

## Spina Bifida Guideline

# Care coordination guidelines for the care of people with spina bifida

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**Abstract.** Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a person's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities. It is often managed by the exchange of information among participants responsible for different aspects of care [1]. With an estimated 85% of individuals with Spina Bifida (SB) surviving to adulthood, SB specific care coordination guidelines are warranted. Care coordination (also described as case management services) is a process that links them to services and resources in a coordinated effort to maximize their potential by providing optimal health care. However, care can be complicated due to the medical complexities of the condition and the need for multidisciplinary care, as well as economic and sociocultural barriers. It is often a shared responsibility by the multidisciplinary Spina Bifida team [2]. For this reason, the Spina Bifida Care Coordinator has the primary responsibility for overseeing the overall treatment plan for the individual with Spina Bifida [3]. Care coordination includes communication with the primary care provider in a patient's medical home. This article discusses the Spina Bifida Care Coordination Guideline from the 2018 Spina Bifida Association's Fourth Edition of the Guidelines for the Care of People with Spina Bifida and explores care coordination goals for different age groups as well as further research topics in SB care coordination.

Keywords: Spina Bifida, myelomeningocele, care coordination, multidisciplinary care, case management neural tube defects

## 1. Introduction

Spina bifida or myelomeningocele (MM) is the most common permanently disabling condition in the United

States [22] and one of the most complex birth defects compatible with life [23]. Over the past 50 years, advances in medicine have resulted in increased survival of children with Spina Bifida [7]. Many of these people, now adults, require long-term coordinated services from a variety of health care professionals and organizations. Great variability exists among programs with services for people with Spina Bifida and their families. During the past 10 to 20 years, they have had greater access to

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care coordination, in part due to systems of care consisting of a variety of organizations and agencies that include independent health care professionals and third-party payers, often with different missions. However, despite increased access in some areas, not all receive appropriate care coordination services, especially as they transition from pediatric to adult care [31]. This article discusses the Spina Bifida Care Coordination Guidelines from the 2018 Spina Bifida Association's Fourth Edition of the Guidelines for the Care of People with Spina Bifida and explores best practice care coordination goals for different age groups as well as further research topics in SB care coordination.

Care coordination is an essential part of the multidisciplinary Spina Bifida care team and vital to improving health care and wellness outcomes. It is recommended, if possible, that Spina Bifida care programs dedicate the necessary financial resources and fund sufficient full-time equivalent staff so that optimal care coordination can be provided by designated, trained, and paid health care professionals. This article in addition to the Spina Bifida Care Coordination Guidelines will also discuss some techniques for measuring the benefits of care coordination activities to patients, and the justification for resource use.

A pediatric medical home is a family-centered partnership within a community-based system that provides uninterrupted care with appropriate payment to support and sustain optimal health outcomes [6]. In their important role of providing a medical home for people with Spina Bifida, primary care providers also have a vital role in the process of care coordination. In concert with the family and the Spina Bifida team [2,4], care coordination includes communication with the primary care provider in a patient's medical home [2,4,5].

There are very few database studies that demonstrate the benefits of Spina Bifida care coordination programs. Adequate research in SB care coordination would hopefully provide evidence of improved health outcomes, decreased morbidity and mortality, higher quality of life, improved success and independence in adulthood and decreased cost of care for people with Spina Bifida. More research needs to be completed to compile scientific evidence of the effectiveness of care coordination programs to develop a best-practices model of care coordination.

## 2. Spina bifida care coordination goals and outcomes

The goals of care coordination are the following:

- Gain access to and integrate patient care services and resources
- Link service systems with the family
- Avoid duplication of services and unnecessary cost
- Advocate for improved individual outcomes

### *Primary Outcomes*

1. Maximize the overall health and functioning of individuals living with Spina Bifida throughout the lifespan by improved access to team-based, patient- and family-centered coordinated care for medical, social, educational, equipment needs, and other developmentally relevant services.

### *Secondary Outcomes*

1. Promote comprehensive, coordinated and uninterrupted access to medical, subspecialty, and allied health professional services throughout the lifespan with appropriate communication between the person with Spina Bifida and members of their care team [8].
2. Promote routine screenings and testing congruent with Spina Bifida guidelines for specific secondary conditions.

### *Tertiary Outcomes*

1. Maintain up-to-date coordinated care for individuals living with Spina Bifida to minimize medical complication rates, help control cost of care, and minimize emergency room use and unanticipated hospitalization, morbidity, and mortality [9].

## 3. Methods

The Care Coordination Guideline for persons living with Spina Bifida across the life span was developed using a combination of literature review and consensus building methodologies [24]. In Phase 1 of the process, clinician and researcher participants were recruited from SBA's Professional Advisory Council (PAC), through SBA's contacts with prominent clinicians and scientists in the field and/or from participants in the Spina Bifida World Congress on Research and Care international meetings. A multidisciplinary working group was formed that included, advanced practice Spina Bifida nurse care coordinators, Spina Bifida clinic administrators and physicians. This group via its chair reported to the Spina Bifida Health Care Guideline Steering Committee who in turn reported to the Spina Bifida Association Medical Director. Members of the Care Coordination working group agreed upon primary, secondary and tertiary outcomes, defined

as the ideal end-result of best practices care coordination. The working group then devised a list of “clinical questions” that, if answered through evidence-based research, would provide guidance on how best to provide care coordination for people with Spina Bifida and achieve best outcomes. In addition, feedback was given and the vetting of the clinical questions was performed by adults with Spina Bifida along with parents of children with Spina Bifida recruited by the SBA and its chapters [24].

