SPINA BIFIDA ASSOCIATION®

How to Get What you Need to Become a Spina Bifida Clinic Care Partner

Introduction to SB Care Partner Standards

The practices and processes that yield the best outcomes for people living with SB based on

- Experiences of other like conditions
- What our adults and families report
- Documentation in the literature

Standard One

Program Delivers care to patients using the Guidelines for the Care of People with Spina Bifida (Guidelines).

S.1 Rationale

The *Guidelines*, 2018, provides directions for assessments and interventions using a rigorously-based process to identify the best available research including expert consensus.

Documentation

Provide written examples that describe how the Guidelines are being used.	Example: Describe how practices have changed in your clinic based on use of the Guidelines; include strategies to implement; identify gaps in ability to implement at this time; indicate N/A if it doesn't apply in your setting.

Standard Two

The clinic must have a medical director from the medical or surgical disciplines. If the medical director has a surgical background (e.g. neurosurgery or urology), the clinic must demonstrate partnership with a provider from physiatry or medicine (general pediatrics, developmental pediatrics, internal medicine, internal medicine/pediatrics, or family medicine) to ensure comprehensive needs are met.

S.2 Rationale

These specialties are trained to look at the whole person without concentration on singular body systems. They look at the overall health of a patient, including physical, behavior, and mental health issues. When these specialties are part of the care team, issues of the whole person can be addressed.

Documentation	
Documentation: Provide the CV of the Medical Director.	Example: Attach the Medical Director's Curriculum Vitae. If the Medical Director is a surgeon, describe the clinic's relationship with a provider from physiatry, or medicine and provide the CV of this person.

Standard Three

The clinic must have a clinical care team that consists of, at a minimum, the Medical Director and nurse or nurse practitioner.

S.3 Rationale

While the multidisciplinary model has long been recommended as necessary to satisfactorily meet the clinical needs of the population with SB, there is little evidence to support this. Therefore, the described clinic care team that is experienced in the care of people with SB, may serve to provide basic care provision when including the other standards referenced in this document.

S.3

Documentation

Documentation: Provide written description of the Spina Bifida Clinic Care Team, including their names and credentials.	Example: Provide names of key personnel, their roles and contact info

Standard Four

The Clinic Care Team collaborates with identified orthopedic surgeons, neurosurgeons, urologists, neuropsychologists, physical and/or occupational therapists, nephrologists, gastroenterologists, dietitians, psychologists, wound care specialists, and others who have expertise and interest in comprehensively treating people with SB using the ***Guidelines***.

S.4 Rationale

"Individuals with SB need access to multiple specialists, generalists who can address health promotion, and an integrated system to deliver this complex care and to align and inform all the diverse providers…" (Liptak)

S.4

Documentation

Documentation: Provide the names of the specialists listed in Standard 4 and a written description of how they can be accessed when needed if they are not included in the clinical care team described in Standard 3. Describe how these members of the care team have been exposed to the ***Guidelines***.	Example: Attach a list of the specialists who are regular members of the SB Clinical Team and who must be accessed by referral.. Include their names and credentials. Detail the methodology used to inform each team member of the ***Guidelines***.

Standard Five

Care is coordinated and integrated for each patient, through designated personnel available five days per week, during normal business hours. In some practices, care coordination is shared among several staff. However, there should be a point person for coordinating care. Coordination of care includes, but is not limited to:

- Communication among providers of care, including the primary care physician, so that care planned and executed between the providers and the patient/family is integrated.
- Creation of a written plan of care between the person with SB/their family, and the healthcare team.
- Follow-up on medical testing – scheduling tests, obtaining results, communicating results to the provider, and other relevant steps.

Standard Five

Care is coordinated and integrated for each patient, through designated personnel available five days per week, during normal business hours. In some practices, care coordination is shared among several staff. However, there should be a point person for coordinating care. Coordination of care includes, but is not limited to:

- Triage of patient calls.
- Plan (within 2 years) for interprofessional training with a Care Coordination Curriculum so that all members of the care team—including the patient and family—understand the importance of care coordination and why it is not the same as care provision. (National Center on Care Coordination Technical Assistance, Care Coordination Curriculum)
- Incorporation of performance measures of care coordination and care integration.
- Development of a mechanism to receive and address urgent and emergency calls and care during non-business hours.

S. 5 Rationale

The ***Guidelines*** recommends the following for an effective and efficient care model:

- Access to integrated services and resources;
- Linked services and systems with the family and/or caregiver;
- Avoidance of duplicative and unnecessary costs; and
- Development of a mechanism to receive and address urgent and emergency calls and care during non-business hours.

S.5

Documentation

Documentation: Provide written evidence of Care Coordination process/policy, who is responsible for the process, plan for interprofessional training with a Care Coordination Curriculum, and performance measures currently used or to be implemented.	Example: In addition to the written Care Coordination policy or process, and the responsible person, describe the training this person received or will receive within the next two years, about Care Coordination. Describe performance measures used to indicate success in coordination of care such as the number of patients with whom a care plan has been shared and the frequency that this is accomplished.

