



SPINA BIFIDA
ASSOCIATION

Improving Care Coordination and Integration for People with Spina Bifida And their Families

To build a better and brighter future for all those impacted by Spina Bifida

Enhancing Care Coordination in SB Clinics

- SBA and You
 - Is care fragmented for your patients?
 - Do you know if there is effective communication among the many HCPs seeing your patients?
 - Do you have FTE committed to care coordination activities?
 - Are care coordination activities reimbursed in your state?
- Can we help you?
 - Assess the experiences of your patients and families?
 - Assess the care coordination activities you perform and the results of these activities?
 - Collect data to make improvements in your patient outcomes?

Objectives

1. Share tools that are freely available and in the public domain to improve care coordination and care integration.
2. Review experience of Spina Bifida clinics across the U.S. in their adaptation and implementation of care coordination tools and measures, participation in the Care Coordination Academy, supported by HRSA

Care Coordination Academy Panel

- Shannon Bevans, Arnold Palmer Hospital, Florida
- Rhonda Cady, Gillette Children's Specialty Healthcare, Minnesota
- Sierra Smith, Living with SB Central Pennsylvania, Support Group
- Jenetta Thomas, Cincinnati Children's Hospital, Ohio

Clinic Care Partner Standard #5

- Care is coordinated and integrated for each patient...
- access to integrated services and resources
 - linked services and systems with the family and/or caregiver
 - avoidance of duplicative and unnecessary costs, and
 - advocacy for improved individual outcomes.

Shannon Bevans

Rhonda Cady

Gillette Children's Specialty Healthcare NCCA Experience and Takeaways

- Clinical Site: Gillette's Complex Care Program → many persons with spina bifida
- Primary Objective: Define our Care Integration 'Value Proposition' → Gillette Leadership, Payers and Patients/Families
 - Parent Perception of Care Integration PRO
 - Purpose: Measure impact of care integration process improvement activities
 - Aligned with National Care Coordination Standards¹
 - PICS (Pediatric Integrated Care Survey)²
 - FECC (Family Experience with Care Coordination Survey)³
 - NSCH (National Survey of Child Health)⁴

1. National Academy for State Health Policy. National Care Coordination Standards for Children and Youth with Special Health Care Needs. In: National Academy for State Health Policy; 2020:31.
2. Ziniel SJ, Rosenberg HN, Bach AM, Singer SJ, Antonelli RC. Validation of a Parent-Reported Experience Measure of Integrated Care. *Pediatrics*. 2016.
3. Gidengil C, Parast L, Burkhart Q, et al. Development and Implementation of the Family Experiences With Coordination of Care Survey Quality Measures. *Acad Pediatr*. 2017;17(8):863-870.
4. Data Resource Center for Child & Adolescent Health, Adolscnt. National Survey of Children's Health. <https://www.childhealthdata.org/learn-about-the-nsch/NSCH>. Published 2021. Accessed 9/27, 2021.

Gillette Children's Specialty Healthcare NCCA Experience and Takeaways

- Care Coordination Activity/Time Tracking (modified CCMT)⁵
 - Purpose: tease out reimbursed vs. unreimbursed time; value add to patient/parents/insurer
 - Data collected by providers, care managers, patient navigators AND Parents
- Care Map⁶⁻⁸
 - Purpose: Visualize Complexity of family care integration work

5. Antonelli RC, Stille CJ, Antonelli DM. Care Coordination for Children and Youth With Special Health Care Needs: A Descriptive, Multisite Study of Activities, Personnel Costs, and Outcomes. *Pediatrics*. 2008;122(1):e216.

6. Belkin L. Gabe's Care Map: What It Really Takes To Care For One Boy With Special Needs. @huffpostparents. https://www.huffpost.com/entry/gabes-care-map-special-needs-children-caregivers_n_2469564. Published 2013. Updated 2013-01-18. Accessed.

7. Adams S, Nicholas D, Mahant S, et al. Care maps and care plans for children with medical complexity. *Child: Care, Health and Development*. 2019;45(1):104-110.

8. Dharmaraj B, Adams S, Beatty M, et al. The Use of Online Care-Maps for Children with Medical Complexity. *Paediatrics & Child Health*. 2021;26(Supplement_1):e59-e60.

Care Map →
 Visualize
 Complexity of
 family care
 integration
 work



Jenetta Thomas

Sierra Smith

Cincinnati Children's Hospital Medical Center Spina Bifida Center: NATIONAL CARE COORDINATION ACADEMY EXPERIENCE

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- April 2019 – August 2019 : **Pediatric Integrated Care Survey (PICS)**

Completed assessment of patient and family experience with care coordination in our multidisciplinary clinic.

Goal: To determine ways to support and engage patients and families during clinic and beyond (transition).

Results: Patients and families generally reported positive experiences with care coordination, but the survey identified areas of improvement surrounding resources, integration, and available supports between visits.

NATIONAL CARE COORDINATION ACADEMY

Goal: To build on the PICS data to learn of ways to engage and support families during and between clinic.

We learned of additional tools available to help assess clinic gaps:

- 1. Family Engagement in Systems Assessment Tool (FESAT)** - This tool helps to assess how well families are being engaged in specific systems-level initiative, policies, or practice. Revealed areas to focus quality improvement efforts:
 - Need for family support due to the impact of the child's diagnosis.
 - Need for active tracking of lost to follow up and re-connecting them to clinic and care coordination services

Results: Improved scores post intervention(s).
- 2. Care Coordination Management Tool (CCMT)** - used to help quantify care coordination activities and better understand care coordination supports needed specific to our patients and families.