Phase 2 of the Care Coordination Guidelines development included an extensive literature review. Databases searched included Medline, PubMed, Web of Science, Cochrane Library, CDC library, PsycInfo, JSTOR, Google Scholar, CINAHL, and ProQuest. The articles that met inclusion criteria and were most relevant to the care coordination topic and clinical questions were forwarded to all working group members for review [24].

Phase III of care coordination guidelines development began with the working group drafting the guidelines using a pre-defined template containing five sections (Introduction, Outcomes, Clinical Questions, Guidelines, and Research Gaps). The introduction summarized the importance of the topic and listed outcomes and clinical questions. Also, a list of recommendations and guidelines for care was developed, based on the clinical questions that were answered by the literature or clinical consensus of experts. Finally, research gaps which were clinical questions that were not answered well by the literature or clinical consensus were identified. The consensus building methodology has been outlined previously in the methodology manuscript by Dicianno [24].

The SB Care Coordination Guidelines were presented by the working group chair at a face-to-face meeting of all guideline professional participants on March 15, 2017. The Nominal Group Technique (NGT) was used to solicit constructive feedback from participants. This technique has been used in the development of guidelines for the care of individuals with other conditions and allows for expert opinion to be included for aspects of care for which medical evidence does not exist or is not robust. The Care Coordination Guidelines was reviewed by six experts in the field for consistency, redundancy, disability-sensitive language, and clarity. It was also reviewed by the SBA Steering Committee chairs for actionable and concise language, use of consistent semantics and ICF terminology, and sufficient justification with clinical consensus or references. Suggested edits were sent back to the working group for

revision and then sent back to SBA for final proofreading and copyediting by SBA staff and SBA’s Medical Director prior to publication on the SBA web site:

Spina Bifida Association. Guidelines for the care of people with spina bifida. 2018. <https://www.spinabifidaassociation.org/guidelines/>.

#### 4. Results

The clinical questions that led to the specific care coordination guidelines are organized by age group, reflecting the changing nature of care coordination goals over time as a person with spina bifida ages. The early age group clinical questions (Table 1) often focus on communication about organizing multidisciplinary care to optimize outcomes, minimize medical complications, and help the family cope with the new diagnosis, including during the prenatal period. As the child ages, the clinical questions become more focused toward care coordination goals of adult independence, and transitioning care to adult providers. For all age groups, there are clinical questions related to the barriers that exist for effective care coordination, and what aspects of care coordination families and individuals find most helpful.

The specific Spina Bifida care coordination guidelines (Table 2) evolve as the child with Spina Bifida ages. Starting in the NICU, the early age group care coordination guidelines focus on family education about the condition of Spina Bifida and coping with the new diagnosis. In addition, efforts focus on coordination of the multiple surgical subspecialty care services needed including orthopedics, urology and neurosurgery. As the child ages through the toddler and preschool years, it is recommended that the care coordinator monitor the availability and progress of early intervention services such as PT, OT and speech. Ideally, the care coordinator is also involved with the IEP (Individual Educational Plan 504 plan) process and transition to school. This process continues as the child progresses through primary and secondary school. The care coordinator monitors the progress through school and helps to assist families when problems with school functioning occur. When necessary, this includes engagement with teachers, school principals, administration, and nursing staff.

The promotion of independence and self-management is a recurring theme throughout most age groups in the care coordination guidelines. This process begins in preschool with greater emphasis as the child ages to adolescence. There is encouragement for children with

Table 1  
Clinical questions that informed the spina bifida care coordination guidelines

