

# Guidelines for the Care of People with Spina Bifida

## Care Coordination

**Workgroup Members: Alex Van Speybroeck, MD, MPH (Chair); Patricia Beierwaltes, DNP, CPNP; Betsy Hopson, MSHA; Suzanne McKee, RN, BSN; Lisa Raman, RN, MScANP, MEd; Ravindra Rao, MD; Rebecca Sherlock, MSN, PNP; Jonathan Tolentino, MD**

### Introduction

“Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’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, and is often managed by the exchange of information among participants responsible for different aspects of care.” — International Journal of Care Coordination<sup>1</sup>

Care coordination (also described as case management services) in the case of people with Spina Bifida and their families, 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 coordination for people with Spina Bifida and their families can be complicated due to the medical complexities of the condition and the need for multidisciplinary care, as well as economic and sociocultural barriers to coordination of care. Care coordination is often a shared responsibility by the multidisciplinary Spina Bifida team.<sup>2</sup> For this reason, the Spina Bifida Care Coordinator has the primary responsibility for overseeing the overall treatment plan for the individual with Spina Bifida.<sup>3</sup> Care coordination includes communication with the primary care provider in a patient’s medical home.<sup>2,4-5</sup>

Care coordination is an essential part of the multidisciplinary Spina Bifida care team and vital to improving the health care and wellness outcomes for people living with Spina Bifida. 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.

There are very few database studies that demonstrate the benefits of Spina Bifida care coordination programs resulting in 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 for the person with Spina Bifida.

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.<sup>6</sup> 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.<sup>2,4</sup>

Over the past 50 years, advances in medicine have resulted in increased survival of children with Spina Bifida.<sup>7</sup> 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, people with Spina Bifida and their families have had greater access to 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 individuals receive appropriate care coordination services, especially as they transition from pediatric to adult care.

Generally, the goals of care coordination are the following:

- gain access to and integrate services and resources,
- link service systems with the family,
- avoid duplication and unnecessary cost, and
- advocate for improved individual outcomes.

## **Outcomes**

### **Primary**

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 related services.

### **Secondary**

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.<sup>8</sup>
2. Promote routine screenings and testing congruent with Spina Bifida guidelines for specific secondary conditions.

### **Tertiary**

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.<sup>9</sup>

## **Pregnancy to 0-11 months**

### **Clinical Questions**

1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?
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?
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?
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.
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?

### **Guidelines**

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 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:

- assist the family with coping with the new diagnosis,
- 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
- provide general information on the signs and symptoms related to Spina Bifida.

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.<sup>10</sup>

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:
  - assists the family to accept the diagnosis, and
  - 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.<sup>10-11</sup>
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. (clinical consensus) (Latex and Latex Allergy in Spina Bifida Guidelines, Neurosurgery Guidelines, Orthopedics Guidelines, Urology Guidelines)
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. (clinical consensus)
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.<sup>2,12</sup>
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.<sup>4,11</sup>
7. When appropriate, it is recommended that the Spina Bifida Care Coordinator should refer families to early intervention services. (clinical consensus) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans)
8. It is recommended that the Spina Bifida Care Coordinator make referrals to local Spina Bifida Association Chapters and parent support groups, as available. (clinical consensus)
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. (clinical consensus)

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. (clinical consensus) (Mental Health Guidelines)

## **1-2 years 11 months**

### **Clinical Questions**

1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?
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?
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?
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.
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?

### **Guidelines**

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.<sup>12</sup>
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. (clinical consensus) (Family Functioning Guidelines, Self- Management and Independence Guidelines)
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.<sup>13</sup>
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.<sup>12</sup>
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 records from the medical home, such as immunizations, growth charts, developmental screenings, and other materials.<sup>4,11</sup>
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. (clinical consensus) (Self-Management and Independence Guidelines)

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. (clinical consensus) (Mental Health Guidelines)

### **3-5 years 11 months**

#### **Clinical Questions**

1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?
2. What evidence exists to show the success of the care coordination program in improving the overall health of children with Spina Bifida?
3. What literature is available to support optimal teaching and education of children and their caregivers throughout the lifespan to maximize early independence?
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?
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.
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?

