

# #ComplexCare4Kids: It's all about partnerships

## Event Recap



Children's Healthcare Canada, together with Alberta Children's Hospital (ACH) and Alberta Health Services, hosted a Pop-up event, All In: Creating Synergy in Pediatric Complex Care on March 25, 2021. The event focused on how we can collectively create synergies to support children, families, and healthcare providers to promote the best possible health outcomes for children with medical complexity and their families.

## Why focus on connecting care for children with medical complexity?

Children's Healthcare Canada identified children with medical complexity (CMC) as a priority population in 2012 and led the development of A Guideline for the Management of Children and Youth with Medical Complexity with our CMC Community of Practice in 2016. Currently Our Practice Network, Connecting Care for CMC, is focused on improving the experiences at point of care transfers for children, families and healthcare providers.

Similarly, Alberta Children's Hospital identified 'complex care' as an area of priority and recognizes the need for broader provincial and national collaboration to foster innovation and system-level advancements. There are a number of innovative projects and programs underway at ACH, and across the country, aimed at improving health transitions and integration of care for complex needs populations. Work continues to create connectivity and linkages across these various initiatives.

## What is a Pop-up event?

Virtual Pop-Up events are focused mini-conferences and another way for Children's Healthcare Canada to bring relevant content to our members in areas of strategic priority. These events are characterized by a focus on a specific area of child and youth health that fits within our identified priorities. They present an opportunity for members to share research, new/promising programs and services, convene thought leaders to identify and prioritize health system issues, identify gaps in research or services, and build national relationships and network with colleagues across the country.

# Innovations in Care Coordination: Practices for improving care for children with medical complexity

Dr. Richard Antonelli, the event's keynote speaker, shared his transformative work in pediatric care coordination to help strengthen health systems globally by improving health outcomes, reducing the burden of care for families, and decreasing healthcare costs.



Care coordination is the set of activities and functions that are required to create and implement a multidisciplinary plan of care in partnership with the child and family. Many of these activities and services take place between visits to providers or the hospital and are identified as important to and perceived to be working - or not - by the child and the family.

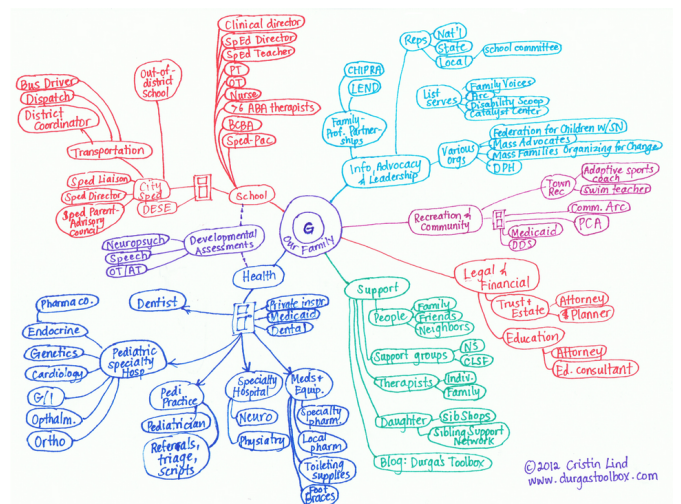
Characteristics of quality care coordination include child- and family-centred care; proactively planned and comprehensive services; promotion of independence and self-care skills development; and cross-organizational, cross-sectoral relationships.

Families of children with medical complexity have been the primary care coordinators for their children, connecting the dots across settings - home, healthcare, school, community. This role has required a great deal of time and added considerable stress with negative health and other impacts on the family. But help is available. Dr. Antonelli and his team have developed a tool, the care map, to assist families and the professionals with whom they partner.

**"This is all about partnerships with children, their families, and service providers. The families are key members, if not the central member, of care teams." - Dr. Richard Antonelli**

To illustrate this complexity as experienced by a child with medical complexity and their family, Dr. Antonelli shared one family's care map, likening it to an intricate subway map (Figure 1).

