2024 SPINA BIFIDA ASSOCIATION
CLINIC CARE PARTNER STANDARDS

Spina Bifida Association (SBA) Clinic Care Partners (CCP) form a network of clinics that works to improve care and outcomes for people living with Spina Bifida (SB). Member clinics are identified and recognized for providing services that positively impact the health of people with SB.

PHILOSOPHY OF SBA CLINIC CARE PARTNERS

SBA's vision is for people with SB to have access to knowledgeable and experienced health care professionals who are connected to and collaborate with SBA and/or its Chapters. This collaboration ensures the provision of care, support, information, and resources needed by people with SB to optimize their health and quality of life.

SBA believes that the critical factors that best support care and outcomes for people with SB include:

1. The best available evidence-based care.
2. A medical director and a team of care providers who advocate within their local medical care system for the needs of people with SB.
3. Care coordination and good communication between subspecialty and primary care providers and community agencies.
4. Linkages with other providers through SBA to provide support, resources, advocacy, and collaborative learning.
5. Care which is holistic and incorporates individuals with SB and their families as partners.
6. Providers who engage in research and/or quality improvement (QI) initiatives to actively improve knowledge and care.
7. Care which seeks to effectively provide transition to adult care and care throughout the lifespan.

GOALS OF SBA CLINIC CARE PARTNERS NETWORK:

1. Connect people affected by SB with each other and with needed information and resources.
2. Link health care providers to an established network of partner clinics.
3. Increase access to patient-centered SB care through the network.
4. Encourage increased collaboration between health care providers and the SBA to better serve people with SB with programs, services, and resources.

REQUIREMENTS FOR SBA CLINIC CARE PARTNERS

STANDARD 1

Program delivers care to patients using the ***Guidelines for the Care of People with Spina Bifida.***

Rationale: ***The Guidelines for the Care of People with Spina Bifida***, both the 2018 version and more recent updates, provide 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 for the Care of People with Spina Bifida* are being used, including plans for expanded use.

STANDARD 2

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 that the comprehensive needs of the patient are met.

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, behavioral, and mental health. When these specialties are part of the care team, issues of the whole person can be addressed.

Documentation: Provide the CV of the Medical Director.

STANDARD 3

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

Rationale: While the multidisciplinary model has long been recommended as necessary to satisfactorily meet the clinical needs of individuals with SB, there is little evidence to support this. Therefore, the clinical care team described above that is experienced in the care of people with SB will provide care according to the standards referenced in this document.

Documentation: Provide written description of the Spina Bifida Clinical Care Team, including their names and credentials.

STANDARD 4

The Clinic Care Team collaborates with identified orthopedic surgeons, neurosurgeons, urologists, neuropsychologists, physical and/or occupational therapists, and, when necessary, nephrologists, gastroenterologists, and dietitians who have expertise and interest in comprehensively treating people with SB using the ***Guidelines for the Care of People with Spina Bifida***.

Rationale: "Individuals with SB need access to multiple specialists and 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)

Documentation: Provide written description of how the specialists listed in STANDARD 4 can be accessed when needed.

STANDARD 5

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. If more than one person is named as a Care Coordinator, please describe the roles of each person. 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.

- Triage of patient calls.
- Plan 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.
- 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.

Rationale: The ***Guidelines for the Care of People with Spina Bifida*** recommend 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
- advocacy for improved individual outcomes.

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 to be/ or are implemented.

STANDARD 6

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

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 programs to identify opportunities for improvement in care processes and interventions.

Documentation: Provide written evidence and aim of current QI project(s) or the hypothesis and timeline of a research project. Provide reports related to most recent QI or research projects. The evidence must include the team members responsible and the reporting plan.

STANDARD 7

If the clinic serves newborns, within one year of this application if a new application, the clinic has or will be working to establish, a relationship with the department where SB diagnoses are made. The relationship will include consultation with the family receiving the diagnosis in a standardized way, e.g., using SBA's *Diagnosis to Birth + 3 Months* information in development.

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.

