

Attachment C9: Clinic Recruitment Letter

[Date]

[Name]

[Address]

[Phone Number]

Dear [Name],

The Spina Bifida Association (SBA) and the Centers for Disease Control and Prevention (CDC) are interested in learning more about care coordination in spina bifida clinics. To accomplish this, we are inviting a limited number of spina bifida clinics to share their experiences with care coordination. The goals of this study are to examine the extent to which care coordination in spina bifida clinics is perceived as effective, identify perceived barriers to providing care coordination in spina bifida clinics, and identify potential best practices related to providing care coordination in spina bifida clinics. Your clinic has been selected to be invited to participate in this project.

The enclosed brochure provides information about this project and describes what your participation would involve. I will soon be contacting you by phone to personally invite your clinic to participate in this project.

This care coordination project builds on the SBA survey your clinic completed recently. Battelle will conduct the interviews and focus groups described in the enclosed brochure.

Thank you in advance for your interest in and assistance with this important project. We believe the information gained can be beneficial to providing optimal care for those we serve. If you have any questions or would like further information, please contact me at xxx-xxx-xxxx. I look forward to talking with you.

Sincerely,

Cindy Brownstein

CEO, SBA

Attachment C10: Clinic Recruitment Brochure

How will staff and patient privacy be protected?

The Institutional Review Board (IRB) at the Battelle Centers for Public Health Research and Evaluation has reviewed and approved the study protocol. If local IRB review is required by your institution, Battelle will assist with preparation of the IRB package.

All data will be in the form of written notes and audio recordings, and no notes or audio recordings will contain identifying information. All data will be summarized and will not identify any one individual. Staff will be interviewed in a private room.

What are the benefits to participating in this study?

These data will help to shape CDC's understanding of care coordination in spina bifida clinics. Sharing your opinions and your clinic's experiences with care coordination will provide CDC with information that may be used to help clinics, local organizations, and national organizations that serve persons with spina bifida.

How can I get more information about this study?

If you have any questions or concerns about this research, please do not hesitate to contact:

Jennifer Brustrom
Battelle Project Director
Battelle Centers for Public Health
Research and Evaluation
Telephone: 770.451.0882
Email: brustromj@battelle.org

or

Judy Thibadeau
CDC Project Coordinator
McKing Consulting Corporation
Division of Human Development and
Disability
National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and
Prevention (CDC)
Telephone: 404.498.3559
Email: jthibadeau@cdc.gov



The Spina Bifida Care Coordination Study

Who is conducting and funding this research?

This study is being conducted by Battelle Centers for Public Health Research and Evaluation, under contract to the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC), in collaboration with the Spina Bifida Association (SBA).

What are the goals of this study?

Your clinic has been invited to participate in a study to (1) examine the extent to which care coordination in spina bifida clinics is perceived as effective, (2) identify perceived barriers to providing care coordination in spina bifida clinics, and (3) identify potential best practices related to providing care coordination in spina bifida clinics.

CPHRE
Centers for Public Health Research and Evaluation

Battelle

What is care coordination? Why is it important for spina bifida patients and families?

The American Academy of Pediatrics defines care coordination as "a process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health". Care coordination occurs when care plans are implemented by a variety of service providers and programs in an organized fashion.¹

Spina bifida is a complex disorder that affects almost all aspects of an individual's life, entails the care of multiple specialists, and involves significant navigation of complex systems of care. The affected child and the family will face many medical and non-medical issues. An individualized assessment and care plan may help to address each person's unique needs. Potential benefits of care coordination include greater patient and family satisfaction with care and better outcomes for the patient.

¹ American Academy of Pediatrics. Care coordination in the medical home: integrating special and related systems of care for children with special health care needs. *Pediatrics* 2005 Nov; 116(5): 1239-44.

How was this clinic selected?

This clinic, one of ten from a national sample, has been invited to participate in this study because it provides care coordination services, based on responses to a recent SBA program survey. The site selection plan also emphasized diversity in clinic characteristics, such as geographic region, population served, and services available.

How will information about care coordination in this clinic be gathered?

Battelle site visit teams will visit the clinic and conduct individual interviews with clinic staff and focus group discussions with caregivers of clinic patients with spina bifida. Questions will cover areas such as the (1) goals of care coordination, (2) the critical components and procedures of this function, (3) the role of care coordinator(s), and (4) family and clinic staff satisfaction with services. These data will be analyzed and summarized in a case study report for this clinic as well as a report that includes data from all ten participating clinics.

Is this study an evaluation of our clinic's care coordination efforts?

No, this is not an evaluation. This is a descriptive study that aims to identify both best practices and barriers to implementation of care coordination. We are interested in your opinions about what works and what does not work, and why or why not. The report prepared, based on our findings, will document clinic and family recommendations for developing, expanding, and/or improving care coordination systems in the spina bifida care environment. No individual clinics or care providers will be identified in the report.

What does participation in this study entail?

Clinics agreeing to participate will (1) assist Battelle in publicizing the study among clinic staff, (2) recommend key staff to be interviewed in order to collect data that will paint a detailed picture of the care coordination function in the clinic, and (3) assist Battelle in recruiting focus group participants. Staff who agree to be interviewed will participate in a 30 to 60-minute individual interview. Approximately five individual interviews with staff and one focus group discussion, with eight to ten caregivers, will be conducted at this clinic.

