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Appendix E SB Focus Group Discussion Guide

INDIVIDUALS/CAREGIVERS OF INDIVIDUALS WITH SPINA BIFIDA FOCUS GROUP DISCUSSION GUIDE

Background and Moderator Introduction	10 minutes
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Hello and welcome to this discussion. It's great to see you all. My name is <NAME>. I am an independent researcher and moderator with KRC Research. The sole sponsor of today's focus group is the Centers for Disease Control and Prevention (CDC). However, no one from CDC will be observing today's focus group.

Thank you for your willingness to participate in this conversation and share your experiences. The findings will be used to help the CDC gain a better understanding of healthcare for individuals with spina bifida and the barriers that may exist in accessing needed care. You were selected to participate in this focus group because you identify as [someone] [a caregiver of someone] who has been diagnosed with spina bifida.

I am a professional researcher, but not a CDC employee or subject matter expert on health topics. My role is to facilitate our conversation for the next 90 minutes. Let me tell you a bit about it:

- There are no wrong answers. You may have different opinions. That's ok—all your experiences and opinions are important, and we want to hear from all of you.
- Since we are having these groups online, we will need to talk one at a time and let everyone have time to speak. Not everyone has to answer each question; however, it's important that everyone participates throughout this conversation.
- We will be showing you information on your screen to look at and respond to. If at any time you can't see the screen well or have difficulty hearing, let me know—we have a technician here who can help us with any technical issues.
- Please silence your cell phones and put away portable devices.
- If you need to step away from our discussion for any reason, you don't have to ask for my permission—just step away and come back as soon as you can.

Because privacy is important, I'm going to show you our Privacy Policy [SHOW ON SCREEN AND READ]

- We will protect your privacy for today's discussion, and nothing you say will be reported in association with your name.

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- We will use first names only during this conversation. You may choose to use a nickname or any other name you prefer.
- Your participation is voluntary—you do not have to answer anything you are uncomfortable with.
- Like our technician who is with us today virtually but who you do not see, a few colleagues are also with me virtually to watch quietly and take notes.
- We are digitally recording today's discussion for transcribing purposes. Because we are speaking with other groups similar to this one, it is important for me to have an accurate record of today's conversation.
- We ask that you not share any information, participants' comments, or participants' identities with others outside of this group.

Do you have any questions or concerns? [PAUSE FOR QUESTIONS].

Participant Introductions

5 minutes

Let's get started by going around and sharing:

- Your first or preferred name
- Where you live (state)
- Something fun you hope to do in the next few months

Experience with SB

10 minutes

To start, I'd like to hear about your current health. Please put your responses in the chat.

1. On a scale of 1 to 5 (with 5 being excellent and 1 being poor) how would you rate [your overall health] [the overall health of the person you care for] over the last week?
2. Thank you! As much as you feel comfortable speaking to it, could you share more on what's influencing the rating you gave to [your] [their] health?
 - a. How would you characterize [your] [your care recipient's] health status currently?
3. **INDIVIDUALS ONLY:** Could you share about when you understood you had spina bifida?
4. **CAREGIVERS ONLY:** Could you share about the time you learned that the person you care for has spina bifida?
5. What are words you would use to describe what having spina bifida means to [you] [the person you care for] and how it may impact how [you] [they] live and do things?

Healthcare Experience

10 minutes

Now, I'd like to talk about [your] [your care recipient's] healthcare experience.

6. [Do you] [Does the person you care for] have a primary care doctor?
 - a. How long has this person been [your] [their] doctor?

7. What key concerns or goals have you discussed with [your] [your care recipient's] healthcare team regarding spina bifida care?
 - a. Have your concerns been addressed by your healthcare team? If yes, in what way?
8. What has been your experience finding a clinic or doctor that understands [your] [your care recipient's] spina bifida?
 - a. What has been your experience receiving care for [your] [your care recipient's] spina bifida?
9. Can you share any experiences that you've had seeking care from healthcare providers or facilities for your [care recipient's] SB?

PROBES

- i. A good experience and a not so good experience
10. What has been your greatest challenge, if any, getting the care that [you need] [the person you care for needs] related to spina bifida?

PROBES

- i. Do you have challenges getting care due to:
 - a. Travel or distance, language barriers, (**CAREGIVERS ONLY**) childcare for other children, insurance coverage
 - b. Lack of knowledge of the condition by [your] [your care recipient's] doctor, lack of a specialist, hours of operations
 - ii. If insurance coverage, how has this played a role in how and where [you access] [the person you care for accesses] care? (Please describe.)

Healthcare Transition (SKIP for caregivers of children with SB)

10 minutes

The next part of our discussion will focus on healthcare transition. By healthcare transition, I mean going from pediatric to adult healthcare for spina bifida.

