



Session Summary and What was Shared:

Key Increasing Behavioral Complexity and Needs of Children and Youth with Neurodevelopmental Disorders

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 Thursday, December 14, 2023, Dr. Robin Friedlander presented on "Increasing Behavioral Complexity and Needs of Children and Youth with Neurodevelopmental Disorders." Dr. Friedlander is a child psychiatrist, clinical professor and director of the Neurodevelopmental Disorders Program within the UBC Department of Psychiatry in Vancouver and founder of the Self Injurious Behavior clinic at BC Children's Hospital.

The presentation discussed the increasing prevalence of Autism Spectrum Disorder and multidisciplinary causes of aggression, as well as explored what services children and youth with behavioural complexity most need, and how to provide those services in an equitable way.

More than 160 people joined this session from areas across the province, representing a variety of perspectives including health care professionals, educators, policymakers, non-profit organizations and others.

Session Takeaways:

While the phenotype of autism, or the rate core symptoms has remained unchanged, the prevalence of autism diagnoses has increased. Some explanations for the observed increase include broadening of diagnostic criteria and diagnostic substitutions. Children with complex neurodevelopmental disorders present behavioral challenges including aggression and rage outbursts. The consequences of these behaviors range from parental burnout to restricted access to school and peers, while the causes can be multifactorial and include the inability to communicate needs and other conditions such as PTSD or depression. The support and treatment needs of children with neurodevelopment disorders and complex behaviors include:

- Assisted communication or behavioral therapy to assist with emotional regulation
- Parent behavioral management training and education on how to manage behavioral challenges
- Treatment of comorbid mental health conditions through medication or psychological counselling
- Respite through increased funding for needy families, respite caregivers, and dedicated facilities for short-term and emergency respite
- Residential treatment and placement for parents that cannot provide long-term or a permanent home for children with behavioral complexity
- Case manager for the most complex cases to help manage different aspects of life and treatment

Dr. Friedlander offered some ideas regarding equitable funding, proposing that diagnoses-based funding is not useful but should be needs based instead. He also noted that aggression is the biggest need and hard data documenting and evaluating aggression metrics are needed.

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 three 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), roles and responsibilities (i.e., which ministry is responsible for what), physical space

Service Planning and Coordination

The predominant theme shared by participants was the necessity to train and educate parents who have children with behavioral complexities – providing them with skills to address challenging behaviors from the point of diagnosis and onward. Participants indicated that if adequate training is provided for parents, they can take a preventative approach to behavioral management and better meet their children’s needs. The benefits of directly planning with parents include the reduced need for respite services and ensuring children stay with families which will be beneficial over the long-term.

Participants emphasized the need for cross-coordination among ministries to deliver support to families more efficiently. Specific examples given in discussion were childcare programs, which often operate in isolation from other programs and the need for greater coordination with health care services to develop a respite system. Other specific suggestions included:

- Improving collaboration between the Ministry of Health and Ministry of Education and Child Care
- Providing school-based interventions and embedding services that families need within schools

In transition planning, a major theme was the need for support for youth transitioning to adulthood. Specifically, participants highlighted the gap in support and services available once youth “age out” of the system until they are placed in adult programs. Participants reiterated the need to have continuing access to youth services until adult services are in place to avoid the loss of skill sets and minimize the gap within this transition.

Service Delivery

Participants indicated there is a need for more skilled professionals and service providers available for families, such as social workers and respite workers, particularly in rural and remote areas where services are more limited. Some participants requested greater funding so families can hire professionals in a 2:1 staffing ratio, but noted that even with increased funding, service providers are often challenged with large caseloads. Participants also noted the need for more training of professionals to increase competency on methods of behavior de-escalation.

When referring to wraparound services, participants provided a range of opportunities for improvement including:

- Providing more mental health supports for families and children
- Developing specialized support worker programs to train and educate workers
- Connecting families with other families to provide support navigating the systems and for mentorship opportunities
- Implementing emergency services (e.g. emergency respite centres)

- Implementing support services and programs in schools and within health care services
- Providing coaching and counselling services
- Augmentative communication services

Overall, participants emphasized the need for robust support in a variety of areas including at home, in community, before and after school etc. Participants indicated the importance of keeping children with families and participants had concerns about initiatives that would separate children from their homes. Suggestions for improvements for direct services for children and youth with support needs include providing more supports for children with diagnoses beyond just Autism Spectrum Disorder, the need for earlier interventions, the use of medication as a complementary tool, and initiatives to address waitlists for respite.

Program Administration

In the context of administrative challenges, discussion centered around challenges in the service pathways. Specifically, participants highlighted that many families from different cultural backgrounds need support to overcome barriers such as language differences. Without this support, it is difficult for families to advocate for themselves. Many families also stressed the critical importance of getting a diagnosis to receive services and funding, as well as for respite care, but noted more professionals are needed in both areas (assessment and respite). For these reasons, participants highlighted the need for services based on need rather than only on diagnoses.

Participants voiced a desire for the Ministry of Children and Family Development to be proactive in planning with families. A specific suggestion was to lessen the responsibility placed on parents and families for finding respite providers. Participants suggested a minimum be set for respite funding for families and indicated funding should allow for a 2:1 staffing ratio, and that both flexible individualized funding, and a hybrid model for funding would be useful.

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:

- Needs vs diagnosis: the importance of assessing a child's needs based on aggression and behavior rather than just diagnoses. Additionally, there are risks associated with diagnostic substitution and diagnostic based eligibility criteria.
- Early childhood: interventions and treatments in early childhood are important in preventing aggressive behaviors as children get older.