

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 General Service Providers

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 service providers. Because you each have unique experiences and work in different fields, 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 where you work, what you do for work, and whether you have attended a *Healthy Native Babies* workshop before, or are a member of the *Healthy Native Babies* Advisory Group.

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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 service providers.

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.
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DOMAIN 1: Provider's knowledge, attitudes, beliefs about SIDS, SUID and safe infant sleep, as well as practices about safe sleep and SIDS

Lead question: In your opinion, what keeps infants safe during sleep?

After the initial questions are asked, state background info: In 1992, the American Academy of Pediatrics (AAP) recommended that all babies should be placed on their backs to sleep to reduce the risk of Sudden Infant Death Syndrome. In 2011 the AAP expanded its guidelines on safe sleep for babies to include some specific information for parents on creating a safe environment for their babies to sleep, to prevent sleep-related deaths such as suffocation and entrapment.

Primary questions:

- Which safe sleep recommendations do you feel are most important?
- In the communities you serve, how are infant sleep recommendations from organizations like the AAP similar or different from traditional Native practices about safe sleep or childrearing?
- In the real world among real people, what barriers do your clients/patients face in trying to practice safe infant sleep?

Probes:

- If you have noticed some differences in approaches between service organizations and Native practices about safe infant sleep, how could these be better integrated to help young parents and other infant caregivers?
- For those of you with children, I'd like you to think now about your own family. How did your infant(s) sleep during the first year?
- How did your family make choices about how your own infant(s) would sleep?

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 components of crib environment? (i.e., soft sleep surfaces or fluffy bedding)
- What about alcohol, smoking, secondhand smoke, and drug use?

Listen for: SIDS risk reduction and safe sleep knowledge and practices.

- 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
- Exposure to tobacco smoke
- Overheating
- Differences in information needs between HNB training participants vs. non-participants.

Facilitator's note: You will need to be familiar with all aspects of most recent (2011) AAP Guidelines < <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: Providing information to clients and patients about safe sleep for infants

Lead question: What conversations do you have with your clients or patients about safe infant sleep?

Primary questions:

- Are there particular topics that you always address with your clients or patients around safe infant sleep? Some that you just don't get to?
- For those of you involved in child care or foster care, what policies does your organization have about infant sleep?
 - If your organization does not have specific policies, what approaches do you take to keep infants safe during sleep?
- What additional information do you need in order to better promote safe infant sleep?

Probes:

- Which topics regarding Sudden Infant Death Syndrome or safe infant sleep are you less comfortable addressing?
- What barriers do your clients or patients experience in implementing safe sleep practices? (Ask this question if it did not get addressed in Domain 1).

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

- At what points during pregnancy or after the baby is born do you address SIDS and safe infant sleep?
- How often is this topic repeated?
- How do you approach SIDS/safe infant sleep or engage families in discussion on this topic?
- What print materials or other teaching tools do you use?

Listen for: The recommended 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
- Firm surface with fitted sheet
- Separate sleep surface from where you sleep, but in same room with parents (room sharing not bed sharing)

Facilitator's note: Facilitators will probe participants regarding what health information and anticipatory guidance is provided in the context of prenatal and postpartum care, especially education that relates to safe infant sleep and risk reduction for accidental death.

DOMAIN 3: Priority issues related to maternal health

Lead question: What are your primary concerns regarding maternal well-being among your clients/patients?

Probes:

- What things support women's health and well-being during and after pregnancy?
- What things harm maternal health and well-being during and after pregnancy?

Listen for:

- 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 factors that increase the risk for SIDS and sleep-related infant death.

DOMAIN 4: Priority issues related to infant health

Lead question: What issues related to infant well-being are of greatest concern to you?

Primary questions:

- How much of a priority are these things in comparison to SIDS?

Probes:

- List those things that support healthy infant development in the first year.
- List those things that harm infant health and development.

