



Ending the Wait

Overcoming systemic delays in the provision of support for neuro-diverse children and youth

Report to Select Standing Committee on Children and Youth with Neuro-diverse Special Needs

Inclusion BC appreciates the opportunity to provide a submission to the Select Standing Committee on Children and Youth's Special Project on Neuro-diverse Special Needs.

We are a non-profit federation working with partners to build community and to enhance the lives of children and youth with special needs, and to support adults with intellectual disabilities and their families. We provide support, education and advocacy where and when it's needed, throughout the lifespan. We also advocate at a systems level for policy change and promote inclusion through public awareness initiatives and campaigns.

Our vision is a world where we all belong.

Our submission will be divided into three sections, each addressing the guiding questions from a unique perspective:

- Children & Youth Services
- K-12 Education
- Transition to Adult Services

Children & Youth Services

The following section was developed by Richmond Society for Community Living (RSCL) Children's Services. RSCL is a valued member of the Inclusion BC Federation.

Briefly describe your experience with children and youth with neuro-diverse special needs.

Richmond Society for Community Living offers several programs and services that meet the changing needs of children and youth with developmental disabilities and their families, including:

- **Infant Development Program (IDP)** – Programs and supports for infants and children who are at risk for a developmental delay;
- **Treehouse Early Learning Centre** – Preschool and daycare program for children of all abilities (typically developing children and those who have additional support needs);
- **Supported Child Development Program (SCDP)** – Support for parents and child care professionals to ensure child care and preschool options are available for children who require additional supports;
- **Youth Connections Program** – Recreation-based out of school program for children and youth with developmental disabilities;
- **Family Resource Program** – Resources, supports and referrals for parents of infants and children with developmental disabilities; and
- **Family Respite** – Access to qualified temporary caregivers for children with developmental disabilities.

What is your experience with how children and youth with neuro-diverse special needs are identified, monitored, and referred for services?

Referrals are received from a variety of professionals: psychologists, pediatricians, public health nurses, doctors, social workers, therapists and child care providers. These professionals may be based out of BC Children's Hospital, Sunny Hill Health Centre for Children, the BC Centre for Ability and other organizations providing Infant Development Programs. Parents can also self-refer to early intervention services.

RSCL's Infant Development Program (IDP) provides early intervention supports for infants and children (birth to 3 years old) who are at risk for, or have been diagnosed with, a developmental delay. IDP is a family-centred program that regards each child and family as unique and offers parents/caregivers of children with neuro-diverse special needs the support to encourage their child's development.

IDP Consultants are professionals that can support parents by monitoring their child's development; providing suggestions of developmentally appropriate play activities and recommending adaptations to routines to promote the child's development. Consultants also connect families to community resources and make necessary referrals for assessment and therapy services.

RSCL's Supported Child Development Program (SCDP) helps families of children with developmental delays/disabilities to access inclusive child care. The program serves families with children from birth to age 19 years, who require additional supports to attend preschool, day care and out-of-school care. SCDP partners with community licensed child care programs, making necessary referrals based on a child's individual needs. Consultants monitor inclusion and offer planning,

training, and resources to successfully include children with extra support needs into typical child care settings. Consultants also support families through the transition to kindergarten and secondary school.

How could children and youth services be improved?

Reduce wait times to improve access to services

Currently, the Richmond Speech & Language Department has a waitlist of 12-15 months. The waitlist for assessment at Sunny Hill Health Centre for Children to receive services is up to 18 months. The BC Centre for Ability has waitlists for services that range from 3-6 months, depending on the discipline (SLP/OT/PT) required. Waitlist for RSCL IDP and SCDP are approximately 3-6 months and typically increase if a child requires additional funding to be supported in a child care setting.

Because of lengthy waitlists, children who receive late referrals often go unsupported upon entry into kindergarten making the transition for the child, parents and educators unnecessarily complicated and stressful. Many families are not able to access early intervention services at all. The supply of service simply cannot keep up with the demand and families get only the minimum service during the waiting period.

Additionally, due to lack of funding families may experience interruptions in service delivery with each transition which can negatively affect their child's developmental outcome. For example a child who receives SCDP support to attend preschool may be placed on a waitlist for out-of-school care at their neighbourhood elementary school which may result in cross-boundary school enrollment. Out-of school care for youth ages 13+ with neuro-diverse special needs ensures that working parents have a needed child care option and provides recreational opportunities

and social inclusion. The lengthy waitlist for Youth Connections (Richmond's only program serving this unique demographic and one of only a handful in the Metro Vancouver) means that many youth will age out of program eligibility before a spot becomes available. The result is parents who become under or under-employed in order to care for their child and decreased social inclusion for the individual who in turn may require increased supports transitioning to adulthood.

Improve education and awareness

Increased and improved public education regarding the benefits of early intervention is vital. Accessing services is often a barrier for immigrant families, families who encounter language barriers, and those who face financial strain. In many cases, families are unaware of the help available.

