



Session Summary and What was Shared:

Inclusion, Quality of Life and Community Networks of Support

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 Tuesday, December 5, Linda Perry presented on "Inclusion, quality of life and community networks of support." For 33 years, Linda was the executive director of Vela Canada, a BC not-for-profit that led to the establishment of a Microboard, assisting individuals with disabilities by developing customized and inclusive support systems. Linda has also significantly contributed to the development of Community Living BC's Individualized Funding Option and is an involved volunteer with various organizations, including the Family Focus Society, Lower Fraser Valley Aboriginal Society, and the Family Support Institute's Board. Additionally, she has served on the Prime Minister's National Volunteer Awards Council and volunteered internationally with the Zero Project, advocating for a world with zero barriers. Today, she continues working with Vela as the special projects' coordinator.

The presentation provided an overview on historical trends in disability support, the importance of collaboration and allyship in driving change, the emotional journey of families, and current trends in disability support, such as person-centered thinking and the importance of creating networks and friendships for individuals with disabilities.

More than 70 people joined this session from areas across the province, representing a variety of perspectives including non-profit organizations, educators, families, health care professionals and others.

Session Takeaways:

- Historically, families of children with disabilities were advised to place their children in institutions, neglecting the negative impacts of isolation. Through sustained efforts and allyship, a group of determined parents in BC led the shift towards community-based care, establishing respite homes and advocating for inclusive education.
- Person-centered thinking prioritizes an individual's interests, needs, and aspirations without editing or limiting them due to financial constraints. Strong family support and diverse networks can support individuals to lead lives, where obstacles are met with solutions.
- Listening to an individual's needs deeply is vital to respecting their concerns, fears, and worries. This includes understanding their communication style and expressions, beyond verbal communication.
- Open and honest discussions about the limitations of advocacy and government services with families are crucial, as they might not meet all the needs of an individual. It is important to also explore alternative opportunities within communities, friends, and family to enhance the lives of children and youth beyond what systems can provide.
- Creating meaningful networks, mentorships, friends and circles, is vital for a fuller life, as isolation significantly impacts mental health.
- Family-driven support is essential. Parents have intricate knowledge that is often overlooked, including the daily routines that impact their child's life. Recognizing this authority can allow families to effectively communicate their needs and contribute to the development of tailored services and supports.
- Creativity is key in seeking solutions for family-driven supports. Despite facing discouragement, taking a moment to relax, consult trusted friends, and brainstorm alternatives beyond the initial "no" is crucial.

Breakout Room Discussion – What Was Shared

Participants were placed in small breakout rooms (ranging from five to 15 participants per room) for a moderated discussion to discuss this question:

Given all the learnings shared today, what one or two considerations stood out for you when informing a system of services for children and youth with support needs?

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

A family-centred approach is desired for a new service delivery system for children and youth with support needs. Participants noted that families know their children and youth best and should be at the centre of determining what is needed. However, it was also noted that families require time and support to learn about their needs, to accept diagnoses and the associated impacts on both personal and logistical levels of the family, as well as to determine their path forward at their own pace. Each family's journey is different, and resources with dedicated funding should be available when the family is ready.

Additionally, service planning must consider each family's unique characteristics, such as language, socio-economic background, family composition, and the support needs of family members, who may have diagnoses as well.

Planning for life transitions, particularly the transition to adulthood, should be part of a new service delivery system. Participants shared that the system should extend supports beyond the age of 19 to support young people in this transition.

Opportunities to connect families, offering places for socialization and community-building were noted as important considerations in a new service delivery approach. A variety of suggestions were offered to help families navigate systems and service planning and put the appropriate supports in place for their child or youth. Peer and community support was shared as a vital component. It was noted that families are often the best resource and could be trained or resourced to serve as navigators for other families.

In terms of service coordination, a desire for centralized resources was put forward, where families can go to one place and information is shared across ministries to better facilitate service delivery. A multi-disciplinary assessment team was proposed – one that could assess the needs of the family and child or youth and align the appropriate resources and services to the needs.

It was also noted that families in rural areas do not have the same access to services, and often have to travel to access support. There was a desire for agencies to work together to improve accessibility of services for those in rural or remote areas. It was also noted that technology can be a useful tool to help support connections for those who live in remote or rural areas.

Service Delivery

Families would like the Ministry for Children and Family Development to focus more on supporting them to choose their path for services to support their child or youth, and less from a protection lens, which can feel vulnerable, particularly if a child or youth's behaviour is challenging.

The microboard model was raised as an important option for families, as was in-home support, especially for families with children or youth with complex needs.

Some would like to see a navigator role that is broader than health care or social work to help families navigate through all necessary services, treatments and supports. For example, a business navigator could help a child

or youth with a disability learn to run a business, or help a family set up a not-for-profit organization or social enterprise.

Additionally, wraparound supports and support to access services that are not traditionally considered health care services but have important health and mental health benefits, such as music lessons or music therapy, or sports and athletic programs, should be part of a new service delivery approach. This is important especially when children or youth need additional supports or accommodations to participate in these types of activities.

It was also shared that a new service delivery approach must find ways to reduce wait times for assessments and services, and provide support to children, youth and families through the period of assessment and diagnosis. A path or mechanism to dispute diagnoses or request a second opinion/assessment was also desired.

Program Administration

Greater funding overall, and broader access to this funding is needed, so families can support their child or youth. For example, widening the access to Autism funding so it is available to all families with children or youth on the Autism spectrum is important. Participants pointed to the New Zealand and Australian models, which offer different types of individualized funding for families, as examples BC could look to.

Support in the form of capacity building and training was also noted as important, where professionals could be matched with individuals and families to help build skill sets within the family.

Equity-centered, Anti-racist, and Inclusive Approaches

A new service delivery approach should include ways to build cultural competency among professionals working in the health care and social services systems. It should also aim to remove barriers that newcomers experience and address systemic racism within the system.

Participant Questions and Comments Summary:

Throughout the presentation, participants shared comments and questions in the Zoom chat function related to designing a new system for children and youth with support needs:

- Inclusive Communities: Suggestions for more collaboration among local communities and organizations to create inclusive environments where individuals with disabilities, their families, and support networks can contribute and feel welcomed.
- Accessibility Support: Emphasis for better understanding of the challenges faced by ADHD or dyslexic individuals who struggle to access necessary support in educational settings. One opportunity for improvement included more assistance for individuals and their families seeking varied support, such as government-funded disability support services for specific needs.
- Self-advocacy: Promoting and supporting individuals who self-advocate while also providing advocacy for others.

- Navigators' Characteristics: Highlighting the ideal characteristics of a navigator as someone who serves as an ally focusing on the needs, preferences, and interests of individuals. Emphasis on the importance of navigators who can explain options clearly, create safety, share new ways of thinking, and are well-connected within the community.
- Improved Processes for Businesses: Consideration of a "business perspective" for example, the need for streamlined processes for businesses and entities involved in supporting neurodiverse individuals. Suggestions included faster payment methods and reduced paperwork.
- Support Specialists: Highlighting the value of family peer support specialists and neurodiversity support specialists, who draw from lived experiences.