Family-centred care planning is a process by which families, including children, youth and young adults work with a member of the care team to co-create an interdisciplinary prioritized list of goals and outcomes, which



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are tracked over time. This co-created plan of care includes tracking the implementation and outcomes of that plan. Priorities within that plan of care are established by the child and family, so their goals are explicitly incorporated into the plan from the start. The heart of child- and family-centered care involves identifying assets and strengths as well as the needs of the child and family; linking them to appropriate resources; and measuring what matters to the child and family. Success is measured by our impact on outcomes of quality and safety, patient and provider experience, and cost of care.

**It is not enough to just provide services. [Care coordination] and integration reduces waste associated with fragmentation in care delivery. Interprofessional integration is essential to reducing disparities due to related social needs (e.g., housing, poverty, violence, food insecurity). - Dr. Richard Antonelli**

**Care integration is essential to achieving high quality, effective care for children with medical complexity [and their families]. - Gemma Vomiero**

#### Resources

- [Care mapping: A how-to guide for families](#)
- [Care mapping: A guide for professionals supporting families](#)
- [Care Coordination Curriculum \(2nd Edition\)](#)
- [Care Coordination Measurement Tool](#)
- [Adaptation and Implementation Guide](#)
- [Pediatric Integrated Care Survey and related tools](#)



## Showcasing Innovations from Alberta

Next on the agenda, our Alberta colleagues shared three innovative programs highlighting great work happening across the local care continuum and the associated challenges. First up, Nadine Gall, described Alberta Children's Hospital's neurodevelopmental disorders care coordination initiative, inspired by Dr. Antonelli's work at Boston Children's Hospital. Pediatric care coordinators act as a hub linking health, school and community to improve care integration and communication across services reducing parent and caregiver stress.

[With care coordination], we are seeing significant reductions in ED visits and acute care use....we want to see a shift to ... less reactive, more preventable, and [anticipatory] care. The tools that Dr. Antonelli talked about have been critical to our demonstrating success. - Nadine Gall

Next, Dr. Tanya Wasielewski, discussed the Community Outreach Assessment and Support (COACH) Program. COACH is a cross-ministerial initiative that aims to meet the needs of children, youth and adults with complex service needs.

Clinical services are delivered in clinic and community settings. To ensure quality continuity of care across the multiple systems and services, COAST uses a case management approach focused on coordination, collaboration, and accountability ensuring that all supports for the person and family understand the person as a whole.

A huge part of the success of [the COAST initiative] has been [being] cross ministerial... We have the advantage of being able to accept referrals from multiple ministries and multiple systems.  
- Dr. Tanya Wasielewski

We then heard from Tammy Island, who shared how the First Nations Health Consortium supports First Nation families in accessing Jordan's Principle and other existing community resources in Alberta through enhanced service coordination. They connect children to health, social and education services and support families in applying for Jordan's Principle funding.

## Resources

- [Family Support for Children with Disabilities \(FSCD\)](#)

## Family Panel

Families of children with medical complexity assume many and varied responsibilities when they first bring their child home from the hospital. These parents have careers, other children, and outside interests. Soon they become trained in specialized medical procedures, and have sophisticated medical equipment in their homes. Their interactions and deep involvement with the multiple systems of care allow them to make clear observations about what works and what does not.

Genevieve Currie, parent advocate, nurse, researcher, and mother of two children with neurodevelopmental disorders led a discussion with three other mothers whose children have been described as medically complex and receive healthcare services in multiple settings.

Some topics included were what complex care means, a typical day-in-the-life, and what has been helpful (or not) for you and your family.

When asked what complex care means to her as a parent, Rachel Martens replied that the term medical complexity doesn't tell the full story of a life and perhaps a new term should be found. These children may fit into a disability diagnosis and will require high technology use at home but they aren't counted as people in data sets, so it is very hard to know where they fit in the larger community and world. It is not just about keeping them alive it is about providing them with a life.

A typical day for Amber Desjarlais caring for children with complex needs is never the same. Each day brings new challenges and new joys. Behaviour disorders and evolving medical issues mean that vigilance is always required to keep her children safe. The joy comes from seeing how far her child has come with the right types of individualized services.

As a mother of a child with complex medical needs who needs full time monitoring, Lia Lousier said that managing through the day means using six hours of respite care to do groceries, get sleep, attend to her other children, and do whatever else needs to be done, but never feeling like you have done enough. This can take a huge physical and emotional toll at times.