Standard Six

The clinic engages in an activity that either promotes knowledge about the care of people with SB, or promotes the improvement of the care of people with SB, or both.

S.6 Rationale

SBA supports efforts to improve the care and outcomes for people living with SB. SBA does this by supporting clinical research in SB, and QI efforts in SB clinics to identify opportunities for improvement in care processes and interventions.

S.6

Documentation

Documentation: Provide written evidence and aim of the QI project or the hypothesis and timeline of the research project. The evidence must include the team members responsible and the reporting plan.	Example: Provide title of the research project including aim, hypothesis, timeline, and responsible people; for a QI project, provide improvement goals, timeline, and persons responsible. Include a summary that includes the team members and the plan to evaluate and report the findings. Note: participation in the NSBPR isn't sufficient. It must be a specific QI or Research project.

Standard Seven

If the clinic serves newborns, the clinic has, or will establish within one year of this application, a formal relationship with programs where prenatal diagnosis is made. The relationship will include opportunities for families to consult with professionals who provide long-term care to people with SB.

S.7 Rationale

SBA supports efforts to improve the care and outcomes for people living with SB. When a family is told that their unborn child has SB, it is important that they receive accurate and timely information by those involved in the care of people with SB. This includes prenatal options and what to expect postnatally. This message should include the identification of SB clinics that are associated with SBA.

S.7

Documentation

Documentation: Provide a description of the relationship with the department that provides prenatal diagnosis of SB, existing, or to be developed, to provide counseling and information to families who have received a diagnosis of SB in their unborn child. The documentation must include the team member(s) responsible for this activity.	Example: Provide a written process of how the delivering of the diagnosis occurs or will be developed. Include in the process the names and credentials of the team members responsible and the information used to inform parents of post-natal clinics to treat people with SB. If NA, please document why.

Standard Eight

The clinic agrees to create a Patient Advisory Committee including patients and their families and convene it within one year of this application. The Patient Advisory Committee will meet regularly with support of the clinic and will advise the clinic of patient/family experiences and improvement opportunities. The Patient Advisory Committee should represent ethnic diversity, geographic distribution and treatment modalities.

S.8 Rationale

SBA advocates for patient-centered care, the practice of caring for patients and their families in ways that are meaningful and valuable to the individual. Patient-centered care is respectful and responsive to individual patient preferences, needs, and values and ensuring that patient values guide team functioning.

S.8

Documentation

Documentation: Provide written evidence of the plan to establish a Patient Advisory Committee, including the timeline for implementation, membership criteria, responsible person(s), and how the Committee will function.	Example: Provide a written plan including when the SB specific Patient Advisory Committee will begin, who will staff it, the Committee responsibilities, and operating procedures, including selection requirements, length of term, and officer positions, that the Committee will follow. Define the role of the clinic in the committee.

Standard Nine

The clinic's program for transition preparation and execution is documented within one year of this application.

S. 9 Rationale

The ***Guidelines*** describes key elements of transition of an individual from the pediatric system of care to that for adults, as follows:

- Coordination of transition to adult-oriented care;
- Flexibility regarding timing of transition based on the individual, i.e., development and health status;
- Beginning transition activities at 12-14 years of age including development of a medical summary, exploration of insurance issues, and the identification of adult healthcare providers; and
- Family-centered and coordinated activities.

S.9

Documentation

Documentation: Provide written evidence of a transition policy and process including timeline to implement.	Example: Provide a written transition policy that **considers** the six components of Got Transition and a plan to implement the policy that includes a starting date, parties responsible, evaluation and reporting plan.

Standard Ten

The SBCCN works to improve the lives of people living with SB. This network includes people with SB, clinics, healthcare professionals, SBA Chapters, and SBA. The clinic must have an active relationship with SBA. The clinic exemplifies this relationship through two of the following means:

- Using specific SBA resources and connecting patients to the resources.
- Providing a speaker for at least one SBA program.
- Participating on an SBA committee or task force.

Standard Ten

The SBCCN works to improve the lives of people living with SB. This network includes people with SB, clinics, healthcare professionals, SBA Chapters, and SBA. The clinic must have an active relationship with SBA. The clinic exemplifies this relationship through two of the following means:

- Participating in SBA activities such as: Walk-N-Roll for Spina Bifida, Teal on the Hill, Awareness Month, Education Days, World Congress on Spina Bifida Research and Care, and Clinical Care Meeting.
- Joining SBA's listserv for SB healthcare professionals.

S.10 Rationale

Having an active relationship with SBA and supporting SBA events strengthens the infrastructure that supports those with SB.

S.10

Documentation

Documentation: Provide written example of participation in two activities a year from the above list.	Example: For each of the years, 2018-2019, list at least two specific examples of relationship with SBA.


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