Age group (from guidelines)	Clinical questions
0–11 months	<ol style="list-style-type: none"> <li>1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?</li> <li>2. How do Spina Bifida Care Coordinators collaborate with team members, allied health services, and community partners to optimize opportunities and overall quality of life?</li> <li>3. What is the best way to communicate effectively between the multiple Spina Bifida care team members and the family so as to best serve the child's needs, prevent complications, and improve the overall experience of care?</li> <li>4. What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic? Examples of barriers include insufficient training, logistical difficulties, and unavailability of personnel and community resources.</li> <li>5. What aspects of a care coordination program do families with a pregnancy or children with Spina Bifida find most helpful and improve their perception of the care they receive?</li> </ol>
1–2 years 11 months	<ol style="list-style-type: none"> <li>1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?</li> <li>2. How do Spina Bifida Care Coordinators collaborate with team members, allied health services, and community partners to optimize the opportunities and overall quality of life of the child?</li> <li>3. What is the best way to communicate effectively between the multiple Spina Bifida care team members, the child, and the family so as to best serve the child's needs, prevent complications, and improve the overall experience of care?</li> <li>4. What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic? Examples of barriers could include insufficient training, logistical difficulties, and unavailability of personnel and community resources.</li> <li>5. What aspects of a care coordination program do families and their children find most helpful and improve their perception of the care they receive?</li> </ol>
3–5 years 11 months	<ol style="list-style-type: none"> <li>1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?</li> <li>2. What evidence exists to show the success of the care coordination program in improving the overall health of children with Spina Bifida?</li> <li>3. What literature is available to support optimal teaching and education of children and their caregivers throughout the lifespan to maximize early independence?</li> <li>4. What is the best way to effectively communicate between multiple Spina Bifida care team members, people with Spina Bifida and their families to best serve their needs, prevent complications, and improve their overall experience of care?</li> <li>5. What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic? Examples of barriers could include insufficient training, logistical difficulties, and unavailability of personnel and community resources.</li> <li>6. What aspects of a care coordination program do families and their children find most helpful and improve their perception of the care they receive?</li> </ol>
6–12 years 11 months	<ol style="list-style-type: none"> <li>1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?</li> <li>2. What evidence exists to show the success of care coordination programs in improving the overall health of children with Spina Bifida?</li> <li>3. How do Spina Bifida Care Coordinators collaborate with team members, allied health services, and community partners to optimize the opportunities and overall quality of life of people with Spina Bifida?</li> <li>4. What is the best way to effectively communicate between multiple team members, people with Spina Bifida and their families to best serve their needs, prevent complications, and improve the overall experience of care?</li> <li>5. What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic? Examples of barriers could include insufficient training, logistical difficulties, and unavailability of personnel and community resources.</li> <li>6. What aspects of a care coordination program do people with Spina Bifida find most helpful and improve their perception of the care they receive?</li> </ol>
13–17 years 11 months	<ol style="list-style-type: none"> <li>1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?</li> <li>2. What evidence exists to show the success of care coordination programs in improving the overall health of people with Spina Bifida?</li> <li>3. How do Spina Bifida Care Coordinators collaborate with team members, allied health services, and community partners to optimize the opportunities and overall quality of life of people with Spina Bifida?</li> <li>4. What is the best way to effectively communicate between multiple team members, people with Spina Bifida and their families to best serve their needs, prevent complications, and improve their overall experience of care?</li> </ol>

Table 1, continued

Age group (from guidelines)	Clinical questions
	<ol style="list-style-type: none"> <li>5. What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic? Examples of barriers could include insufficient training, logistical difficulties, and unavailability of personnel and community resources.</li> <li>6. What aspects of a care coordination program do people find most helpful and improve their perception of the care they receive?</li> <li>7. What is the Spina Bifida Care Coordinator's role in 1) educating and bringing adult providers into the care team to ensure seamless transition of care and in 2) developing transition goals and processes for people as they age out of the pediatric system to ensure continuity of care?</li> </ol>
18+ years	<ol style="list-style-type: none"> <li>1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?</li> <li>2. What evidence exists to show the success of care coordination program in improving the overall health of people with Spina Bifida?</li> <li>3. How do Spina Bifida Care Coordinators collaborate with team members, allied health services, and community partners to optimize the opportunities and overall quality of life of people with Spina Bifida?</li> <li>4. What is the best way to effectively communicate between multiple team members, people with Spina Bifida and their families to best serve their needs, prevent complications, and improve their overall experience of care?</li> <li>5. What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic? Examples of barriers could include insufficient training, logistical difficulties and unavailability of personnel and community resources.</li> <li>6. What aspects of a care coordination program do people find most helpful and improve their perception of the care they receive?</li> <li>7. What is the Spina Bifida Care Coordinator's role in 1) educating and bringing adult providers into the care team to ensure seamless transition of care and in 2) developing transition goals and processes for people as they age out of the pediatric system to ensure continuity of care?</li> </ol>

Spina Bifida to participate in age appropriate peer activities outside of the school setting. During adolescence, there are guidelines for specific topics relevant to this age group including sexuality, substance use, mental health, driver education and preparation for college.

Finally, for the adult age group, care coordination guidelines focus on having a successful transition to adult care and independence. This includes the care coordinator taking an inventory of self-care skills. The care coordinator should know about the adult programs and Spina Bifida care providers in their area and be able to educate families on care plans when no adult multidisciplinary Spina Bifida clinics exist. It is recommended that the care coordinator be able to assist families with referrals to employment or vocational training programs when appropriate. In addition, for those living with Spina Bifida and significant intellectual disability, the care coordinator should be able to assist with the conservatorship process when appropriate.

Certain SB care coordination guidelines were relevant and included in all age groups. An example is the importance of the care coordinator using two-way communication with families, acting in partnership and communicating regularly with the person's primary care physician. For all age groups it is recommended that the Spina Bifida Care Coordinator should serve as the lead contact person and information provider for the Spina Bifida clinic and monitor individual needs and

prescriptions for durable medical equipment, supplies, and medications as needed. In addition, for all age groups, it is appropriate that the care coordinator assist with insurance authorizations as well as other services such as SSI social security, etc. Mental health needs and services are part of the care coordination guidelines including screening and referral for mental health treatment when necessary. The Spina Bifida care coordination guidelines for are presented below (Table 2). For each guideline, when published evidence exists, the associated reference is cited next to the guidelines. For those guidelines for which no published evidence exists, clinical consensus of the working group or other SB care guidelines are cited.