#### **Guidelines**

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). (clinical consensus) (Bowel Function and Care Guidelines, Mental Health Guidelines, Mobility Guidelines, Neuropsychology Guidelines, Skin (Integument) Guidelines, Urology Guidelines)
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. (clinical consensus)
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.<sup>2,12</sup>
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. The Spina Bifida Care Coordinator should also assist with referrals to mental health and social services when appropriate. (clinical consensus) (Mental Health Guidelines)
5. 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.<sup>4,11</sup>

6. 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.<sup>11</sup>

## **6-12 years 11 months**

### **Clinical Questions**

1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?
2. What evidence exists to show the success of care coordination programs in improving the overall health of children with Spina Bifida?
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?
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?
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.
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?

### **Guidelines**

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). (clinical consensus) (Bowel Function and Care Guidelines, Mental Health Guidelines, Mobility Guidelines, Neuropsychology Guidelines, Skin (Integument) Guidelines, Urology Guidelines)
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. (clinical consensus) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans)
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.<sup>2,12</sup>
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. (clinical consensus) (Mental Health Guidelines)

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.<sup>14</sup> Teach self-advocacy and encourage the child to participate as much as possible in his or her own self-management.<sup>15</sup> (Self-Management and Independence Guidelines)
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.<sup>4,11</sup>
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.<sup>11,16</sup>

## **13-17 years 11 months**

### **Clinical Questions**

1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?
2. What evidence exists to show the success of care coordination programs in improving the overall health of people with Spina Bifida?
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?
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?
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.
6. What aspects of a care coordination program do people find most helpful and improve their perception of the care they receive?
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?

### **Guidelines**

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). (clinical consensus) ( Bowel Function and Care Guidelines, Mental Health Guidelines, Mobility Guidelines, Neuropsychology Guidelines, Skin (Integument) Guidelines, Urology Guidelines)

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. (clinical consensus)
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.<sup>2,12</sup>
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.<sup>4,11</sup>
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.<sup>14</sup> 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.<sup>17-19</sup> (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.<sup>15,20-21</sup> (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**

### **Clinical Questions**

1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?
2. What evidence exists to show the success of care coordination program in improving the overall health of people with Spina Bifida?
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?
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?
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.
6. What aspects of a care coordination program do people find most helpful and improve their perception of the care they receive?
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?

### **Guidelines**

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.<sup>15</sup> (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 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. (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.<sup>2,12,17</sup> (Mobility Guidelines, Neurosurgery Guidelines, Orthopedics Guidelines, and Urology Guidelines)

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.<sup>15</sup>
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.<sup>17,20</sup> (Health Promotion and Preventive Medicine Guidelines, Mobility Guidelines, Neurosurgery Guidelines, Nutrition, Metabolic Syndrome, and Obesity Guidelines, Orthopedics Guidelines, Urology Guidelines)

## **Research Gaps**

1. What database studies demonstrate the benefits of Spina Bifida care coordination programs, specifically regarding improved health outcomes, decreased morbidity and mortality, higher quality of life, improved success and independence in adulthood and decreased cost of care?
2. What research exists regarding the effectiveness of care coordination programs to develop a best-practices model of care coordination for the person with Spina Bifida?
3. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as the person with Spina Bifida ages?
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.
5. What aspects of a care coordination program do families and individuals with Spina Bifida find most helpful and improve their perception of the care they receive?
6. What evidence exists to show the success of the care coordination program in improving the overall health of people with Spina Bifida?
7. What literature is available to support optimal teaching and education of children and their caregivers throughout the lifespan to maximize early independence?
8. 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?

