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Appendix B SB FG Screening Tool

INDIVIDUALS/CAREGIVERS OF INDIVIDUALS WITH SPINA BIFIDA: Focus Group Participant Screener

NOTE: TEXT IN BOLD IS PROGRAMMING LANGUAGE WILL NOT BE VISIBLE TO PARTICIPANTS VIEWING THE SCREENER SURVEY

You indicated that you are interested in participating in a focus group held online using a tablet, laptop, or desktop computer. The sole sponsor of this activity is the Centers for Disease Control and Prevention (CDC).

To start, we will ask you a few questions about yourself. This information will not be associated with your name or other identifying information and will not be shared with CDC.

IF TERMINATED: Thank you for completing the screener. Based on your responses, we have determined that you are not eligible to participate in the focus groups. We greatly appreciate the time you took to complete these questions.

Demographic Information

This section is for basic demographic information about yourself.

1. What is your age?
 - a. [numeric entry field] **TERMINATE IF < 18**
2. What is your preferred language of communication? (Note that this will not affect your eligibility to participate in the focus group)
 - a. English
 - b. Spanish
 - c. Other (please specify): [text entry]
 - d. Prefer not to answer
3. Are you comfortable participating in a 90-minute focus group where the discussion will take place in English?
 - a. Yes
 - b. No **TERMINATE**

4. Have you been diagnosed with any of the following conditions? **RANDOMIZE**
 - a. Spina bifida **CODE AS INDIVIDUAL**
 - b. Muscular dystrophy
 - c. Down syndrome
 - d. Hemophilia
 - e. Cleft lip/palate
 - f. Tay-Sachs disease
 - g. Congenital heart defects
 - h. None of the above
5. **ASK IF NOT AN INDIVIDUAL WITH SB** Are you the primary caregiver for another person or child?
 - a. Yes
 - b. No **TERMINATE**
6. Has the person or child you care for been diagnosed with any of the following conditions?
RANDOMIZE, TERMINATE IF SB NOT SELECTED
 - a. Spina bifida **CONTINUE, CODE AS CAREGIVER**
 - b. Muscular dystrophy
 - c. Down syndrome
 - d. Hemophilia
 - e. Cleft lip/palate
 - f. Tay-Sachs disease
 - g. Congenital heart defects
 - h. None of the above
 - i. Not a caregiver

Healthcare (IF INDIVIDUAL)

The following questions will ask about spina bifida.

7. What type of spina bifida do you have?
 - a. Spina bifida occulta **TERMINATE**
 - b. Non-myelomeningocele (such as lipomyelomeningocele, meningocele, fatty filum, terminal myelocystocele, or split cord malformation)
 - c. Myelomeningocele
 - d. Don't know **TERMINATE**
8. Do you have a shunt?
 - a. Yes
 - b. No
 - c. Don't know
 - d. Other (please specify): [text entry]
9. What is your lesion level? The greatest level of voluntary movement is described in parentheses.
 - a. Thoracic (I can control the trunk of my body but not my legs)
 - b. High lumbar (I can control the trunk of my body and can move my thigh towards the trunk)

- of my body)
 - c. Mid lumbar (I can control the trunk of my body and can straighten my leg)
 - d. Low lumbar (I can control the trunk of my body, can straighten my leg, and can flex my foot)
 - e. Sacral (I can control the trunk of my body, can straighten my leg, can flex my foot, and can point my toes)
 - f. Don't know
 - g. Not applicable
 - h. Other (please specify): [text entry]
10. Do you need a device to help you get around when you leave the house, for example to go to the grocery store? (Select all that apply.)
- a. Crutches
 - b. Wheelchair
 - c. Braces
 - d. Walkers
 - e. Other (please specify): [text entry]
 - f. No aid(s) needed
11. At what age did you become fully independent in your bladder care?
- a. [numeric entry] years
 - a. I am not fully independent in bladder care.
 - b. I was fully independent, but things have changed, and I am no longer fully independent with bladder care.
 - c. I have had surgery that excludes my need for bladder care (for example, a urostomy or suprapubic tube).
 - d. Don't know
12. When was the last time you received healthcare for spina bifida?
- a. Less than 6 months ago
 - b. 6 to 11 months ago
 - c. 1 to 2 years ago
 - d. 3 to 5 years ago
 - e. More than 5 years ago
 - f. Never
 - g. Don't know or can't remember

Healthcare (IF CAREGIVER)

The following questions will ask about spina bifida. These questions refer to the person you care for, sometimes referred to as "your care recipient" or "they."

13. What type of spina bifida does the person you care for have?
- a. Spina bifida occulta **TERMINATE**
 - b. Non-myelomeningocele (such as lipomyelomeningocele, meningocele, fatty filum, terminal myelocystocele, or split cord malformation)

- c. Myelomeningocele
- d. Don't know **TERMINATE**

14. How old is the person you care for?

- a. 0-17 years
- b. Eighteen or older

15. Does the person you care for have a shunt?

- a. Yes
- b. No
- c. Don't know
- d. Other (please specify): [text entry]

16. What is your care recipient's] lesion level? The greatest level of voluntary movement is described in parentheses.

- a. Thoracic (I can control the trunk of my body but not my legs)
- b. High lumbar (I can control the trunk of my body and can move my thigh towards the trunk of my body)
- c. Mid lumbar (I can control the trunk of my body and can straighten my leg)
- d. Low lumbar (I can control the trunk of my body, can straighten my leg, and can flex my foot)
- e. Sacral (I can control the trunk of my body, can straighten my leg, can flex my foot, and can point my toes)
- f. Don't know
- g. Not applicable
- h. Other (please specify): [text entry]

17. Does your care recipient need a device to help them get around when they leave the house, for example to go to the grocery store? (Select all that apply.)