Results: In progress – plan to institute Fall / Winter 2022
- 3. We are also working to develop a registry** in our electronic health record (Epic) to help support care coordination and population health management efforts.

Our experience:

NATIONAL CARE COORDINATION ACADEMY

Through participation in the National Care Coordination Academy, we have been able to:

- **Network with other** multidisciplinary Spina Bifida clinics, providers and organizations.
- **Strengthen our relationship** with our local Spina Bifida Coalition which supported expansion to Eastern Ohio and West Virginia.
- Form relationship with **Support Services** at CHMC:
(Ohio Parent 2 Parent and Family to Family)

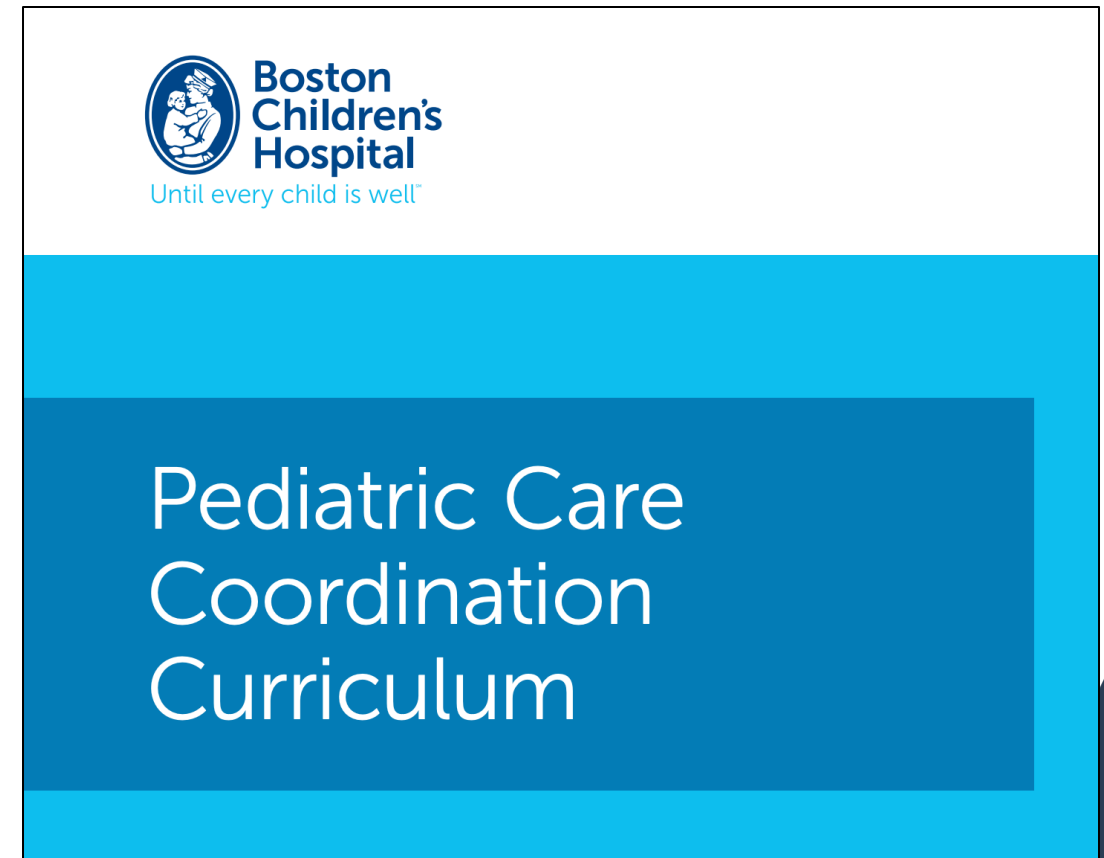
Growth of our Spina Bifida Patient Advisory Committee:

- Advocacy for caregiver Covid-19 vaccine on Capitol Hill
- CHMC website content & photo update, diagnosis day brochure, clinic welcome packet
- Live clinic support with local Spina Bifida Coalition
- Library resources – book delivery during clinic library story time
- Building considerations for accessible entry to clinic space
- Clinic scheduling adjustments

Pediatric Care Coordination Curriculum, 2nd Edition



- **An interprofessional resource to effectively engage patients and families in achieving optimal health outcomes (2nd Edition)**
- **Modules**
 - High-Value Integrated Care Outcomes Depend on Care Coordination
 - Developing and Sustaining Strong Family/Professional Partnerships
 - Social Determinants of Health
 - Measurement
 - Using Technology to Improve Care Planning & Coordination
 - Evaluation



Accessing the Archive of the HRSA Funded National Care Coordination Academy Resources



Step 1: Create an account on OPENPediatrics: <https://learn.openpediatrics.org/learn/register>

Step 2: Log into your account and go to the user menu at top left

Step 3: Choose My Channels

Step 4: Enter NCCA2022 into the Enrollment code option

Step 5: Refresh the page

Step 6: Access the platform that includes recorded lectures, slides, and supportive articles/links to tools.

Direct link to the NCCA page: <https://learn.openpediatrics.org/learn/dashboard/channel/103>

Care Coordination Technical Assistance Support



- If you have any questions about adapting and using any of the measurement tools, the ***National Center for Care Coordination Technical Assistance (NCCCTA) is available to assist!***
- Visit the NCCCTA website to learn more: <https://www.childrenshospital.org/integrated-care/national-center-care-coordination-technical-assistance>
- To request technical assistance email: NCCCTA@childrens.harvard.edu



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