



Session summary and what was shared:

Trends Related to Children and Youth with medically Complex Support Needs

About the Symposium Speakers' Series

As part of the Children and Youth with Support Needs (CYSN) engagement, a virtual speaker series was held to connect professionals in the field of child and youth development and disability with British Columbians. The series was also an opportunity to participate in a facilitated dialogue to help inform a new provincial CYSN service approach that is balanced with local situations and individual needs.

This virtual symposium speaker series was open to all British Columbians and provided a unique opportunity to foster collaboration and sharing among families, professionals, service providers, and interested parties. The breakout room discussions provided participants with an opportunity to engage in inclusive conversations, share insights, best practices, and explore research and session learnings through an anti-racism lens.

Session Overview

On November 21, 2023, Esther Lee and Brenda Lenahan presented on the topic of "Trends Related to Children and Youth with Medically Complex Support Needs." Esther Lee is a pediatrician and medical lead at BC Children's Hospital, and a palliative medicine specialist for Canuck Place Children's Hospital. Brenda Lenahan is a mother of a medically complex son, and co-founder of the grassroots group BC Complex Kids.

The presentation focused on sharing literature to help caregivers and healthcare professionals provide meaningful feedback to shape agencies that support children with medical complexity.

More than 180 people joined this session from areas across the province, representing a variety of perspectives, including health care professionals, non-profit organizations, families, education professionals and others.

Session Takeaways:

- The term 'children with medical complexity', was defined by four domains: high healthcare use, functional limitations, substantial family identified needs and chronic conditions. This term is not solely based on diagnosis, instead it is child-centered and considers the needs of families and caregivers. However, there are limitations with this term. For example, the lack of specificity within each definition creates a barrier in application within healthcare settings.

- Children with medical complexity makeup approximately 1% of the population. In BC, this is roughly 10,000 children. Despite their small percentage, they account for 35% of total pediatric healthcare usage. This underscored the significant healthcare needs of families caring for children with medical complexity, often overlooked in the system.
- Service efficiencies, coordination and collaboration tailored to children with medical complexity are beneficial for caregivers, families, and the broader healthcare system.
- Current and new literature supports standardizing care for all Canadian children and youth with medical complexity and improving the health care and systems of support. A list of literature referenced during the presentation is on the last page of this summary.

Breakout Room Discussion – What Was Shared

Following the presentation, participants were placed in small breakout rooms (ranging between five and 15 participants per room) for a moderated discussion about these questions:

- What points were new or surprising for you to hear?
- What points made you feel seen?
- What areas are most urgent to address through policy changes in BC? What will make the biggest difference for your family today and into the future?

The comments reflect participants' lived experiences and ideas for an effective system of services for children and youth with support needs across BC.

Participant comments have been themed into four categories:

1. Service Planning and Coordination: direct planning with families, transition planning (of any type), cross-program/ministry coordination.
2. Service Delivery: direct CYSN Services, wraparound services, workforce considerations.
3. Administration: funding, service processes and pathways (e.g., intake; prioritization), ministry roles and responsibilities (i.e., which ministry is responsible for what), and physical space.
4. Equity-centered, Anti-racist, and Inclusive Approaches.

Service Planning and Coordination

Ideas shared to support families included coordination support (e.g., a navigator), a one-stop shop for services, for agencies to proactively reach out to families, and information sharing across ministries and organizations:

- The Ministry of Education and Child Care, Ministry of Children and Family Development, Ministry of Health and Ministry of Social Development and Poverty Reduction could benefit from greater cross-ministry collaboration.

- Cross-ministry collaboration to support Indigenous families, including support for childcare workers and educators.
- Formalized process to support cross-ministry collaboration; some participants shared that they would like to see cross-ministry efforts supported through a formally recognized process.

Supporting the transition for when youth become adults; some participants shared that families could benefit from support for transitions between provinces, as systems differ.

Service Delivery

Participants shared that a trained and stable workforce is critical. For example, increasing the number of nursing and respite providers is needed. Service providers – those professionals working with children with medical complexity – need to be supported with training. Participants indicated that wraparound services and supports for the wider family is important; there is a need for specific services such as home and vehicle modification, counselling, administrative support, nursing support, and funding for early intervention. Existing services and programs could be scaled up and enhanced.

Program Administration

Participants expressed that more administrative supports to assist families in accessing services could help address filling out forms and administrative overload. Participants advised that any proposed changes need to include adequate funding to avoid instances of families having to compete for a share of limited funds. Overall, financial support is crucial to making an equitable system that families in different circumstances can navigate.

Equity-centered, Anti-racist, and Inclusive Approaches

A recurring theme was the desire for a more equitable approach to CYSN service delivery and resources available to families. Participants expressed a need for flexibility in eligibility criteria, recognizing children and youth have diverse needs. Participants shared that standardized assessments could help match families with the relevant support services.

To limit families having to travel for services and support accessing services when they need to, participants called for increases to capacity within rural and Northern communities. For example, through recruiting professionals, providing additional training, and securing funding to assure stability.

Integrating Indigenous-centered knowledge and care in service delivery resonated with many participants. This included meaningfully integrating Indigenous perspectives, prioritizing partnerships between Indigenous governments and service providers, and centering Indigenous culture in the care continuum. Calls were made for Indigenous agencies to take a leading role in delivering services for Indigenous children to ensure cultural competency. A rights-based approach with community involvement was deemed essential for any services or supports geared towards children and youth within Indigenous communities.

Overall, families and other stakeholders would like the new system to foster an inclusive environment where individuals receive the support they require, regardless of diagnosis or geographical location.

Participant Questions and Comments Summary:

Throughout the presentation, participants were encouraged to share their comments and questions in the Zoom chat function. Below is a summary of what was shared by participants:

- Digital Record Systems and Information Sharing: Care could be enhanced through technologies that allow for better information sharing and digital records systems.
- Support for Transitional Lifespan: Individuals need adequate support through life transitions (from infancy to childhood and youth, from youth to adulthood etc).
- Early Identification and Lifetime Support: Early and ongoing support is important throughout an individual's lifetime.
- Systemic Barriers and Discriminatory Policies: A new system of support should aim to address barriers and discriminatory policies, so families have improved access to necessary resources.
- Child-Centered Approach for Family Needs: The child or youth's needs must be met in order to then meet the needs of the family.
- Indigenous Values and Decolonization: Indigenous values and systems should be incorporated into support services to advance decolonized approaches to service provision.

Literature

1. Children with medical complexity: and emerging population for clinical and research initiatives,"
2. CAPHC Guideline for the Management of Medically Complex Children and Youth Through the Continuum of Care (2018)
3. Children and youth with Medical Complexity in Canada (CIHI, 2020)
4. Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family (RCY, 2018)
5. Left Out: Children and youth with special needs in the pandemic (RCY 2020)
6. Still Left Out: Children and youth with special needs in the pandemic (RCY 2023)
7. BCCH Complex Care – Nurse Key Worker
8. Careplan – myBookletBC.com
9. The Impact of COVID-19 of British Columbia's Children with Medical Complexity and their Families
10. Can you hear me OK?": Caregivers of Children With Medical Complexity and Their Perspectives of Virtual Care During COVID-19
11. Experiences of medical traumatic stress in parents of children with medical complexity

12. Disaster support for families and children with medical complexity and special healthcare needs: A rapid scoping review of communication strategies
13. Perceived Disability-Based Discrimination in Health Care for Children with Medical Complexity
14. Cliff or bridge: breaking up with the pediatric healthcare system