Documentation: Provide a description of the program, existing or to be developed, to provide counseling and information to families who have received a diagnosis of SB in their unborn child. Include the team members responsible for this activity as well as the information used, preferably *SBA's Diagnosis to Birth + 3 Months Care Plan* when developed.

STANDARD 8

The clinic agrees to create a Patient/Family Advisory Committee (PFAC) which includes patients with SB and their families, and convene it within one year of this application, if a newly established partnership. The PFAC will meet regularly with support of clinic staff, and will advise the clinic of patient/family experiences and improvement opportunities. Members of the PFAC should represent ethnic diversity, geographic distribution and treatment modalities.

Rationale: SBA advocates for patient-centered care, which is 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.

Documentation: Provide written evidence of the plan to establish a Spina Bifida Patient/Family Advisory Committee (PFAC), including the timeline for implementation, membership criteria, responsible person(s), and how the

Committee will function. If this application is a partnership renewal, please provide a report of the status of the functioning PFAC.

STANDARD 9

The clinic’s program for transition preparation and execution is documented within one year of this application if a newly established partnership.

Rationale: The ***Guidelines for the Care of People with Spina Bifida*** 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.

Documentation: Provide written evidence of a transition policy and process, including a timeline to implement it if a newly established partnership. Ensure that the identification of primary and subspecialty adult providers are included in your plan.

Standard 10

The clinic will establish a bowel management program informed by SBA’s Lifespan Bowel Management Protocol (LBMP), and will designate staff to oversee its implementation.

Rationale: Bowel incontinence is one of the most impactful issues for people living with SB. Thus, it is critical to address this condition with the families of young children and manage a plan frequently and throughout life.

Documentation: Provide written evidence of your plan to implement the LBMP within one year of this application and the person(s) responsible, including:

- If you have already implemented the LBMP, how do you plan to practice it more fully in the future?
- How has your practice changed based on the LBMP?
- What are your strategies to implement the LBMP?

- Identify gaps in your ability to implement all of the LBMP at this time.

Standard 11

Patient care is informed by comprehensive evaluation of the patient’s individual cognitive strengths and weaknesses (e.g., memory, executive functioning, visuospatial processing, speed of processing, etc.). Provider knowledge of the patient’s unique cognitive strengths and weaknesses informs intervention, patient education, and transition planning.

- It is recommended that individuals with SB undergo neuropsychological evaluation at least once before age 17, with consideration of neuropsychological evaluation at other key transition periods as well (e.g., kindergarten, fourth grade, middle school, etc.).
- Ideally, neuropsychological testing report(s) should be reviewed by the SB care team and used to inform care. The clinic should also have a consultative relationship with a neuropsychologist familiar with SB who can support the integration of the findings into the provision of care.

Rationale: Hospital safety standards require documentation of how patients best learn information. This is essential to support the participation of the patient in their own medical care, the development of independence, and successful transfer to adult care.

Documentation: Provide written documentation of how the collaborating neuropsychologist(s) can be accessed when needed. In the absence of a consultative relationship, document how the clinic team will access the findings from the evaluation(s), share the information with the team, and use it to inform care.

STANDARD 12

The Spina Bifida Collaborative Care Network (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 relevant resources developed by SBA and connecting patients to these resources.
- Providing a speaker for at least one SBA educational program.
- Participating on a committee or task force of the SBA.

- Participating in SBA activities such as: Walk-N-Roll for Spina Bifida, Teal on the Hill, Awareness Month, Education Events World Congress on Spina Bifida Research and Care, and Clinical Care Meeting.
- Joining and participating in both of SBA's listservs: SB Researchers and Health Care Professionals, and SBA Clinic Care Partners.

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

Documentation: Provide written example of participation in two activities a year from the above list.

APPLICATION PROCESS

New and updated designations are determined by a consensus of the SBA Professional Advisory Council. The process to become a recognized SBA Clinic Care Partner consists of:

1. Completing and submitting an application with appropriate documentation.
2. This designation is in effect for five years.

Thank you for your interest and efforts to apply for a Spina Bifida Association Clinic Care Partner designation!