## 5. Discussion

The Spina Bifida Care Coordination Guidelines will be updated as new data become available. As such, these should be considered as guidelines and options, not standards of care. It is hoped that these Care Coordination Guidelines will not only guide health care providers but also patients and families, so that they can have the best and most scientifically-based care and treatments throughout their ever-longer and higher-quality lives. Care coordination is an essential component of health care delivery [25]. At the core, patient-

Table 2  
Spina bifida care coordination guidelines

Age group	Guidelines	Evidence
0–11 months	<p>1. After the Spina Bifida diagnosis has been made, it is recommended that the Spina Bifida Care Coordinator should be readily available to the family to provide support [9] and education throughout the pregnancy. These consults may take place as part of a maternal fetal health visit in a high-risk pregnancy center. The goals of the consults may include to:</p> <ul style="list-style-type: none"> <li>– assist the family with coping with the new diagnosis,</li> <li>– provide overall education on what the family can expect ages 0–11 months and while in their stay in the neonatal intensive care unit (NICU) stay, and</li> <li>– provide general information on the signs and symptoms related to Spina Bifida.</li> </ul> <p>The Spina Bifida Care Coordinator may assist in synchronizing prenatal visits for other subspecialties that could include neurosurgery, urology, and orthopedics. The primary role of the Spina Bifida Care Coordinator during this stressful time for families is to convey the message that the family is not alone because a well-prepared team will be on hand to provide them with the support they need to help care for their child [10].</p>	[9,10]
	<p>2. It is recommended that the Spina Bifida Care Coordinator should use the time during pregnancy or 0–11 months to introduce the family to the Spina Bifida clinic and multidisciplinary team (when one is available) and begin the process of arranging post-discharge follow-up. Through counseling and encouragement, the Spina Bifida Care Coordinator:</p> <ul style="list-style-type: none"> <li>– assists the family to accept the diagnosis, and</li> <li>– contacts the medical home of the family and infant with Spina Bifida and identifies the specific lead professional or nurse case manager who will serve as the point of contact for the family to provide education, resources, and support [10,11].</li> </ul>	[10,11]
	<p>3. It is recommended that the Spina Bifida Care Coordinator provide families with a broad and appropriate early education across the spectrum of symptoms and conditions related to Spina Bifida. This may include educating the family on early urologic work-up and management and possibly teaching them about clean intermittent catheterization (CIC). Other topics may include education on latex allergy and precautions, education regarding early orthopedic interventions, and education to help families recognize potential neurosurgical complications.</p>	Clinical consensus, Latex and Latex Allergy in Spina Bifida Guidelines, Neurosurgery Guidelines, Orthopedics Guidelines, Urology Guidelines
	<p>4. It is recommended that the Spina Bifida Care Coordinator work closely with the NICU staff to ensure that parents have the necessary skills and education for discharge and a smooth transition to home care.</p>	Clinical consensus
	<p>5. It is recommended that the Spina Bifida Care Coordinator should communicate and collaborate between the family and the multidisciplinary and sub-specialty Spina Bifida team members to arrange and execute the child's follow-up appointments, monitoring, and care plan [2,12].</p>	[2,12]
	<p>6. When applicable, it is recommended that the Spina Bifida Care Coordinator should update the child's primary care provider and/or medical home on the current care goals and recommendations of the Spina Bifida multidisciplinary care team. Use two-way communications to identify and address medical concerns and obtain updated records from the medical home, such as immunizations, growth charts, developmental screenings, and other materials [4,11].</p>	[4,11]
	<p>7. When appropriate, it is recommended that the Spina Bifida Care Coordinator should refer families to early intervention services [10].</p>	Clinical consensus, Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans [10]
	<p>8. It is recommended that the Spina Bifida Care Coordinator make referrals to local Spina Bifida Association Chapters and parent support groups, as available.</p>	Clinical consensus
	<p>9. It is recommended that the Spina Bifida Care Coordinator should monitor the parent's and caregiver's compliance with appointments, and problem-solve with them if non-compliance is noted.</p>	Clinical consensus
	<p>10. When appropriate, it is recommended that the Spina Bifida Care Coordinator should assess family dynamics in how they are coping with the diagnosis, evaluate psychosocial stressors for the family, and assist them with referrals to mental health and social services professionals.</p>	Clinical consensus, Mental Health Guidelines

