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Care Coordination Plenary Panel and Spina Bifida Association Care Coordination Guidelines for Persons Living With Spina Bifida

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Guidelines for the Care of People with Spina Bifida

- **An Initiative of the Spina Bifida Association**
  The Guidelines were developed to provide every healthcare professional–from generalists to specialists–a road map of the best evidenced-based and expert treatment available from birth through adulthood.
- One hundred Spina Bifida experts from around the world spent three years developing these Guidelines that cover 25 topics ranging from bowel management to sexuality to physical activity and more.
- www.spinabifidaassociation.org

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Guidelines for the Care of People with Spina Bifida 25 Topics available at www.spinabifidaassociation.org

- **System of Care** • Care Coordination Health Promotion and Preventive Health Care Services • Prenatal Counseling • Transition
- **Psychosocial Context for Self-Management** • Family Functioning • Mental Health • Self-Management and Independence • Quality of Life
- **Neuropsychology and Neurosurgery** • Neuropsychology • Neurosurgery
- **Mobility, Orthopedics, and Physical Activity** • Mobility • Orthopedics • Physical Activity

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Guidelines for the Care of People with Spina Bifida 25 Topics available at www.spinabifidaassociation.org

- **Urology and Sexual Health** • Men's Health • Sexual Health and Education • Urology • Women's Health
- **Specific Health Issues** • Bowel Function and Care • Endocrine: Puberty and Precocious Puberty • Endocrine and the Use of Human Growth Hormone • Integument (Skin) • Latex and Latex Allergy in Spina Bifida • Nutrition, Metabolic Syndrome, and Obesity • Sleep-Related Breathing Disorders
- **Appendix** • Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans

Core Concepts SB Guidelines 4th Edition

- Care coordination is an essential component of health care delivery.
- Patient- and family-centered care within a medical home is a foundational component.
- Outcomes are optimized when there collaboration among the multiple medical systems and providers, community services, and support agencies with whom families and people with Spina Bifida interact.
- Effective care coordination typically requires dedicated paid personnel.
- Care coordination activities are not the sole responsibility of a single individual or provider. Rather, all people who interact with patients and families have a role to play in care coordination.

Core Concepts SB Guidelines 4th Edition

- The second concept, team-based care.
- Co-management with defined roles, data sharing, and collaborative care protocols among primary care, community-based services, and subspecialty care.
- Full implementation of these Guidelines to optimize outcomes for people with Spina Bifida cannot rest with the Spina Bifida clinic alone.
- 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.

Care coordination from SB Healthcare Guidelines Definition

- “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

Care coordination from SB Healthcare Guidelines Definition

- Care coordination (also described as case management services), in the case of patients 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 patients 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 . For this reason, the care coordinator, or spina bifida team, has the primary responsibility for overseeing the overall treatment plan for the individual with Spina Bifida. The care coordination includes communication with the primary care provider in a patient’s medical home.

Goals of Care Coordination

- 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 organization

- Primary: 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: 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. Promote routine screenings and testing congruent with Spina Bifida guidelines for specific secondary conditions.
- Tertiary: 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.

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General Organization

- Pregnancy to 11 months
- 1-2 years
- 3-5 years
- 6-12 years
- 13-17 years
- 18+ years

- Clinical Questions
- Followed by Care Coordination Guidelines Related to a specific age range and developmental stage

- Research Gaps and Future Directions

Clinical Questions Similar Between Age Groups

- 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?

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Older Age Group Questions

- Older age group Clinical Questions
- 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
- 2) developing transition goals and processes for people as they age out of the pediatric system to ensure continuity of care?

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Examples of some Age Specific Guidelines Birth to 1

- Pregnancy Through Age 11 months Spina Bifida Coordinator May
- 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.
- Assist family with coping with diagnosis
- Assist NICU Staff with discharge planning and multidisciplinary appointments
- Introduce concept of multidisciplinary team to family and provide broad general education on Spina Bifida topics to the family

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Examples of some Specific Guidelines Ages 1-3

- Spina Bifida Care Coordinator work with the family and the multidisciplinary 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.
- Educate family on recognizing common complications and emergencies
- Assess Family coping Skills: Mental Health Referrals if Needed
- Monitor and document enrollment in therapies and early intervention programs

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Examples of some Specific Guidelines Ages 3-5

- The coordinator should improve the family knowledge base specifically related to the preschool period mobility progress, skin inspection, bowel and bladder care, speech/cognitive development.
- Coordination with PMDs (all ages)
- Prepare the family for early independence, entering preschool, and planning special education and health related services in the school.

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Examples of some Specific Guidelines Ages 6-12

- Monitor primary school functioning IEPs and school 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.
- Engage the school nurse to help facilitate self management and independence.
- Teach self-advocacy and encourage the child to participate as much as possible in his or her own self-management.

