

## Attachment C13: Interview Guide, Care Coordinator

Form Approved

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### **A. *Introductory Questions***

A1. What is your position in this clinic? What are your responsibilities in relation to the spina bifida patients and their families who come to this clinic?

### **A2. How long have you been involved with this clinic?**

A3. How would you describe the spina bifida patient population that you interact with?

(e.g., age range, numbers served, race/ethnicity, SES)

### **A4. What types of services does this clinic provide to spina bifida patients?**

- Support groups
- Education
- Counseling
- Mental health
- Medical assessments (multi-specialty care)
  - o Probe for specific medical assessments routinely performed: (i.e., bladder/bowel continence, musculoskeletal, neurological, organ function, shunt, psychosocial development, sexual health, spine, etc.)
- Bowel-related care
- Other medical care
- Referral services
- Funding services
- Medical equipment and supplies

## **B. Care Coordination**

We would like to talk about how care is coordinated in this clinic.

B1. What are the goals of care coordination in this clinic? [What are the outcomes care coordination should achieve to be considered successful?]

Possible Probes:

- Developing plan for appropriate services
- Assistance in accessing needed services and resources (including medical supplies and prescriptions)
- Communication among multiple professionals
- Avoidance of duplication of services and costs
- Optimize physical and emotional health and well-being
- Improve child and family quality of life

B2. What do you consider the critical components of care coordination in this clinic? [For example, how is care coordination organized – team or single care coordinator?]

B3. How would you describe your roles and functions as care coordinator in this clinic?

*Probe for the following areas:*

- Assessment: Helping to assess the needs of the children brought to the clinic
- Planning: Creating a plan of care for each child
- Implementation: Helping to provide care to each child such as by providing referrals to services
- Communication: Communicating with families such as by providing education about spina bifida
- Coordination: Working directly with various providers about each child's needs and advocating for services
- Monitoring: Following up to ensure that services are provided and monitoring progress
- Evaluation: Helping to assess whether care coordination is working well in the clinic

B4. How do you develop a plan of care for each patient and his or her family?

Who is involved?

How is the plan of care communicated to the patients and families?

What is the process for implementing the plan of care?

How often is the plan of care reviewed or revised to meet the needs of the families?

How, and where, is the plan of care recorded?

B5. Can you walk us through all of the steps you would complete with a typical spina bifida patient? If possible, please include what you would do during the clinic and what activities you would do outside of clinic hours.

B6. For each patient, approximately what percentage of care coordination is provided by a) staff at this clinic, b) the patient's family, and c) other entities?

### **C. Transition**

I'd like to talk specifically about services you provide to help families plan for the transition of their children to adulthood...

C1. Do you have a formal process to plan for the transition of your patients from care in a pediatric setting to adult-centered care? How is the plan recorded and how is it managed?

### **C2. In what ways do you address transition in the following areas?**

- Linkage to providers
- Education/vocation
- Health care
- Independent living according to the abilities of the young adult
- Social participation
- Financial/insurance

### **D. Service Systems**

D1. What types of health and other service systems (outside of the clinic) do you interact with in your role as care coordinator? (e.g., with schools, community services, external medical care providers or allied health professionals)?

D2. How do you coordinate these other service systems for each patient and his or her family?

D3. What type of follow-up do you do to make sure patients and families are receiving the services they are referred to?

*Probe for feedback from families or service providers.*

### **E. Barriers and Facilitators**

E1. What would you say are the challenges to providing care coordination in this spina bifida clinic?

*Include challenges that have been overcome in offering care coordination and challenges that have not been overcome.*

Possible probes:

- Staff training
- Provider attitudes or beliefs regarding value of care coordination
- Reimbursement/cost issues
- Staff time
- Communication between care providers or different care systems
- Organization of systems of care
- Capacity to meet all needs of all patients

- Families' ability to take advantage of services offered.
- Ability to determine who is eligible for services.

E2. How have the challenges to providing care coordination been overcome in this clinic?

[Probes] For those challenges you say have not been overcome, what is it that keeps the clinic from being able to overcome them? What do you think it would take to be able to overcome those challenges?

E3. What benefits have you achieved from having a care coordination program in this clinic? (How effective has it been in reaching its goals?)

What aspects have worked best?

What aspects have not worked well?

E4. If you were giving advice to a spina bifida clinic that is considering introducing care coordination, what are the most important things they should consider?

E5. What about if a spina bifida clinic already has some level of care coordination, but wants to expand or improve it; what advice would you give them on how best to improve the service they offer?

## ***F. Closing Questions***

F1. Do you have any other ideas or recommendations for how best to offer care coordination in spina bifida clinics in general?

F2. Is there anything else you would like to tell us about care coordination services in this clinic (that we may have forgotten to ask)?

## **F3. Do you have any questions for us before we end the interview?**

Thank you very much for taking the time to discuss these issues with us. Your knowledge and perspective is very important to our study. If you have anything else you would like to tell us, or any questions for us, please feel free to contact us.