Everyone agreed that there is a greater need for policy makers to think about system change rather than technical worries about privacy. Families need to be involved in the system redesign and in control of their data and information.

At the end of the day these families want other families to understand that their stories have value and that they are not alone.

**Every family deserves to be able to say in the end "We did good".  
- Rachel Martens**

## **Improving pain in children with complex medical needs**

Children with complex medical needs are faced with many sources of pain, including from medical procedures, interventions, and from chronic conditions. Assessing and managing pain for children with complex medical needs can be further complicated by differences in communication and other presenting concerns. In this session the speakers discussed the challenges and emerging advances to improve pain for children with complex medical needs. Speakers included a parent with lived experience caring for a child with complex medical needs, a complex care physician and researcher, and a child life specialist.

Sarah Penny, a professional engineer and mom of two teens, kicked off the session by sharing her lived experience as a parent of a child with complex medical needs and their journey to manage his pain. She highlighted the importance of including parents in the development of the care plan as they hold the critical outlook and intuition as to what the root cause of the pain can be.

Dr. Tammie Dewan spoke to medically complex children and their experience with chronic pain. During this session the PIUO (Pain and Irritability of Unknown Origin) Study was highlighted to develop a pathway to establish if the child has a specific treatable cause of pain or should they be thinking about a parent pain treatment.

**Establishing the clues and patterns are the most helpful ways to get started in evaluating the pain. - Dr. Tammie Dewan**

Kate Ross discussed the use of Specialized Care Plans and how they can be incorporated in the child's treatment with the intention to best support everyone involved. These plans can be put into action with the support of Child Life through the hospital by the referring physician or the family can submit it as well.

#### Resources

- [Pain Detectives website](#)
- [Initial Validation of GRASP: A Differential Diagnoses Algorithm for Children With Medical Complexity and an Unknown Source of Pain \(not public access\)](#)
- [Holland Bloorview Pain Toolbox](#)



## **Precision Health Genomics: Ending the Diagnostic Odyssey for Complex and Rare Disease Patients**

Rare genetic disorders disproportionately affect children, and often result in complex medical and social needs. Addressing these needs can further be complicated when a definitive diagnosis is not available. Rapid advances in genomics are providing an opportunity to arrive at a definitive diagnosis as a foundation for improving the care and support of families with these chronic diseases. Dr. Francois Bernier provided an overview of the undiagnosed disease program (UDP), bridging clinical care and research to achieve the goal of ending the diagnostic odyssey for children and families with rare genetic diseases.

More specifically, Dr. Bernier spoke about how to optimize outcomes, the value of diagnosis, how to better support families, and child health and wellness strategies. He

also provided overviews of various fantastic advancements to help families and providers in this community.

I have learned that prognosis cannot be based on small numbers. Functional programming is paramount, and care providers do much by just listening, being innovative, curious, and willing to try non-proven strategies. - attendee, Pediatrician and mother of child with rare disorder

## Patient Navigation as a Solution to Helping Children with Complex Care Needs and their Families Access Care in a Complex Maze of Services

Shelly Doucet and Dr. Allison Luke described the development, implementation, and evaluation of NaviCare/SoinsNav, a patient navigation centre for children and youth with complex care needs, their families, and the care team in New Brunswick. Patient navigation can serve as a novel approach to improve the integration of care for individuals with complex care needs in an increasingly fragmented system.

## Closing session: Reflections on the Emergence of Pediatric Complex Care in Canada

Dr. Eyal Cohen closed the day reminding everyone of the opportunity that the pandemic has provided us to look at our systems, focus on what's worked well, and rid ourselves of what did not, and create a new system for children and families in Canada.



When we partner together with ...organizations, families, government agencies ...that's when solutions - really exciting solutions - happen and there's a ton of promise again. ...Our stories are powerful and valuable. Our communities are strong. There's a huge appetite for reform in the system. - Dr. Eyal Cohen

## Join one of our networks!

Click one of the following links if you would like to join the [Connecting Care for Children with Medical Complexity \(CMC\) Practice Network](#) or the [Family Network](#). Please fill out the form, and we will be in touch.