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Examples of some Specific Guidelines Ages 13-17

- Identify and or improve gaps in the family knowledge base specifically related to the teenage age period sexuality, academic/cognitive development, social functioning at school and with peers, high risk behaviors.
- Monitor secondary school functioning including preparation for college or other higher education opportunities.
- Where appropriate, provide information for driver education and training programs for the teenager with Spina Bifida.
- Self Management Assessment
- Transition to Adult Care
- Conservatorship if appropriate

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Examples of some Specific Guidelines Ages 18+

- Knowledge of resources for adults with Spina Bifida in their geographic area
- Coordinate the successful transition from pediatric to adult providers for adults with Spina Bifida. 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.
- Conduct an inventory of the adult’s ability to provide self-management, complete activities of daily living, and manage mobility equipment and transportation needs
- Employment or Vocational Training if needed

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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?

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Research Gaps

- 4. What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic?
- 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 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?

Thus Care Coordination is a very big job

- How Can We Measure the Care Coordination Services we provide?
- How can we ascertain how our patient/family consumers experience these benefits and their perceptions of the quality of the care coordination programs within their Spina Bifida Center

- CCMT Care Coordination Measurement Tool
  - A care coordination Value Capture Tool
- PICS Pediatric Integrated Care Survey
  - A family experience of care integration

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Overview Partnership

SBA/ National Center for Care Coordination Technical Assistance partnership

Learning collaborative clinics will implement the Pediatric Integrated Care Survey (PICS) and/or the Care Coordination Measurement Tool (CCMT)

Both tools are intended to collect data that moves the care team closer to triple aim outcomes: improved patient experience, improved health outcomes, reduced cost (and improved provider experience!)

Generally, anonymized data collection and rapid cycle QI methodology allow for IRB exemption but would be decision of home institution

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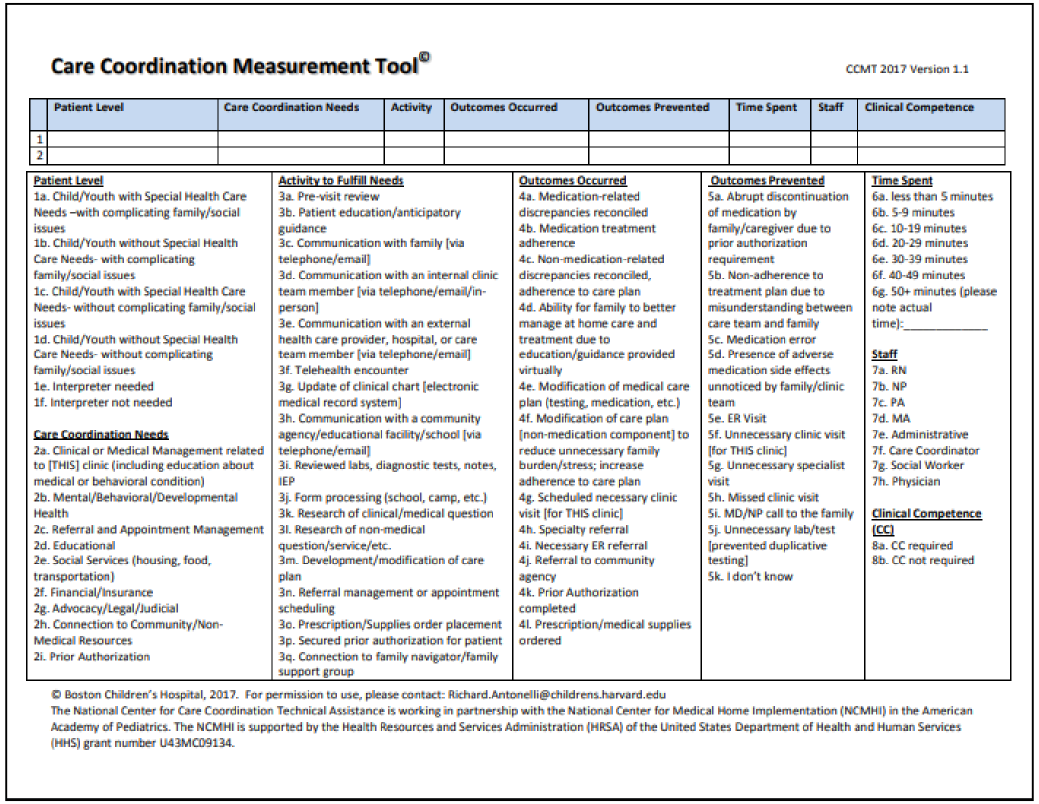
Care Coordination Value Capture

- Best way to improve coordination is to measure it
- Intended to be adapted to reflect activities and outcomes of teams in diverse settings
- Tool can be implemented in different ways depending on goal of collecting data
- Paper version or web-based versions have been used in past
- Access CCMT



Care Coordination Measurement Tool©

CCMT 2017 Version 1.1

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

Patient Level 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 **Care Coordination Needs** 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	**Activity to Fulfill Needs** 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	**Outcomes Occurred** 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	**Outcomes Prevented** 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	**Time Spent** 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):_____________ **Staff** 7a. RN 7b. NP 7c. PA 7d. MA 7e. Administrative 7f. Care Coordinator 7g. Social Worker 7h. Physician **Clinical Competence (CC)** 8a. CC required 8b. CC not required

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Thank you for your attention. Save Questions for the End of all presentations please