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.
- Preterm birth, low birth weight
- Conditions of everyday life

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 5: Attitudes and provider communications regarding use and secondhand exposure to tobacco during pregnancy and postpartum

Lead question: How do you address commercial tobacco use among your patients/clients?

Primary questions:

- How do you talk with your patients/clients about the effects of second hand smoke exposure on pregnant women and infants?
- It can be hard for young parents to talk to family members about not smoking near the baby or in the house. How are your clients/patients dealing with this?
- This is a particularly difficult conversation to have with elders. How do your clients or patients approach secondhand smoke with elders in their families?

Probes:

- How do you think your clients and patients view smoking as it relates to SIDS?
- How do you think your clients and patients view secondhand smoke as it relates to SIDS?
- What have you heard that your clients/patients do to protect their infants from exposure to secondhand smoke from other family or household members?
- What are community perceptions about e-cigarettes in terms of popularity and safety?

Listen for: The amount of commercial tobacco use among their clients and patients, exposure to secondhand smoke during pregnancy and postpartum, and strategies for avoiding secondhand smoke exposure.

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. You are also exploring how various health service providers address these issues.

DOMAIN 6: Attitudes and provider communications about substance use (alcohol, illicit drugs, prescription drugs) and exposure during pregnancy and postpartum

Lead question: Among your clients and patients, how common is the use of or exposure to alcohol and other drugs during pregnancy and the postpartum period?

Primary questions:

- How do you address substance use in the context of infant sleep risks among your clients or patients?
- What makes it difficult to address the topic of substance use in the context of infant sleep risks patients/clients?
- What additional resources would be helpful for you?

Probes:

- What do you think about harm reduction or risk reduction approaches to substance use?
- Among your clients and patients, what drugs are most commonly used during pregnancy and postpartum?

Listen for: Specific mention of alcohol, illicit drugs, or misuse of prescription drugs. Whether providers cite their own clinical experience, 'common knowledge' or another source of evidence related to prevalence of use. Listen for discussion of clinical best practices.

Facilitator's note:

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.

DOMAIN 7: Continuing education and professional development

Lead question: In general, what are the ways in which you get continuing education or professional development?

Primary questions:

- Specifically, how have you received professional development on safe infant sleep?
- What professional development resources are you familiar with that are tailored to Native populations and communities?

Probes:

- What is offered or required by your workplace?
- What do you do on your own?
- Do you prefer to receive professional development at your work site, offsite, or online through webinars or self-paced courses? Any other way?

Listen for: Types of continuing education that health service workers are seeking and utilizing, particularly with regard to safe infant sleep.

Facilitator's note: Do not spend a lot of time on this domain. Facilitators will use this question to assess what learning modalities health service workers are likely to use.

DOMAIN 8: Provider use of Internet and social media

Lead question: How do you use the Internet to research health or parenting topics related to your work?

Primary questions:

- Do you conduct outreach or education to your patients/clients via email, text, social media, blogs, or a website?
- For either professional or personal purposes, which social media sites do you use, such as Facebook, Twitter, You Tube, Instagram, Pinterest?
- How would you describe your comfort level or interest in using social media sites for exchanging information for professional purposes?
- What programs are you aware of that use social media for promotion of health or social issues?

Probes:

- What about searching online for health or parenting information for your own personal use?
- Are you allowed to use work computers for work-related social media purposes?
- What health-related apps for tablets or SmartPhones do you use?

Listen for: How participants get, find, and use health care information for themselves and for their clients or patients.

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

DOMAIN 9: Professional Collaborations

Lead question: Think back to collaborations with other organizations that you have participated in. What types of collaborations and partnerships were they and with which organizations?

Primary questions:

- What kinds of collaborations around the theme of “safe infant sleep” have you participated in?
- From your experience, what makes a successful collaboration?

Probes:

- In collaborating with others, what went well?
- What didn’t go well?

Listen for: Why teaming up with partners can make sense, and what strategies work best.

Facilitator’s note: Give particular attention to “what makes a successful collaboration.”

WRAP-UP

Facilitator say: 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 as a thank you for your time and participation.