questions in each domain
 - **Probes:** suggested questions for helping participants explore specific dimensions of each domain; probes do not have to be used verbatim or at all
 - Cues on what to **listen for** as participants contribute to the discussions. Observe the flow of the conversation and when "**listen for**" issues come up, help move the conversation in this direction.
 - **Facilitator's notes:** extra guidance for you, including the topics and issues you should be familiar with beforehand, and references and websites. As the group facilitator, it is imperative that you be familiar with the critical issues affecting the families and communities represented by participants.
-

DOMAIN 1: Mothers knowledge, attitudes, beliefs and behaviors about safe sleep and SIDS

Lead question: Thinking back over your baby's first year, how did you put your baby to sleep?

Primary questions:

- What do you think is most important in keeping a baby safe during sleep? What is most risky?
- What information do you wish had been shared with you that *was not provided* to you about safe infant sleep? This might include your unanswered questions or things you were not sure about.
- What makes it hard to follow the advice that you get? (Facilitator: Generate list of real world barriers to safe infant sleep.)

Probes:

- What or who influenced your decision about how you put your baby to sleep?
- Let's talk about your baby's sleep in general. How is that going for you? What difficulties did your baby have in sleeping through the night or napping? How did you help your baby get to sleep?
- How does your baby's sleep pattern affect your sleep or your husband or partner's sleep?
- What did you do when you got different advice from different people?

If these topics don't come up in discussion, you might ask,

- What about bed sharing?
- What about the back to sleep position?
- What about soft sleep surfaces or fluffy bedding?
- What about overheating?
- What about exposure to tobacco smoke?
- What happens when other family members care for baby?

Listen for: Knowledge and attitudes about specific safe sleep recommendations.

- Use of a firm sleep surface
- Room sharing without bed sharing
- Avoid overheating
- Avoid soft bedding
- Avoid soft objects in the crib
- Avoid exposure to tobacco smoke

Facilitator's note: You will need to be familiar with all aspects of most recent (2011) AAP Guidelines, particularly so that you can state which safe sleep practices are recommended. < <http://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/AAP-Expands-Guidelines-for-Infant-Sleep-Safety-and-SIDS-Risk-Reduction.aspx>>

DOMAIN 2: Mother's concerns about maternal health

Lead question: What do you think of when you hear the phrase “healthy pregnancy”?

Primary questions:

- What did you do to stay healthy during your pregnancy?
- What were your biggest concerns during your pregnancy?
- What did your provider communicate to you about being healthy during your prenatal care visits?

Probes:

If it does not come up in discussion, you might ask:

- Which specific health issues you worried about, if any?
- What were other things in your life that you worried would impact your pregnancy?
- Were prenatal visits important to you? How come?

Listen for: Factors that may be related to increased SIDS or infant sleep risks. Values that may help frame safe sleep messaging.

- Preterm birth, low birth weight
- Maternal health postpartum (recovery, depression, etc)
- Conditions of everyday life
- Safety in the home and abuse
- Chronic health conditions such as diabetes
- Infant feeding and breastfeeding
- Traditional native practices to support health and protect infant's spirit.

Facilitator's note: Do not spend a lot of time on this domain. Facilitators will use this question to get at maternal health issues that impact SIDS risks—keeping in mind both what promotes optimal health and affects the continuum of risk for sleep-related infant death.

DOMAIN 3: Priority issues related to infant health

Lead question: What do you think is most important in terms of keeping your infant healthy and safe?

Primary questions:

- What have you done to make sure your baby has the best start in life?

Probes:

- Which specific infant health issues did you worry about, if any?
- What were other things in your life that you worried would affect your baby?

Listen for: Both the things that promote optimal health and well-being, and those that increase risk to the infant's health and well-being.

- Failure to thrive
- Immunizations
- Safety in the home, abuse
- Use of wood burning stoves
- Breastfeeding and other issues related to infant feeding.
- Traditional native practices to support health and protect infant's spirit.

Facilitator's note: Do not spend a lot of time on this domain. Facilitators will use this domain get at health issues that impact SIDS risks—keeping in mind both what promotes optimal health and affects the continuum of risk for sleep-related infant death.

DOMAIN 4: Mother's source(s) of health information

Lead question: Which people or other resources do you trust most for information about health, infant care, parenting, and safe infant sleep?

Primary questions:

- What information did you get from health service providers? What would make the advice they provide more helpful?
- How often do you search online for information about health, infant care or parenting? Are there particular websites that you use?

Probes:

- What do you do if a health service provider recommends that you do one thing, but a family member suggests you to do something else?
- This next question is for mothers who provide special care because of their infant's special needs. If your baby has a health condition, or was born early, or at a low birth weight, do you feel you received different or more information about infant care than mothers of other babies?
- Have you ever looked online for information specifically on SIDS or safe infant sleep online?

Listen for: Specific sources and quality of health information.

- Physician (family practice doctor, obstetrician, pediatrician)
- Nurse
- Midwife
- Doula
- Friends
- Family members
- Books – which ones?
- Magazines – which ones?
- Internet/Websites/Blogs – which ones?

