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Eunice Kennedy Shriver National Institute of Child Health and Human Development

Safe to Sleep Telephone Focus Groups

MODERATOR'S GUIDE

—60 Minute Focus Group with Breastfeeding Women—

Background Information and Self-Introductions (~7 minutes)

Introduction Good afternoon/good evening, depending on your time zone. My name is

and I am the moderator for today's focus group discussion. All of you on this call are breastfeeding moms. The main purpose of our discussion is to get your opinions about breastfeeding and infant health issues affecting babies under the age of 12 months. Your feedback will inform a safe infant sleep campaign being implemented by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, or "the NICHD."

Feel free to agree and disagree with each other about any of the topics we will be discussing. I am an independent researcher, so I will not be offended by anything you say. Thank you, in advance, for being candid.

We have a very limited amount of time together—our discussion will end at about X:XX p.m. Eastern Time. If I interrupt you, please do not take it personally—I am simply trying to make sure we cover all of our discussion topics before our time is up. It is also critical that each of you speaks one at a time and that you 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, your individual name will never be connected to a comment you make during the discussion. This means your feedback is confidential and secure to the extent permitted by law. With that in mind, do I have everyone's permission to proceed?

Self-Intros

I am now going to go around the virtual table. When I call your first name, please introduce yourself using the name you would like me to use during the discussion, and tell us your city and state, the number of weeks you have been breastfeeding, and the age of the child that you are breastfeeding.

^{*} Public reporting burden for this collection of information is estimated to average 60 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 (0925-0590). Do not return the completed form to this address.

General Breastfeeding Experiences (~5 minutes)

- 1. What do you like most about breastfeeding?
- 2. What do you like least about breastfeeding?
- 3. What has surprised you about breastfeeding? (Something that you didn't expect until you began breastfeeding.)

Safe Infant Sleep Environment (~5 minutes)

4. Please take a moment to visualize a safe sleep environment for an infant under 12 months. What does this environment look like?

Listen for:

- O Placing the infant on his or her back to sleep.
- O Use of a firm sleep surface.
- o Room sharing without bed sharing.
- o Avoid overheating.
- o Avoid soft bedding.
- O Avoid soft objects in the crib.
- O Avoid exposure to tobacco smoke.

Awareness of Breastfeeding and Safe Infant Sleep Recommendations (~10 minutes)

5. What kinds of conversations have you previously had with your health providers about breastfeeding?

Listen for:

Breastfeeding can reduce the risk of Sudden Infant Death Syndrome (SIDS).

6. What kinds of conversations have you previously had with your health providers about safe infant sleep?

Probe:

Did any of your health providers review recommendations for safe infant sleep with you? If so, what recommendations did they give you?

These safe infant sleep behaviors can reduce the risk of all sleep-related causes of infant deaths, including Sudden Infant Death Syndrome (SIDS) and suffocation.

- Back sleeping
- No soft bedding, loose blankets, toys
- Firm surface
- Separate sleep surface from where you sleep (room sharing)
- 7. What have you heard about the American Academy of Pediatrics (AAP) recommendation on breastfeeding?

Listen for:

Breastfeeding helps reduce the risk of SIDS.

8. What have you heard about the American Academy of Pediatrics (AAP) recommendation on safe infant sleep?

Listen for:

- O Placing the infant on his or her back to sleep (supine position).
- O Use of a firm sleep surface.
- O Room sharing without bed sharing.
- Breastfeeding
- O Consideration of the use of a pacifier.
- o Avoid overheating.
- o Avoid soft bedding.
- o Avoid soft objects in the crib.
- O Avoid exposure to tobacco smoke.
- o Avoid alcohol.
- o Avoid illegal drugs.
- o Routine immunizations.

9. What have you heard about the American Academy of Pediatrics (AAP) recommendation related to bed sharing?

Probe:

What is the recommendation related to an infant sleeping with his/her mother or caregiver in a bed? Couch or chair?

10. What have you heard about the American Academy of Pediatrics (AAP) recommendations related to breastfeeding and bed sharing with respect to sleep-related infant deaths, including SIDS (Sudden Infant Death Syndrome) and accidental suffocation?

Safe Infant Sleep Behaviors (~15 minutes)

I will now read the official American Academy of Pediatrics (AAP) recommendation on safe infant sleep and breastfeeding:

"The American Academy of Pediatrics (AAP) recommends that parents keep the infant's sleep area close to the parents' bed, but separate from, where they and others sleep. The infant should not sleep in a bed or on a couch or armchair with adults or other children, but he or she can sleep in the same room as his or her parents. If the mom brings the infant into bed with her to breastfeed, she should put him or her back in a separate sleep area, such as a crib, bassinet, or play yard when finished. In addition, there is no evidence that devices marketed to make bed sharing safe (e.g., in-bed co-sleepers) reduce the risk of SIDS or suffocation or are safe. These devices are not recommended."

11. How many of you follow this recommendation?

12. What keeps you, as breastfeeding mothers, from following this recommendation?

Probe:

- O Please describe your experiences related to this recommendation?
- O Are these American Academy of Pediatrics (AAP) recommendations realistic to you? Why/why not?
- 13. What helps you, as breastfeeding mothers, to follow this recommendation?
- 14. What kinds of resources would support you in following this recommendation?

Probe:

- o Health education materials
- O Conversations with a health provider
- O Guidance from a lactation consultant/midwife/doula
- O Support group with other breastfeeding mothers
- 15. What organizations, institutions, people, or other resources do you trust most for information about breastfeeding and safe infant sleep?

Listen for:

- O American Academy of Pediatrics (AAP)
- o NICHD
- o CDC
- O La Leche League
- o Your pediatrician
- o Your nurse
- o Your midwife
- O Your doula
- O Your lactation consultant
- O Your friends who are also breastfeeding
- O Your family members?
- O Books which ones?
- O Magazines which ones?
- o Websites/Blogs which ones?

Probe: For those of you who are not following the AAP breastfeeding/safe infant sleep recommendation, what would it take for you to follow the recommendation?

Suggestions to the NICHD (~3 minutes)

16. What are your suggestions for how the NICHD could better promote breastfeeding and safe infant sleep, in accordance to American Academy of Pediatrics (AAP) recommendations, among breastfeeding moms like you?

Safe Infant Sleep Messages (~15 minutes)

I am now going to read you 6 statements related to the American Academy of Pediatrics (AAP) safe infant sleep recommendations. Please let me know how effective you think each statement would be in catching <u>your</u> attention. Please also let me know how you might change each statement to make it even more attention-getting.

- 1. The Centers for Disease Control and Prevention (CDC) reports accidental suffocation is the leading cause of injury death among children aged <1 year in the United States, accounting for nearly 1,000 infant deaths annually.
- 2. Studies have shown that sharing a bed with your baby increases your baby's chances of dying from SIDS (Sudden Infant Death Syndrome) [by three times] or suffocation.
- 3. The safest place for a baby to sleep for the first 12 months is in a crib, bassinet, or play yard in the same room as a parent.
- 4. Room sharing is a safe and effective alternative to bed sharing.
- 5. Breastfeeding decreases the chance your baby will die of SIDS.
- 6. You can successfully breastfeed and practice safe infant sleep by room sharing, not bed sharing.

Are there any other statements/messages that you think would be important to include?

What other information about this topic would you like to have?

What questions do you have about this topic that you would like answered?

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 breastfeeding and safe infant sleep. An incentive of \$20 will be given to you as a thank you for your time and participation.