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Appendix E FGD Guide

INDIVIDUALS/CAREGIVERS OF INDIVIDUALS WITH MUSCULAR DYSTROPHY: Focus Group Discussion Guide

Background and Moderator Introduction **10 minutes**

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 discussion 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 help the CDC gain a better understanding of the healthcare experiences of individuals with muscular dystrophy and the barriers that may exist in accessing needed care. You were selected to participate in this focus group discussion because you identify as [someone] [a caregiver of someone] who has been diagnosed with muscular dystrophy.

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]**

Appendix E FGD Guide

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

10 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

General Healthcare Experience

25 minutes

Let's begin by talking about your experiences with healthcare providers and specialists. I want to take this time to explain what we mean by that.

- Healthcare providers are anyone [you] [the person you care for] receive(s) healthcare from. This could include doctors, physician assistants, nurse practitioners, nurses, or others who work in healthcare settings.
- Specialists are healthcare providers who focus specifically on certain types of healthcare. For example, this could be a neurologist, pulmonologist, cardiologist, or physical therapist, or physician assistants or nurse practitioners who specialize in these areas.

Let's talk about the health care that [you receive] [the person you care for receives].

1. How often [do you] [does the person you care for] see a healthcare provider for general care, not related to MD?

- a. What typically prompts these visits?

PROBES

- i. *When sick, annual checkup, something else?*

2. When [you receive] [your care recipient receives] health care, where do [you] [they] usually go?

PROBES

- i. *Family doctor, clinic, urgent care, something else?*

3. Are there instances where [you] [the person you care for] would not see a general care practitioner? Tell me about that.

4. How do you currently manage [your] [your care recipient's] condition?

PROBES

- i. *Doctor visits, medicines, therapies, information gathering, other preventative measures and routines*

- a. How has this evolved since diagnosis?

5. Where [do you] [does the person you care for] currently receive care that specializes in muscular dystrophy?

PROBES

- i. *At a general practice facility, urgent care, hospital, at home, somewhere else?*

- a. How often [do you] [does the person you care for] receive care for muscular dystrophy?
- b. How far is the facility from your home?
- c. What do you like about where [you receive] [the person you care for receives] MD care?
- d. What would you change about the facility to make it better for [you] [the person you care for]?

6. What types of healthcare providers do [you] [does the person you care for] see to receive MD care? PROBE: neurologist, pulmonologist, cardiologist, physical therapist, occupational therapist

- a. Any other types of providers such as naturopaths, chiropractors, etc.?

7. What has been your experience with finding a clinic or doctor for [your] [the person you care for] MD?

8. [Have you] [Has the person you care for] always seen the same specialists or has that changed over time?

- a. If it's changed over time, what was the reason for the change in specialists?

9. Can you share any experiences that you've had seeking care from healthcare providers or facilities for your [care recipient's] MD? PROBE: a good experience and a not so good experience

Journey to Diagnosis

20 minutes

I'd like to shift a little to talking about [your diagnosis with MD] [the diagnosis of your care recipient with MD], specifically the [condition type].

10. At what age [were you] [was the person you care for] diagnosed with MD?

- a. Thinking back, what did you know about MD at the time of diagnosis?
- b. What questions did you have?
- c. How did you educate yourself on this diagnosis, if you did? PROBE: sources of information

11. What type of healthcare provider or facility provided [you] [your care recipient] with [your] [their] first diagnosis?

- a. Did they tell you what type of MD [you] [your care recipient] had at this time?
 - b. What did they tell you about it?
 - c. Did the healthcare provider or facility provide information or resources?
 - a) **IF YES:** What were they? Were they helpful?
 - d. How has your understanding of MD changed over time, if it has?
12. Has the type of MD that [you were] [your care recipient was] originally diagnosed with changed? That is, did a healthcare provider tell you that [you] [they] have a different or more specific type than the original diagnosis?
 - a. **IF YES:** what did the provider tell you about this?
 - b. What was the reasoning for the change in diagnosis?
 - c. What did the change in diagnosis mean for how you [manage your] [support their] care?
13. [Were you] [Was the person you care for] misdiagnosed with any other conditions prior to being diagnosed with MD?
 - a. If so, what conditions?
 - b. Take me through that process and the final diagnosis by the provider.
14. How long did [you] [the person you care for] have symptoms associated with MD prior to being diagnosed?
 - a. What were the symptoms?
 - b. How did you first begin to manage those symptoms?
 - c. When did you first begin to realize that there might be an issue?
15. **INDIVIDUAL:** What other information can you share about your experience getting diagnosed with MD?
CAREGIVER: What other information can you share about the diagnosis process from your experience caring for someone with MD?
 - a. Did you suspect that [you] [the person you care for] had MD before getting diagnosed?
 - b. If so, how long did you suspect this prior to diagnosis?

Barriers to Healthcare

15 minutes

Now we'd like to talk about barriers to healthcare.

16. What challenges, if any, have you experienced when accessing or receiving care [for your care recipient]?
PROBES
 - i. *travel, lack of transportation, or distance, language barriers, lack of knowledge of the condition by your doctor, lack of a specialist, hours of operations, insurance coverage*
 - ii. How have you attempted to overcome these challenges, if you have? What was the result?
17. Of these challenges discussed, what has been your greatest challenge, if any, in accessing or receiving the care that you need for [your] [your care recipient's] MD?

- a. What makes you say that?
18. If [you haven't] [your care recipient hasn't] received care in the past year, could you share the reasons for not receiving care?
- a. **FOR CAREGIVERS ONLY:** Have you tried to get care (for your care recipient), but couldn't?
 - i. If so, what are the reasons you weren't able to get care?
 - b. Can you describe any barriers you encountered related to getting care (for your household member) in the past?
19. Thinking about all of these different challenges, what would lessen these challenges?

Healthcare Transition

10 minutes

Now, I'd like to hear from you about your experiences preparing for and transitioning from childhood to adulthood care.

20. **INDIVIDUALS ONLY:** If you were diagnosed when you were young, 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 became an adult? How did your care change, if it did?
 - c. What information, if any, has been most helpful?
21. **INDIVIDUALS ONLY:** For those of you who received muscular dystrophy care as a child, when you became an adult, did you change to a place that sees adults for muscular dystrophy?
- 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 who you regularly see as you've gotten older?
 - i. **IF YES:** How has that impacted your ability to address healthcare concerns?
22. **CAREGIVERS ONLY:** What kind of information, if any, have you received from your household member's doctors or nurses about the need for specialized care throughout their life?
- a. Have you discussed with your household member the need for specialized care throughout their life?
 - i. **IF YES:** Tell me about those conversations and what you discussed with them.
23. **CAREGIVERS ONLY:** What role do you think caregivers/families play in preparing their household member to transition from pediatric to adult care for muscular dystrophy?
- a. What role do you think the individual with muscular dystrophy 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 do you think could help to improve the transition to adult care for individuals with MD and their caregivers/families?

24. **BOTH INDIVIDUALS AND CAREGIVERS** What has been your experience finding a clinic or doctor that understands muscular dystrophy care for adults?

a. What would have been helpful to you to navigate transition to adult care?

PROBES

i. *Certain types of information or resources, support/guidance from pediatric healthcare providers, feedback/support from other adults with MD*

Wrap Up

5 minutes

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

Thank you for your time!