- a. Crutches
- b. Wheelchair
- c. Braces
- d. Walkers
- e. Other (please specify): [text entry]
- f. No aid(s) needed

18. At what age did your care recipient become fully independent in their bladder care?

- a. [numeric entry] years
- b. They are not fully independent in bladder care.
- c. They were fully independent, but things have changed, and they are no longer fully independent with bladder care.
- d. They have had surgery that excludes their need for bladder care (for example, a urostomy or suprapubic tube)
- e. Don't know

19. When did the person you care for last receive healthcare for spina bifida?

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- a. Less than 6 months ago
- b. 6 months to 11 months ago
- c. 1 to 2 years ago
- d. 3 to 5 years ago
- e. More than 5 years ago
- f. Never
- g. Don't know or can't remember

Additional Demographic information

20. What is your sex? **RECRUIT A MIX**

- a. Female
- b. Male

21. What is your ethnicity?

- a. Hispanic or Latino
- b. Not Hispanic or Latino

22. What is your race? (Select all that apply.) **RECRUIT A MIX**

- a. American Indian or Alaska Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or other Pacific Islander
- e. White

23A. **IF INDIVIDUAL:** Are you covered by health insurance or some other kind of health care plan?

- a. Yes
- b. No
- c. Don't know
- d. Prefer not to answer

23B. **IF CAREGIVER:** Is the person you care for covered by health insurance or some other kind of health care plan?

- a. Yes
- b. No
- c. Don't know
- d. Prefer not to answer

24A. **IF 23A = A** Which type of health insurance are you covered by? (Select all that apply.)

- a. Medicaid
- b. Medicare
- c. Private (employer, marketplace, individual)
- d. Military/TRICARE/VA
- e. Other (please specify): [text entry]
- f. Don't know
- g. Prefer not to answer

24B. **IF 23B = A** Which type of health insurance is your care recipient covered by? (Select all that apply.)

- a. Medicaid
- b. Medicare
- c. Private (employer, marketplace, individual)
- d. Military/TRICARE/VA
- e. Other (please specify): [text entry]
- f. Don't know
- g. Prefer not to answer

23. What state do you reside in?

- a. [Dropdown list of states] **RECODE INTO FOUR US REGIONS**

24. Which type of area do you live in? **RECRUIT A MIX**

- a. Rural
- b. Suburban
- c. Urban
- d. Prefer not to answer

25. Which of the following categories best describes your employment status? **RECRUIT A MIX**

- a. Employed, working full-time
- b. Employed, working part-time
- c. Not employed, looking for work
- d. Not employed, NOT looking for work
- e. Disabled, not able to work
- f. Student
- g. Retired
- h. Other (please specify): [text entry]
- i. Prefer not to answer

26. Including yourself, how many people living in your household are the following ages? **IF**

CAREGIVER: If you do not live in the same household as the person you care for, say so.

- a. There are [Numeric text field] people living in my household that are under the age of 18.
- b. There are [Numeric text field] people living in my household that are 18 years of age or older.
- c. I do not live in the same household as the person I care for.
- d. Prefer not to answer

27. Which of the following best describes your annual household income?

- a. Under \$15,000
- b. \$15,000 - \$24,999
- c. \$25,000 - \$34,999
- d. \$35,000 - \$49,999
- e. \$50,000 - \$74,999

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- f. \$75,000 - \$99,999
- g. \$100,000 - \$149,000
- h. \$150,000 or greater
- i. Don't know
- j. Prefer not to answer

28. What is the highest level of education you have completed? **RECRUIT A MIX**

- a. Less than high school diploma
- b. High school diploma or equivalent (e.g., GED)
- c. Some college but no degree
- d. Associate or 2-year degree
- e. Bachelor or 4-year degree
- f. Graduate degree (e.g., MS, PhD, JD, MD, etc.)
- g. Prefer not to answer

Focus group participation

29. Would you be interested in participating in a 90-minute virtual focus group discussion? You will receive \$75 as a token of appreciation for your participation, which will be provided to you after the completion of the focus group.

- a. Yes
- b. No **TERMINATE**

30. Thanks for completing the screener. Based on your responses, we have determined that you may be eligible to participate in the focus groups. If you are selected to participate, we will reach out via email to provide more information and determine your availability.

- a. Please enter your name. [text entry field]
- b. Please provide the best email address and phone number to reach you at if you are selected to participate in the focus group. [text entry field]
- c. What is the best phone number to reach you? [numeric entry field]

Thank you for completing this survey. We greatly appreciate the time you took to answer these questions.