11. **INDIVIDUALS ONLY:** What kind of information, if any, did you receive during childhood or adolescence from your doctors or nurses about the need for specialized care throughout your life?
 - a. Did your family discuss with you the need for specialized care throughout your life? What did they say?
 - b. What happened as you transitioned to an adult? How did your care change, if it did?
 - c. What information, if any, has been most helpful?
12. **INDIVIDUALS ONLY:** For those of you who received spina bifida care as a child, when you became an adult, did you change to a place that sees adults for spina bifida?
 - a. When did that happen? What did that change look like?
 - b. How did the care change, if it did?
 - c. Have you changed the providers whom you regularly see as you've gotten older?
 - i. IF YES: How has that impacted your ability to address healthcare concerns?

13. **CAREGIVERS OF ADULTS ONLY:** What kind of information, if any, have you received from your care recipient's doctors or nurses about the need for specialized care throughout their life?
 - a. Have you discussed with the person you care for the need for specialized care throughout their life?
 - i. IF YES: Tell me about those conversations and what you discussed with them.
14. **CAREGIVERS OF ADULTS ONLY:** What role do you think caregivers/families play in preparing the people they care for to transition from pediatric to adult care for spina bifida?
 - a. What role do you think the individual with spina bifida should have in their healthcare transition?
 - b. What advice do you have for other caregivers/families? What do you wish you had known at the time?
 - c. What can be done for a smooth transition to adult care?
15. **BOTH INDIVIDUALS AND CAREGIVERS OF ADULTS:** What has been your experience finding a clinic or doctor that understands spina bifida care for adults?
 - a. What do you wish you would have done or learned before you had to navigate transition to adult care?

Healthcare Transition with Children (ONLY for caregivers of children with SB)

10 minutes

The next portion of our discussion will focus on healthcare transition, which refers to the transition from pediatric to adult healthcare for spina bifida.

16. What kind of information, if any, have you received from your care recipient's doctors or nurses about the need for specialized care throughout their life?
 - a. Have you discussed the need for specialized care throughout their life with the people you care for?
 - i. IF YES: Tell me about those conversations and what you discussed with them.
17. What role do you think caregivers/families play in preparing the people they care for to transition from pediatric to adult care for spina bifida?
 - a. What role do you think the individual with spina bifida should have in their healthcare transition?
 - b. What can be done for a smooth transition to adult care?
18. Have you made any plans to navigate the transition to adult care? What have you done?
 - a. If not, what might you do in the future?
 - b. If yes, has this impacted your current healthcare priorities?
19. Is there any information or resources that might support you in preparing the child you care for to transition to adult care?

Self-care and Self-management

20 minutes

Now, let's discuss [your] [your care recipient's] self-care and management of daily needs.

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20. Which family members or other people share the responsibilities for [your] [your care recipient's care]? How do they help?

PROBES

- i. *Who schedules [your] [your care recipient's] medical appointments?*
- ii. *What responsibilities related to [your] [your care recipient's] spina bifida do you wish [you] [they] could manage on [your] [their] own?*

21. To help [you] [the person you care for] better care for [yourself] [themselves], what do you wish family members/teachers/healthcare teams/employers would do differently?

Next, let's focus on skin health.

22. What do you know about skin injuries (e.g., pressure wound, burn, etc.) as it relates to having spina bifida?

PROBES

- i. *What kind of information have you received, if any, about [your] [your care recipient's] skin health?*
 - i. *Was the information written/oral?*
 - ii. *Did you understand the information and have opportunities to ask any follow-up questions?*
- ii. *Were you able to reach a healthcare professional if you were unclear on how to care for [your] [your care recipient's] skin injuries?*
- iii. *What information was provided when you followed up?*

Now, we'll focus on bladder and bowel management.

Please describe [your] [your care recipient's] experience with reaching [your] [their] bladder and bowel goals, and any difficulties you might have come across.

23. What kind of difficulties, if any, have you experienced that may have kept [you] [the person you care for] from achieving bladder and bowel goals?

PROBES

- i. *Incontinence, urgency to use bathroom, catheters, long trips, personal safety, transportation access, etc.*

24. How has bladder and bowel management changed through time for [you] [the person you care for] and what challenges specifically have you faced as [you've] [they've] gotten older?

25. At what age did [you] [the person you care for] begin to learn about care specific to bladder and bowel control?

26. Who from or where (family/caregiver, healthcare team, schools, etc.) did you get information about bladder and bowel control?

- a. *Was the information written/oral?*

27. Please describe how important it is for [you] [the person you care for] to stay completely clean (of stool) or fully dry (of urine)?

Information Sources

10 minutes

The next part of our discussion will focus on your information sources related to spina bifida.

28. Where do you learn about or get information about [your] [your care recipient's] spina bifida?

PROBES

- i. *What is your primary source of information on spina bifida?*
- ii. *What do you like about these sources of information? Is there anything you wish they did better?*
- iii. *How easy or difficult is it to ask your healthcare team questions about [your] [your care recipient's] healthcare / treatments / procedures?*

29. Do you talk [about having] [about the person you care for having] spina bifida with your family, friends, and teachers?
- a. In what situations does it come up?
 - b. What do you talk about?

Wrap Up

5 minutes

30. Is there anything you'd like to share that we haven't asked about in the focus group discussion around [your] [your care recipient's] spina bifida?

Thank you for your time!