Table 2, continued

Age group	Guidelines	Evidence
1–2 years 11 months	<p>1. It is recommended that the Spina Bifida Care Coordinator work with the family and the multidisciplinary Spina Bifida care team to ensure that the child with Spina Bifida is up to date on all sub-specialty care visits, imaging, monitoring, and equipment needs where appropriate. This may include assistance with insurance authorization or referrals [12].</p> <p>2. It is recommended that the Spina Bifida Care Coordinator provide education across the spectrum of symptoms and conditions related to Spina Bifida to empower families and children to manage their own care and recognize complications and emergencies. The Spina Bifida Care Coordinator should also identify gaps in the family knowledge base.</p> <p>3. It is recommended that the Spina Bifida Care Coordinator monitor and document family enrollment in and progress with therapies and treatments and encourage continued participation in early intervention services [13].</p> <p>4. It is recommended that the Spina Bifida Care Coordinator collaborate with team members to identify gaps or barriers to achieving the goals of the person's care plan and assist with additional referrals as appropriate [12].</p> <p>5. When applicable, it is recommended that the Spina Bifida Care Coordinator update the primary care provider and/or medical home on the current care goals and recommendations of the Spina Bifida multidisciplinary care team. Use two-way communications to identify and address medical concerns and obtain updated [11] records from the medical home, such as immunizations, growth charts, developmental screenings, and other materials [4,11].</p> <p>6. It is recommended that the Spina Bifida Care Coordinator begin emphasizing the child's path towards independence with the family. Encouraging activities such as learning to help put on shoes and braces will promote greater independence and autonomy and promote further discussions of independence as the child ages.</p> <p>7. It is recommended that the Spina Bifida Care Coordinator assess family dynamics in how they are coping with the diagnosis, evaluate psychosocial stressors for the family, and assist them with referrals to mental health and social services professionals when appropriate.</p>	<p>Clinical consensus [12]</p> <p>Clinical consensus, Family Functioning Guidelines, Self-Management and Independence Guidelines</p> <p>[13]</p> <p>[12]</p> <p>[4,11]</p> <p>Clinical consensus, Self-Management and Independence Guidelines</p> <p>Clinical consensus, Mental Health Guidelines</p>
3–5 years 11 months	<p>1. It is recommended that the Spina Bifida Care Coordinator provide developmentally appropriate care education across the spectrum of symptoms and conditions related to Spina Bifida to empower families and children to manage their own care and be able to recognize when complications and emergencies arise. The coordinator should also identify and/or improve gaps in the family knowledge base specifically related to the preschool period (mobility progress, skin inspection, bowel and bladder care, speech/cognitive development, and more).</p> <p>2. It is recommended that the Spina Bifida Care Coordinator prepare the family for early independence, entering preschool, and planning special education and health-related services in the school.</p> <p>3. It is recommended that the Spina Bifida Care Coordinator coordinate with the family and multidisciplinary Spina Bifida care team to ensure that the child with Spina Bifida is up-to-date on all sub-specialty care visits including, imaging, monitoring, and equipment needs, where appropriate, including assistance with insurance authorization when needed [2,12].</p> <p>4. It is recommended that the Spina Bifida Care Coordinator assess family dynamics in coping with the diagnosis and evaluate psychosocial stressors for the family [12]. The Spina Bifida Care Coordinator should also assist with referrals to mental health and social services when appropriate. When applicable, it is recommended that the Spina Bifida Care Coordinator update the primary care provider on the current care goals and recommendations of the Spina Bifida multidisciplinary care team. Use two-way communications to identify and address medical concerns and obtain updated records from the person's primary care provider such as immunizations, growth charts, developmental screenings, and other materials [4,11].</p> <p>5. It is recommended that the Spina Bifida Care Coordinator serve the family as the lead contact person and information-provider for the multidisciplinary medical services for the child with Spina Bifida. The Spina Bifida Care Coordinator should monitor the family's needs and prescriptions for durable medical equipment, supplies, and medications, as needed [11].</p>	<p>Clinical consensus, Bowel Function and Care Guidelines, Mental Health Guidelines, Mobility Guidelines, Neuropsychology Guidelines, Skin (Integument) Guidelines, Urology Guidelines</p> <p>Clinical consensus</p> <p>[2,12]</p> <p>[4,11,12]</p> <p>Clinical consensus, Mental Health Guidelines</p> <p>[11]</p>

Table 2, continued

Age group	Guidelines	Evidence
6–12 years 11 months	<ol style="list-style-type: none"> <li>1. It is recommended that the Spina Bifida Care Coordinator provide developmentally appropriate care education across spectrum of symptoms and conditions related to Spina Bifida to better empower children and their families to manage their own care and be able to recognize complications and emergencies. Identify and/or improve gaps in the family knowledge base specifically related to the school age period (mobility progress, skin inspection, bowel and bladder care, academic/cognitive development, school and social functioning, and more).</li> <li>2. It is recommended that the Spina Bifida Care Coordinator monitor primary school functioning and update school education and health plans. Encourage participation in age-appropriate activities outside of school with peers, with and without Spina Bifida. Encourage participation in activities such as camps or special family weekends that provide safe places to develop peer relationships with children who may have similar medical challenges [13].</li> <li>3. It is recommended that the Spina Bifida Care Coordinator coordinate with the family and multidisciplinary Spina Bifida care team to ensure that the child is up-to-date on all sub-specialty care visits, imaging, monitoring, and equipment needs, where appropriate. This may include assistance with insurance authorization when needed [2,12].</li> <li>4. It is recommended that the Spina Bifida Care Coordinator assess family dynamics in coping with the diagnosis and evaluate psychosocial stressors for the family. Assess for depression and anxiety and assist with referrals to mental health and social services when appropriate.</li> <li>5. It is recommended that the Spina Bifida Care Coordinator should work with the child, his or her family and Spina Bifida team members and therapists to start progress on self-management goals and education. Monitor family progress in self-management at regular intervals and clinic visits. Engage the school nurse to help facilitate self-management and independence [14]. Teach self-advocacy and encourage the child to participate as much as possible in his or her own self-management [15].</li> <li>6. When applicable, it is recommended that the Spina Bifida Care Coordinator update the primary care provider on the current care goals and recommendations of the Spina Bifida multidisciplinary care team. The Spina Bifida Care Coordinator should use two-way communications to identify and address medical concerns and obtain updated records from the primary care provider and/or medical home such as immunizations, growth charts, developmental screenings, and other materials [4,11].</li> <li>7. It is recommended that the Spina Bifida Care Coordinator serve the family as the lead contact person and information-provider for the multidisciplinary medical services for the child with Spina Bifida and monitor family needs and prescriptions for durable medical equipment, supplies, and medications, as needed [11,16].</li> </ol>	<p>Clinical consensus, Bowel Function and Care Guidelines, Mental Health Guidelines, Mobility Guidelines, Neuropsychology Guidelines, Skin (Integument) Guidelines, Urology Guidelines</p> <p>Clinical consensus, Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans [13]</p> <p>[2,12]</p> <p>Clinical consensus, Mental Health Guidelines</p> <p>[14,15] Self-Management and Independence Guidelines</p> <p>[4,11]</p> <p>[11,16]</p>
13–17 years 11 months	<ol style="list-style-type: none"> <li>1. It is recommended that the Spina Bifida Care Coordinator provide developmentally-appropriate care education across the spectrum of symptoms and conditions related to Spina Bifida to better empower children and families to manage their own care and recognize complications and emergencies. Identify and or improve gaps in the family knowledge base specifically related to the teenage age period (mobility progress, skin inspection, bowel and bladder care, sexuality, academic/cognitive development, social functioning at school and with peers, high risk behaviors, and more).</li> <li>2. It is recommended that the Spina Bifida Care Coordinator monitor secondary school functioning and update the school education and health plan so that it includes preparation for college or other higher education opportunities. Encourage participation in age-appropriate activities with peers outside of school. Where appropriate, provide information for driver education and training programs for the teenager with Spina Bifida.</li> <li>3. It is recommended that the Spina Bifida Care Coordinator communicate with the family and multidisciplinary Spina Bifida care team to ensure the individual with Spina Bifida is up-to-date on all sub-specialty care visits, imaging, monitoring, and equipment needs where appropriate. This may include assistance with insurance authorization when needed [2,12].</li> <li>4. It is recommended that the Spina Bifida Care Coordinator update the primary care provider on the current care goals and recommendations of the Spina Bifida multidisciplinary care team. The coordinator should use two-way communications to identify and address medical concerns and obtain updated records from the primary care provider such as immunizations, growth charts, developmental screenings, and other materials [4,11].</li> </ol>	<p>Clinical consensus, Bowel Function and Care Guidelines, Mental Health Guidelines, Mobility Guidelines, Neuropsychology Guidelines, Skin (Integument) Guidelines, Urology Guidelines</p> <p>Clinical consensus</p> <p>[2,12]</p> <p>[4,11]</p>