## References

1. Butler, M., Kane, R., Larson, S., Jeffery, M., & Grove, M. (2012). Quality Improvement Measurement of Outcomes for People With Disabilities: Closing the Quality Gap: Revisiting the State of the Science. Evidence Report/Technology Assessment, (208).
2. Brustrom, Jennifer, Thibadeau, Judy, John, Lisa, Liesmann, Jaime, & Rose, Shyanika. (2012). Care Coordination in the Spina Bifida Clinic Setting: Current Practice and Future Directions. *Journal of Pediatric Health Care*, 26(1), 16-26.doi: <http://dx.doi.org/10.1016/j.pedhc.2010.06.003>
3. Ziring, P & The Committee on Children with Disabilities. (1999). Care Coordination: Integrating Health and Related Systems of Care for Children with Special Health Care Needs. *Pediatrics*, Volume 104, Issue 4:978-981
4. Liptak, Gregory S., & Revell, Gail M. (1989). Community Physician's Role in Case Management of Children With Chronic Illnesses. *Pediatrics*, 84(3), 465-471.
5. Van Cleave, J., Okumura, M. J., Swigonski, N., O'Connor, K. G., Mann, M., & Lail, J. L. (2016). Medical homes for children with special health care needs: primary care or subspecialty service?. *Academic pediatrics*, 16(4), 366-372.
6. Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2002). The medical home. *Pediatrics*, 110(1), 184-186.
7. Oakeshott, P., Hunt, G. M., Poulton, A., & Reid, F. (2010). Expectation of life and unexpected death in open spina bifida: a 40-year complete, non-selective, longitudinal cohort study. *Developmental Medicine & Child Neurology*, 52(8), 749-753.
8. Miller, A., Condin, C., McKellin, W., Shaw, N., Klassen, A., & Sheps, S. (2009). Continuity of care for children with complex chronic health conditions: parents' perspectives. *BMC Health Services Research*, 9:242. Doi: 10.1186/1472-6963-9-24
9. West, C., Brodie, L., Dicker, J., & Steinbeck, K. (2011). Development of health support services for adults with spina bifida. *Disability and Rehabilitation, Early Online*, 1-8. Doi: 10.3109/09638288.2011.568664
10. Dunleavy, Mary Jo, (2007). The Role of the Nurse Coordinator in Spina Bifida Clinics. *The Scientific World Journal* 7, 1884-1889. Doi: 10.1100/tsw.2007.305
11. Cohen, Eyal, Kuo, Dennis Z., Agrawal, Rishi, Berry, Jay G., Bhagat, Santi K. M., Simon, Tamara D., & Srivastava, Rajendu. (2011). Children with Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics*, 127(3), 529- 538.doi: 10.1542/peds.2010-0910
12. Dicianno, Brad E., Fairman, Andrea D., Juengst, Shannon B., Braun, Patricia G., & Zabel, T. Andrew. (2010). Using the Spina Bifida Life Course Model in Clinical Practice: An Interdisciplinary Approach. *Pediatric Clinics of North America*, 57(4), 945-957. Doi: <http://dx.doi.org/10.1016/j.pcl.2010.07.014>
13. Burke, R., Liptak, G., & The Council on Children with Disabilities. (2011). Providing a Primary Care Medical Home for Children and Youth with Spina Bifida. *Pediatrics*, Volume 128, Number 6. Doi: 10.1542/peds.2011-2219
14. Oakeshott, P., Hunt, G. M., Poulton, A., & Reid, F. (2010). Expectation of life and unexpected death in open spina bifida: a 40-year complete, non-selective, longitudinal cohort study. *Developmental Medicine & Child Neurology*, 52(8), 749-753.
15. Peter, Nadja G., Forke, Christine M., Ginsburg, Kenneth R., & Schwarz, Donald F. (2009). Transition From Pediatric to Adult Care: Internists' Perspectives. *Pediatrics*, 123(2), 417-423. Doi: 101542/peds.2008-0740
16. Dunleavy, Mary Jo, (2007). The Role of the Nurse Coordinator in Spina Bifida Clinics. *The Scientific World Journal* 7, 1884-1889. Doi: 10.1100/tsw.2007.305

17. Binks, J.A., Barden, W.S., Burke, T.A., & Young, N.L. (2007). What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medicine and Rehabilitation*, 88, 1064-1073.
18. West, C., Brodie, L., Dicker, J., & Steinbeck, K. (2011). Development of health support services for adults with spina bifida. *Disability and Rehabilitation*, Early Online, 1-8. Doi: 10.3109/09638288.2011.568664
19. Stille, C. and Antonelli, R., (2004). Coordination of care for children with special health care needs. *Current Opinion in Pediatrics*. 16:700-705
20. Mukherjee, Shubhra (2007). Transition to Adulthood in Spina Bifida: Changing Roles and Expectations. *The Scientific World Journal* 7, 1890-1895. Doi: 10.1100/tsw.2007.179
21. Ridosh, M., Braun, P., Roux, G., Bellin, M., & Sawin, K. (2011). Transition in young adults with spina bifida: a qualitative study. *Child: care, health and development*, 37, 6, 866-874. Doi: 10.1111/j.1365-2214.2011.01329.x

### **References Not Included in Guidelines**

22. Trute, B., Hiebert-Murphy, D., & Wright, A. (2008). Family-centered service coordination in childhood health and disability services: the search for meaningful service outcome measures. *Child: Care, Health and Development*, 34(3), 367-372. Doi: 10.1111/j.1365-2214.2008.00819x
23. Walker, William O., Jr. (2008). Primary care providers and medical homes for individuals with spina bifida. *Journal of Pediatric Rehabilitation Medicine*, Approach 1, 337-344.