

Attachment C1: Focus Group Moderator's Guide

Form Approved

OMB No. **0920-XXXX**

Exp. Date

__xx/xx/20xx__

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Background 5 minutes

I'd like to welcome you all and thank you for making time in your busy schedules to talk with us today.

I am _____ with Battelle Centers for Public Health Research and Evaluation. [Moderator background] My colleague _____ from Battelle is here to serve as the assistant moderator.

The Centers for Disease Control and Prevention (CDC) is very interested in learning about and better understanding the opinions of caregivers of children with spina bifida have about the need for care coordination and experiences with care coordination services provided in this clinic and other similar clinics around the country. By "care coordination" we mean some kind of planning and organization for the care that a person with spina bifida receives. You are participating in this group because [information about clinic specific recruitment e.g., you called a toll-free number on a flyer OR were asked to participate by clinic staff OR signed up to participate in this group].

In a moment, I will have each of you tell us a little bit about yourself and your experience with the clinic. Before I do that, I will give you some brief information about how we will conduct the discussion, which is called a focus group.

Our conversation today will include some specific questions for you to consider. We have a number of topics we would like to cover, and I would like you all to feel free to share your ideas. We value your time, and we'll keep things moving to be sure we end within our scheduled 2 hours. There are lots of topics that we could talk about for a long time, so please help us cover everything.

There are no right or wrong answers to these questions, just different points of view. Since each of you has had different experiences, we would like to hear from everyone. It's important that we hear the range of ideas, so please feel free to support or expand on each other's comments, or

to offer another point of view or discuss if your experience differs from or is similar to someone else's. All points of view are valued.

I have asked for our discussion to be recorded, and also for _ (co-moderator) _ to listen and take notes. Now, I'd like to give you some information on safeguards for the privacy of responses. During the session, we'll be using first names only. If anyone inadvertently mentions their last name, we will not transcribe it in the written notes. You may use a name other than your own or your child's if you would prefer.

We will be using an audiotape recorder. After the group, when the information on the audiotape is typed up, a number will be assigned to you instead of your name. We do not plan to use anyone's name in any written reports. Once the focus group session has been typed up and upon completing the data collection, the audiotape and the master list linking your name to the identification number will be destroyed.

No information you provide today will affect the care you receive at this clinic in any way. We plan to send only group information back to the clinic and CDC. It is important for you to know that you may decide not to answer any question that you do not wish to..

Finally, my role will be to ask questions and then listen. I won't be joining in the discussion, so please feel free to talk and respond to each other.

[Provide any site specific information (e.g., parking, bathrooms/water fountain location, entry/exit procedures, child care, food/beverage, etc.)]

First, though, do you have any questions before I ask you to introduce yourselves?

A. Introduction 5 minutes

A1. I'd like to go around the table to make introductions. Could you tell us your first name and the first name, age and gender of the child you bring to the clinic, and the length of time you have been coming to this clinic? Could I start with you?

B. Critical Components and Procedures of Care Coordination 25 minutes

I'd like to talk a little about how care coordination happens in this clinic. Again, by "care coordination" we mean some kind of planning and organization for the care that a person with spina bifida receives. Since children may need several types of clinical and support services it may help that these services are coordinated to best meet his or her needs.

B1. What types of services does your child receive at the clinic?

Probe for:

- Support groups
- Education
- Counseling
- Mental health – assessment, treatment, or referral
- Psychoeducational testing
- Medical assessments and multi-specialty care
- Bowel-related care
- Other medical care
- Referral services
- Funding services
- Medical equipment & supplies

B2. How are those services coordinated? (Specifically, we are interested in knowing to what extent and how do clinic staff help to coordinate the services that your child receives)?

Probes (if not heard):

- Who at the clinic helps to coordinate the services provided to your family? (Probe for care coordinator, case manager, nurse, physician, team of people?)

- How do you communicate with that person/group?
- How often do you work with that person/group?

B3. What types of services does your child receive outside of the clinic? We mean things like with schools, physical therapists, occupational therapists, recreation services, respite services, or counselors, for example.

B4. Does the clinic provide any care coordination with services received outside of the clinic? How does that happen?

Probe:

- Do you work with any other care coordinators (outside of the clinic) such as through the state or schools who help to coordinate the services your child receives?