Table 2, continued

Age group	Guidelines	Evidence
	5. It is recommended that the Spina Bifida Care Coordinator work with the teenager and his/her families, Spina Bifida team members, and therapists to continue progress on self-management goals and education. Monitor family progress at regular intervals in self-management and clinic visits with the goal of achieving as much independence as is realistically possible. Engage the school nurse to help facilitate self-management and independence [14]. Teach self-advocacy and encourage the teenager to participate as much as possible in his or her own self-management. When appropriate, discuss what limitations to independence the teenager may have due to deficits in memory, cognition, and executive functioning and provide the parents with additional resources and support services, as needed [17–19].	[17–19] Self-Management and Independence Guidelines
	6. It is recommended that the Spina Bifida Care Coordinator begin preparing the teenager for transition to adult health care, including familiarizing them and their family with the Transition Guidelines and Self-Management and Independence Guidelines. Encourage the family to develop and assemble their own health care folder and records for use during travel, appointments in hospitals that are away from their home area, and other occasions when they will be away from the medical home. Encourage the person to make his or her own medical appointments once she or he is capable of doing so, and to start leading the conversation with specialists and other providers during clinic visits. Assist the family by making them aware that transition to adult life involves many aspects beyond health care, including educational planning or job training, making arrangements to live independently, and financial planning [15,20,21].	[15,20,21] Self-Management and Independence Guidelines, Transition Guidelines
	7. It is recommended that the Spina Bifida Care Coordinator assess family dynamics in coping with the diagnosis and evaluate their psychosocial stressors. Collaborate with primary care provider to review age-appropriate screenings and assist with referrals to mental health and social services when appropriate.	Clinical consensus, Mental Health Guidelines
	8. It is recommended that the Spina Bifida Care Coordinator serve the family as the lead contact person and information provider for the multidisciplinary medical services for the person with Spina Bifida and monitor family needs and prescriptions for durable medical equipment, supplies, and medications, as needed.	Clinical consensus
	9. It is recommended that the Spina Bifida Care Coordinator conduct an inventory of the person's ability to provide self-management, complete activities of daily living, and manage mobility equipment and transportation needs. For a person with a significant intellectual disability who may not be able to live independently, assist the family with the conservatorship process prior to age 18, and with maintaining Supplemental Security Insurance (SSI) and other types of insurance coverage.	Clinical consensus, Self-Management and Independence Guidelines
18+ years	1. It is recommended that the Spina Bifida Care Coordinator be knowledgeable about the resources for adults with Spina Bifida in their geographic area and coordinate the successful transition from pediatric to adult providers for adults with Spina Bifida. Where appropriate, educate adults with Spina Bifida about the key differences between adult and pediatric providers, including the possibility that there may not be an adult multidisciplinary Spina Bifida team nearby. Inform adults with Spina Bifida on the importance of having a primary care provider [15].	[15] Transition Guidelines
	2. It is recommended that the Spina Bifida Care Coordinator conduct an inventory of the adult's ability to provide self-management, complete activities of daily living, and [16] manage mobility equipment and transportation needs. For those who have a significant intellectual disability and may be unable to live independently, assist the family with the conservatorship process and with maintaining Supplemental Security Insurance (SSI) and other types of insurance coverage.	[16] Clinical consensus, Self-Management and Independence Guidelines
	3. It is recommended that the Spina Bifida Care Coordinator assist with referrals to vocational and employment training opportunities, as needed.	Clinical consensus
	4. It is recommended that the Spina Bifida Care Coordinator assist with referrals to driver education training opportunities, as needed and/or referral for appropriate pre-driver training evaluations including vision, ability to use lower extremities vs. hand controls and other driving requirements.	Clinical consensus
	5. It is recommended that the Spina Bifida Care Coordinator coordinate with Spina Bifida care providers to determine if the person is up-to-date on all sub-specialty care visits, imaging and monitoring and equipment needs, where appropriate. This may include assistance with insurance authorization [2,12,17].	[2,12,17] Mobility Guidelines, Neurosurgery Guidelines, Orthopedics Guidelines, and Urology Guidelines

