

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 Elders**

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 elders. Because you each have unique experiences as elders, 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: 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. Please briefly tell us how many children you have raised, and what one thing you did to keep your babies healthy. Also please state whether you have attended a *Healthy Native Babies* workshop before, or are a member of the *Healthy Native Babies* Advisory Group.

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 elders. Be careful not to challenge the elders' authority or knowledge while facilitating the focus group, particularly when probing or providing requested information about what we currently know about safe infant sleep practices.

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: General exploration of what is important about childrearing and keeping a baby healthy

Lead question: What advice do you give parents regarding childrearing and keeping their babies healthy?

Primary question:

- How has the “common wisdom” about keeping babies healthy and safe changed since you raised your own children?

Probes:

- What things are important in raising healthy infants?

Listen for:

- Often, older native women are considered the “opinion leaders” in their communities. What are they saying?

Facilitator’s note: Do not spend a lot of time on this domain. Facilitators will use this question to get the conversation started, and to listen for what elders believe promotes optimal infant health.

DOMAIN 2: Elders' knowledge, attitudes/beliefs, and behaviors (KAB) about infant sleep and SIDS

Lead question: Please think back to when your children were young. How did you put your babies to sleep?

Primary question:

- How do you put your grandchildren to sleep these days?
- How do you think things like where the infant sleeps or the baby's sleeping position are related to accidental infant death or Sudden Infant Death Syndrome (SIDS)?

Probes:

- What do you think is most important in keeping a baby safe during sleep?
- What things do you feel are most risky, or unsafe, for infants when they 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 soft sleep surfaces or fluffy bedding?
- What about overheating?
- Traditional practices

Listen for:

- Often, older native women are considered the "opinion leaders" in their communities. What are they saying?
- Ways in which you can present knowledge about safe infant sleep in a way that does not confront or question the elder's knowledge or authority.
- How elders can impact the beliefs and behaviors of young parents.
- Are there knowledge gaps between how elders raised their own children and contemporary recommendations regarding safe sleep practices?
- What strategies are best for outreaching to elders so that they can spread safe sleep messages in their communities?

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

Facilitator's note: This Domain is used to identify any gaps that might exist between elder's knowledge and attitudes about safe infant sleep and current safe sleep recommendations. You will need to be familiar with all aspects of most recent (2011) AAP Guidelines, particularly so that you can state what 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 3: Elders' wisdom versus advice from medical system

Lead question: What have you heard about the advice parents get from their health care providers, or from health programs, about how babies should be put to sleep?

Primary questions:

- What do you think about the advice parents are getting?
- How is it similar or different from what you think they should do?
- If you heard new information about how to keep babies safer when they sleep, would you be willing to do something new?
- Are there traditional practices that should be used in addition to what parents are being taught today about how babies should sleep? Which ones?
- Do you think you could be an advocate in your family, or community, for the safe infant sleep messages and practices that are considered up-to-date?

Probes:

- How can elders assist the community in learning skills and practices for keeping babies safe?
- How can elders help parents balance the knowledge about childrearing that comes from two worlds: native culture (home and family) and medical systems (outside world)?
- How can elders help families and communities achieve positive results in keeping native infants safe and healthy?

Listen for:

- Strategies for involving elders in spreading messages
- What messages elders feel are important
- What messages make elders uncomfortable

Listen for: Safe sleep messages and practice for which elders could become advocates.

- 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 notes: Throughout indigenous communities, elders are considered a source of traditional knowledge, and are given a central role in maintaining cultural practices. This

Domain explores the ways in which advice from elders and medical sources may differ, and what to do in those cases. And how elders can be encouraged to be advocates for the contemporary safe sleep messages and practices.

DOMAIN 4: Elders' involvement in childrearing and decision-making

Lead question: What role have you had in raising your grandchildren?

Primary questions:

- What influence do you have in your family on decision-making about childcare practices?
- What traditional practices do you think are important for today's young families to practice?

Probes:

- What do you wish your role could be in raising your grandchildren?

Listen for: SIDS risk reduction and safe sleep knowledge. What involvement elders have on childrearing, and specifically, their impact on decision making about infant sleep.

Facilitator's note: Be careful not to challenge the elders' authority or knowledge while offering suggestions about what we currently know about safe infant sleep practices. Also, some community elders may have been raised away from the community (in non-voluntary boarding schools or foster homes). As a result they may lack context for current childrearing practices from their own childhoods.

DOMAIN 5: Attitudes about use and exposure to tobacco during pregnancy and postpartum

Lead question: What do you think about family members smoking around pregnant women and their infants?

Primary questions:

- How do you think smoking around pregnant women affects them?
- How do you think smoking around infants affects them?
- It can be hard for a young parent to talk to family members about not smoking near his or her baby or in the house. What would be the best way to approach the conversation with elders?

Probes:

- Are there any rules about tobacco use in your house?
- How do you think elders feel when young parents ask them not to smoke around their infants?
- What are your thoughts on how secondhand smoke relates to Sudden Infant Death Syndrome (SIDS)?

Listen for:

- Reaction to HNB guidelines about secondhand smoke exposure.
- How to communicate this message to elders in a respectful manner.
- If a young parent who respects their elders needed to know how to have a conversation about the risks of exposing the baby to secondhand smoke, what would an elder advise them to do?

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, including sleep risks. Particularly, we are probing to find out how to have a conversation with elders about the risks of exposure to secondhand smoke that is both respectful and effective.

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

Lead question: How do you think using alcohol and drugs affects pregnant women and their infants?

Primary questions:

- What are your thoughts on how alcohol or drug use relates to SIDS or accidental infant death?
- Sometimes other family members use drugs and alcohol. How do you think this impacts the baby?
- What have you or your family members done to protect babies from the effects of alcohol or drug use?

Probes:

- Which drugs do you think are riskier or less risky to mom and baby?
- From what you hear in general, what are the most common drugs that women use?
- Why do you think some women keep using drugs when they are pregnant?

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

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.

Specifically, we are probing to find out elders' point of view.

WRAP-UP

Facilitator say: If you had one minute to tell us the most important way to keep the babies in your community safe and healthy, what would it be?

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.