B5. Thinking about all of the care coordination that your child needs, about what percentage of the care coordination do you do yourself?

C. Functions and Roles of Care Coordinators 20 minutes

I'd like to talk a bit about the [care coordinators previously mentioned] who help to coordinate the services your family receives.

C1. What do you see as the main functions (services) that [care coordinator] provides to your family?

Prompt respondents by reading list of care coordination functions:

- **Assessment:** Helping to assess the needs of the child you bring to the clinic
- **Planning:** Creating a plan of care for your child
- **Implementation:** Helping to provide care to your child such as through providing referrals to needed services
- **Communication:** Communicating with you and your family such as by providing education about spina bifida
- **Coordination:** Working directly with various providers about your child's needs and advocating for services
- **Monitoring:** Following up to ensure that services are provided and monitoring progress

C2. Are there any other services that [care coordinators] offer to help to coordinate for your child that you do not take advantage of? Are there any specific reasons why you do not use those services?

D. Plan of Care 5 minutes

D1. Does the child you bring to the clinic have a plan of care? (By "plan of care" we mean a comprehensive written document that describes the goals of the treatment services that your child receives and provides a plan for how to achieve those goals. The plan can include services your child receives both inside and outside of the clinic.)

- If yes
 - o How was that plan created?
 - o Who was involved?
 - o What type of information did you get about your child's plan of care?
 - o Do you talk with clinic staff about how the plan is going?

- o Do you keep a copy of the plan of care?
- If no
 - o Have staff at the clinic discussed creating a plan of care with you?
 - o (Other than a plan of care) What other written information do you get at the clinic about the care your child receives?

E. Satisfaction 5 minutes

E1. Overall, how satisfied are you with the way in which services your child receives are coordinated at this clinic? How satisfied are you with the way in which the clinic communicates with your child, you, and your family regarding care coordination?

Probe: How satisfied are you with the way the clinic coordinates the following types of services:

- specialist care
- community services
- external medical care providers
- schools/teachers
- mental health providers
- any other services your child receives

F. Barriers and Facilitators 20 minutes

F1. What types of things make it difficult for you to take advantage of care coordination services offered by the clinic?

Probes/For example:

- Time needed to access services (e.g., clinic hours, or amount of time needed to keep appointments)
- Financial/cost issues (e.g., reimbursement, need to pay for services)
- Information about services available
- Provider attitudes toward coordinating care
- Communication with clinic staff
- Eligibility requirements

F2. Are there any specific things you can think of that would make it easier for you to use these care coordination services?

F3. What are the things you think the clinic does well in helping to coordinate care for your child?

G. Transition 10 minutes

[Note: **only** ask this section for focus groups of caregivers of children aged 11-21 – otherwise, spend more time on previous section]

As your children get older, we are particularly interested in any services you may have received at the clinic related to planning for the transition to adulthood.

G1. Have you and your child participated in transition planning in any of the following areas:

G1a. Health-care to adult-centered care

- o primary care
- o specialist care

G1b. Independent living as appropriate to the abilities of your child

G1c. Financial/insurance

G1d. Education/vocation to life after high school

G2. [Specifically related to transition planning regarding education or vocation after high school] Does your child have a Transition plan as part of his or her Individualized Education Plan (IEP)?

If Yes:

- How was the plan developed?
- Who facilitated the plan with you?
- Is it in writing and do you have a copy?

H. Effectiveness and Recommendations 20 minutes

H1. Do you think care coordination services have made a difference for your child? An example of care coordination making a difference is that the child has been able to reach expectations set for him/her. If so, how? If not, what factors were barriers?

Do you think care coordination services have made a difference for you as a caregiver, or for your family? If so, how? If not, what factors were barriers?

H2. Do you have any recommendations about how the clinic could improve the way in which services for your child are coordinated to meet your needs and the needs of your family better?

Probe:

- Are there any services that you need that you think would be helpful for [care coordinators] to help you with?

I. Conclusion 5 minutes

We are almost at the end of our time. Your participation has been extremely valuable for us in helping to understand the care coordination services that are available and your opinions about those services.

I1. Before we end, do you have any thing else to add to our discussion?

Thank you for your participation. [Provide information regarding reimbursement, other site specific announcements.]