Table 2, continued

Age group	Guidelines	Evidence
	6. It is recommended that the Spina Bifida Care Coordinator assess individual dynamics in coping with living with Spina Bifida and evaluate psychosocial stressors for the individual. Collaborate with primary care provider to review age-appropriate screenings and assist with referrals to mental health and social services, when appropriate.	Clinical consensus, Mental Health Guidelines
	7. It is recommended that the Spina Bifida Care Coordinator should serve as the lead contact person and information provider for the Spina Bifida clinic and monitor individual needs and prescriptions for durable medical equipment, supplies, and medications as needed. Special considerations may be needed to apply care coordination principles to assist adults who see multiple providers independently [15].	[15]
	8. It is recommended that the Spina Bifida Care Coordinator assess and monitor for clinical deterioration, loss of mobility, chronic pain, obesity, and use two-way communication between the Spina Bifida Care Coordinator and the primary care provider and/or medical home to assess and address concerns and assist with medical referrals, as appropriate. [17,20].	[17,20] Health Promotion and Preventive Medicine Guidelines, Mobility Guidelines, Neurosurgery Guidelines, Nutrition, Metabolic Syndrome, and Obesity Guidelines, Orthopedics Guidelines, Urology Guidelines

and family-centered care within a medical home is a foundational component; outcomes are optimized when there is cross-sector collaboration among the multiple medical systems and providers, community services, and support agencies with whom families and those with Spina Bifida interact. While effective care coordination typically requires dedicated paid personnel, care coordination activities are not the sole responsibility of a single individual or provider [26]. Rather, all people who interact with patients and families have a role to play. The second concept, in the context of patient- and family-centered care, is that for people with Spina Bifida, care may be provided via a medical neighborhood with team-based care [27,28]. Within this framework is co-management with defined roles, data sharing, and collaborative care protocols among primary care, subspecialty care, and community-based services. Full implementation of these guidelines to optimize outcomes cannot rest with the clinic alone. Indeed, guidance provided on many topics should be implemented through primary care providers and efforts of community services. While the Spina Bifida clinic may direct the overall health care planning in many cases, optimal care is best achieved as a partnership between families and people with Spina Bifida, primary and subspecialty care providers, health systems, and community services.

During the process to create the Care Coordination Guidelines, several gaps in the research literature, and opportunities for future studies, were identified. For example, what database studies demonstrate the benefits of Spina Bifida care coordination programs, to improve health outcomes, decrease morbidity and mortality, promote higher quality of life, improve success and independence in adulthood, and decrease cost of care?

What research exists regarding the effectiveness of care coordination programs to develop a best-practice model of care coordination? How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time with aging? What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic? Examples of barriers could include insufficient training, logistical difficulties, and unavailability of personnel and community resources. What aspects of a care coordination program do families and individuals find most helpful and improve their perception of the care they receive? What evidence exists to show the success of the care coordination program in improving overall health? What literature is available to support optimal teaching and education of children and their caregivers throughout the lifespan to maximize early independence? What is the Spina Bifida Care Coordinator's role in educating and bringing adult providers into the care team to ensure seamless transition of care, and in developing transition goals and processes for people as they age out of the pediatric system to ensure continuity of care?

To begin the process of addressing the research gaps in Spina Bifida care coordination and to develop methods to effectively measure the results of care coordination intervention services, the Spina Bifida Association (SBA) began a joint project with the National Center for Care Coordination Technical Assistance (NCCCTA) at Boston Children's Hospital [29]. The goals of the SBA/NCCCTA partnership were to involve SBA clinical partners in the adaptation and implementation the Pediatric Integrated Care Survey (PICS) and/or the Care Coordination Measurement Tool (CCMT) from

**Care Coordination Measurement Tool<sup>®</sup>**

CCMT 2017 Version 1.1

Patient Level	Care Coordination Needs	Activity	Outcomes Occurred	Outcomes Prevented	Time Spent	Staff	Clinical Competence
1							
2							

  

