

## Attachment C12: Interview Guide, Clinic Director

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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 of this clinic?**

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

**A4. How often are spina bifida clinics held? How long is a routine clinic day?**

**A5. On a routine clinic day, about how many patients are seen at this clinic?**

**A6. What types of services does this clinic provide to spina bifida patients?**

- Support groups
- Education
- Counseling
- Mental health
- Medical assessments
  - 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

A7. 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?

A8. Is ancillary patient testing (radiology, lab, pathology) done at your facility?

Probe: Which types of testing are done at the facility, and which are referred to other facilities?

Probe: Is ancillary patient testing done on clinic day – or are patients required to have testing completed on some day prior to when they are seen at the clinic?

A9. What process does your clinic routinely use for visits with specialists? For example, do patients stay in one room and specialists come to each patient's room for the visit? Or does each specialist have an exam room within the clinic location and patients move from room to room to see each specialist?

A10. We would like to ask about who is responsible for different activities in the clinic. For example:

- Is there a team meeting either before or after clinics?
- Who organizes the appointments?
- Who gets the insurance approval?
- Who collates the information on patients (single person or team)?
- Who communicates with families between visits?

**A11. Which, if any, hospital or university does your program affiliate with?**

## ***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? [Why do you perform care coordination? 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
- 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 was the process followed for deciding which services to include in care coordination in this clinic?

*Probe for when care coordination was introduced, who was responsible, if there was a needs assessment or other study to determine needs.*

B3. 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?]

B4. How would you describe the roles and functions of the [care coordinator(s)] 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

## **B5. How is a plan of care developed?**

Who is involved?

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

What is the process for providing 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?

B6. What kind of feedback do you get from families on the services offered at this clinic (and how often)?

Probe: How does the clinic assess patient/family satisfaction with the services offered here?

## **B7. How is care coordination funded in this clinic?**

*Probe for the following:*

Federal or state government program funding?

Private insurance?

About what percentage of your patient-generated revenue is Medicaid supported?

About what percentage of your patient-generated revenue is Medicare supported?

B8. Over the past three years, has the amount of funding your program receives from sources other than patient-generated revenue increased, decreased, or stayed the same? Are there any threats to the amount of funding that your program receives from non-patient generated sources?

### **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) does the care coordinator interact with in the process of care coordination? (e.g., with schools, community services, external medical care providers or allied health professionals)?

D2. What is the process for coordinating these other service systems for each patient and his or her family?

D3. What type of follow-up is done to make sure patients and families are receiving the services they are referred to by the care coordinator?

*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 clinic?

*Include barriers that have been overcome in offering care coordination and barriers 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 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.