Listen for: Recommended safe sleep messages. The following safe infant sleep behaviors can reduce the risk of all sleep-related infant deaths, including Sudden Infant Death Syndrome (SIDS):

- Back sleeping
- No soft bedding, loose blankets, crib bumpers, toys in infant sleep area
- Firm surface with fitted sheet
- Separate sleep surface from where adult(s) sleep, but in same room with parents (room sharing)

Facilitator's note: The point here is to assess where mothers/caregivers get their information, who they trust, and what they do when they receive contradictory information. This domain is also a lead-in to the next question regarding use of Internet and social media.

DOMAIN 5: Mother's use of social media

Lead question: How often do you use social media?

Primary questions:

- Which social media sites do you use?
- What kinds of parenting or health information are shared among peers in your social media network?

Probes:

- Which of the following technology do you use: mobile phone (personal or shared), texting, web access on your phone, Internet on a computer?
- What parenting or health related apps have you downloaded?
- Do you follow or like any parenting or health-related Facebook pages, blogs, Twitter feeds? Which ones?
- Do you follow or like any Native-focused Facebook pages, blogs, websites or Twitter feeds? Which ones?
- Have you ever signed up to receive health or parenting emails or texts? Which ones? What do you like about them?

Listen for: How participants get, find, and use health information.

Facilitator's note: The starting point for the conversation is how much participants use the social networking sites in general and for what purposes. Then probe on use for health and parenting information.

DOMAIN 6: Attitudes about use and exposure to tobacco during pregnancy and postpartum

Lead question: What are your thoughts about the effect of smoking commercial tobacco on pregnant women or their babies before they are born?

Primary questions:

- What are your thoughts about the impact of secondhand smoke on pregnant women?
- What about infants after they are born?
- It can be hard to talk to family members about not smoking near your baby or in your house. What conversations have you had about this? Especially with elders? Has anything you said worked well? What hasn't worked well?

Probes:

- What are your thoughts on how smoking and secondhand smoke relate to SIDS?
- What do you do to protect your infant from exposure to secondhand smoke from other family or household members?
- How common are e-cigarettes in your community? Do you think they are safer than regular cigarettes?

Listen for: The amount of exposure to smoking and secondhand smoke during pregnancy and postpartum, and strategies for avoiding secondhand smoke exposure. Also listen for messages that resonate with women about quitting or cutting down, and elements of successful conversations with family members.

Facilitator's note: The point of this Domain is to explore how smoking and exposure to secondhand smoke during pregnancy and postpartum can cause health problems for both mothers and infants, and impair an individual's functioning as a parent, thus affecting the health and safety of newborns and young infants, including safe sleep.

DOMAIN 7: Attitudes about substance use (alcohol, illicit drugs, prescription drugs) and exposure during pregnancy and postpartum

Before beginning this section the facilitator should say: *Next I want to get a better idea about mothers' opinions about substance use, even if you have never used drugs or alcohol. I know that this can be a very sensitive topic, but your thoughts are very important. To protect your privacy in this group, I will not ask you to share whether you have ever used drugs or alcohol. Remember, your participation in this focus group is voluntary. If you feel uncomfortable, you do not have to participate in this conversation.*

Lead question: What are your thoughts on how use of alcohol and drugs affect pregnant women and their infants?

Primary questions:

- What are your thoughts, specifically, on how alcohol or drug use relates to SIDS or accidental infant death?
- From your perspective as a parent, what could be the risks and benefits to talking about substance use during pregnancy? With family and friends? With prenatal care providers?

Probes:

- From what you hear in general, what are the most common drugs, other than alcohol, that women use? Is this true in your community, or is it different?
- Which drugs do you think are riskier or less risky to mom and baby?
- Why do you think some women keep using drugs when they are pregnant?
- Sometimes other family members use drugs and alcohol. How do you think this impacts the baby?
- What have you done to protect your baby from the effects of alcohol or drug use in the community?

Listen for:

- Perceptions of how risky/not risky drug and alcohol use is during pregnancy and postpartum, and how prevalent it is
- How drug and alcohol use affects parenting
- How drug and alcohol use affects infant health and safety
- What support services and prevention and treatments services are available
- Ways that pregnant and postpartum women are protected against stigmatization, discrimination, marginalization, which puts them and their infants at higher risk, and disconnects them from linkages to social and medical services

Facilitator's note: Before you begin this section, make it clear to participants that you are simply asking them to share their thoughts and perceptions about drug use, including

attitudes and norms in their communities. We are *not asking participants to self-disclose about their own experience* with drug use.

The point of this Domain is to explore attitudes around alcohol and drug use during pregnancy and postpartum, and knowledge and attitudes about how alcohol and drug use affect the health and safety of newborns and young infants, including safe sleep.

Before conducting the focus group, make sure to review all training materials related to substance use during pregnancy.

WRAP-UP

Facilitator say: I'd like to end this focus group by asking each of you to briefly share one positive thing you learned about yourself since becoming a parent.

Thank you very much for your honest and invaluable feedback. Information from this and other focus groups will help inform the NICHD's campaign on safe infant sleep and the *Healthy Native Babies Project*. You will receive \$40 in appreciation for your time and participation.