<b>Patient Level</b>	<b>Activity to Fulfill Needs</b>	<b>Outcomes Occurred</b>	<b>Outcomes Prevented</b>	<b>Time Spent</b>
1a. Child/Youth with Special Health Care Needs –with complicating family/social issues 1b. Child/Youth without Special Health Care Needs- with complicating family/social issues 1c. Child/Youth with Special Health Care Needs- without complicating family/social issues 1d. Child/Youth without Special Health Care Needs- without complicating family/social issues 1e. Interpreter needed 1f. Interpreter not needed  <b>Care Coordination Needs</b> 2a. Clinical or Medical Management related to [THIS] clinic (including education about medical or behavioral condition) 2b. Mental/Behavioral/Developmental Health 2c. Referral and Appointment Management 2d. Educational 2e. Social Services (housing, food, transportation) 2f. Financial/Insurance 2g. Advocacy/Legal/Judicial 2h. Connection to Community/Non-Medical Resources 2i. Prior Authorization	3a. Pre-visit review 3b. Patient education/anticipatory guidance 3c. Communication with family [via telephone/email] 3d. Communication with an internal clinic team member [via telephone/email/in-person] 3e. Communication with an external health care provider, hospital, or care team member [via telephone/email] 3f. Telehealth encounter 3g. Update of clinical chart [electronic medical record system] 3h. Communication with a community agency/educational facility/school [via telephone/email] 3i. Reviewed labs, diagnostic tests, notes, IEP 3j. Form processing (school, camp, etc.) 3k. Research of clinical/medical question 3l. Research of non-medical question/service/etc. 3m. Development/modification of care plan 3n. Referral management or appointment scheduling 3o. Prescription/Supplies order placement 3p. Secured prior authorization for patient 3q. Connection to family navigator/family support group	4a. Medication-related discrepancies reconciled 4b. Medication treatment adherence 4c. Non-medication-related discrepancies reconciled, adherence to care plan 4d. Ability for family to better manage at home care and treatment due to education/guidance provided virtually 4e. Modification of medical care plan (testing, medication, etc.) 4f. Modification of care plan [non-medication component] to reduce unnecessary family burden/stress; increase adherence to care plan 4g. Scheduled necessary clinic visit [for THIS clinic] 4h. Specialty referral 4i. Necessary ER referral 4j. Referral to community agency 4k. Prior Authorization completed 4l. Prescription/medical supplies ordered	5a. Abrupt discontinuation of medication by family/caregiver due to prior authorization requirement 5b. Non-adherence to treatment plan due to misunderstanding between care team and family 5c. Medication error 5d. Presence of adverse medication side effects unnoticed by family/clinic team 5e. ER Visit 5f. Unnecessary clinic visit [for THIS clinic] 5g. Unnecessary specialist visit 5h. Missed clinic visit 5i. MD/NP call to the family 5j. Unnecessary lab/test [prevented duplicative testing] 5k. I don't know	6a. less than 5 minutes 6b. 5-9 minutes 6c. 10-19 minutes 6d. 20-29 minutes 6e. 30-39 minutes 6f. 40-49 minutes 6g. 50+ minutes (please note actual time): _____  <b>Staff</b> 7a. RN 7b. NP 7c. PA 7d. MA 7e. Administrative 7f. Care Coordinator 7g. Social Worker 7h. Physician  <b>Clinical Competence (CC)</b> 8a. CC required 8b. CC not required

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Fig. 1. CCMT care coordination measurement tool [29].

the National Center for Care Coordination Technical Assistance. Both tools are intended to collect care coordination data that leads to outcomes of improved patient experience, health outcomes, reduced cost, and provider experience. This data can be used to justify the costs associated with quality care coordination services and measure the benefits of those services. Many challenges exist for families that receive care in multidisciplinary Spina Bifida clinics, including fragmentation of care, lack of coordination of services and supplies, reimbursement for services and equipment by insurance, and the necessary resources to provide care coordination. This contributes to poor health outcomes, less than optimal family experience, and use of high cost, unnecessary emergency services. The Pediatric Integrated Care Survey (PICS) tool is a family experience measure of care integration consisting of 19 validated experience questions plus health care status/utilization and demographic questions [30]. The PICS tool allows ascertainment of how patient/family consumers experience these benefits and their perceptions of the quality

of the care coordination programs within their Spina Bifida Center. The Care Coordination Measurement Tool (CCMT) is a care coordination value capture tool. The CCMT (Fig. 1) can be used by multiple disciplines within the Spina Bifida clinic including nurses, social workers, patient navigators, case managers primary and subspecialty care providers. The CCMT is designed to be adapted to the specific care coordination data collection and Quality Improvement needs of individual SB clinics. The CCMT enables care providers to record the types of encounters that necessitate care coordination activities including complexity level of patient requiring care coordination, activities performed, outcomes that occurred and were prevented as a result of successful care coordination. Already several SBA designated clinical care partners have embarked on pilot studies and quality improvement projects using the tools from the National Center for Care Coordination Technical Assistance to improve the care coordination experience of families within their clinics. We look forward to the publication of the results from these clinics so that

the current Spina Bifida Care Coordination Guidelines can be updated in the future using the best available scientific evidence.

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This edition of the Journal of Pediatric Rehabilitation Medicine includes manuscripts based on the most recent “Guidelines For the Care of People with Spina Bifida,” developed by the Spina Bifida Association. Thank you to the Spina Bifida Association for allowing the guidelines to be published in this forum and making them Open Access.

The Spina Bifida Association has already embarked on a systematic process for reviewing and updating the guidelines. Future guidelines updates will be made available as they are completed.

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### Conflict of interest

The authors have no conflicts of interest to report.

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