It is also important to educate family doctors and other healthcare professionals who provide various referrals for infants and toddlers. Knowledgeable public health nurses and doctors can identify delays in routine visits and immunization appointments. Referrals also come from the Neonatal Intensive Care Unit (NICU), social workers and other professionals such as speech and language pathologists.

Standardize assessment tools

RSCL often identifies children with additional support needs by talking to the parents, observing children at play and in their daily routine, and using assessment tools, e.g. ASQ. Consultants also connect with the Early Intervention Team and medical professionals when there are concerns about a child's development. This process can be improved if some standardized checklist/assessment tools were designed for each condition, e.g. ASD, FASD.

Children & Youth Services (continued)

What do you find are the gaps, barriers and challenges with respect to assessments? Do they adequately take into account the needs of the child and the skills and capacities of parents and caregivers? Are there additional factors that should be taken into consideration?

Wait times

Long wait lists and wait times are a significant barrier with respect to assessments. Wait times for services across BC, in all organizations are too long and are directly impact a child's outcomes as they develop. Children are waiting too long for early intervention services that could benefit their development and long-term prognosis. Early intervention has been proven to give children the best chance of success in life.

Cost

Long wait lists and wait times create financial inequities based on a family's ability to pay for a private assessment. The cost of private assessments and private therapies are barriers for families, many of whom are not able to access grants to help pay for these private assessments. Further, diagnoses such as bipolar, dyslexia, FASD, ADHD, sensory processing, and other diagnoses don't have funding allocated to access therapy or services.

Education and Awareness

More education and awareness are needed, especially within communities facing cultural, financial and social adversity. This would create a more open conversation and de-stigmatize disabilities and the need for help. If professionals had lighter caseloads, they could provide education more effectively and track progress more closely and intensely.

Recommendations:

- Eliminate wait times for assessments so that children and youth can access the supports and services they need.
- Increase funding for services for infants, children and youth to eliminate waitlists.
- Increase and improve public awareness and education of existing programs and services.
- Standardize assessment tools for all professionals.
- Eliminate geographical barriers to assessments by regionalizing assessment centres.

A Care Pathway for BC Kids

Inclusion BC supports the submission A Care Pathway for BC Kids in Care which highlights the need for trauma informed and integrated care for this population is a vital and necessary shift in paradigm for special needs services in BC - Meghna Halder & Lori Bel

K-12 Education

The following section was prepared by Inclusion BC.

Briefly describe your experience with children and youth with neuro-diverse special needs.

Inclusion BC provides advocacy support to people with intellectual disabilities and family members who need our help. This could mean connecting them with resources in their community or standing by their side as they advocate for the services they need. Inclusion BC supports more than 600 people and their families each year through this program. Approximately half of our calls are related to K-12 education.

What is your experience with how children and youth with neuro-diverse special needs are identified, monitored, and referred for services?

Inclusive Education is the right of all students in BC. However, too many diverse learners are being excluded from our public school classrooms, are being restrained or secluded, or do not have access to full days in the classroom. Consequently they are not reaching their educational goals or potential as they grow and progress through life. The 2017/18 completion rate of 62.2% for students with special needs may be a reflection of this situation.

Better educational outcomes for children and youth with neuro-diverse special needs begins with early identification and assessment. This is often provided during the preschool years, but we hear from many families that they are on a waiting list for several years and often enter school without a diagnosis, developmental or functional assessment or intervention services. This is particularly apparent in rural BC where access to specialists is an issue.

School-aged assessments should also be more readily accessible once school-based teams have identified the need. There are lengthy waitlists for

“Improve the funding for School-Age Extended Therapies by providing the opportunity to pool therapy funding so that they can focus on the specific needs of their child, improving their health and helping them obtain the maximum level of independence”

**BC Parents of Complex Kids,
Recommendation: At Home Program.**

Inclusion BC supports the submission make the *BC Parents of Complex Kids, Recommendation: At Home Program*. Their submission outlines many inequities experienced by families receiving Children and Youth Special Needs Service (CYSN), but one that stood out for Inclusion BC is the need to improve school age therapies.

K-12 Education (continued)

psychoeducational assessments in school districts and outside assessments cost upwards of \$5,000. This is unacceptable.

Without the assessed information, an effective individualized educational plan (IEP) is unlikely to be produced. If a student enters the school system without an IEP, they can experience severe difficulties in adapting due to a lack of support. Children and youth often exhibit unwanted behaviour when they are not understood, or their developmental needs have not been identified. School districts often rely on these assessments in order to access supplemental funding from the Ministry of Education before providing the needed support to the classroom. This is not Ministry policy as the expectation is that ALL students will receive the necessary supports. However, most of the calls to our office for advocacy support are about the lack of educational support, gaps in educator training, and exclusion.

For example, a 9-year-old girl has a diagnosis of Attention Deficit Disorder and Oppositional Defiant Disorder. She may also have Autism. She has been waiting for an autism assessment for over a year. She has moved to 3 different schools in the last couple of years and is currently attending school only for 1.5 hours a day. Her mother (a single mother of 3 children) has a language barrier and is unable to go to school to improve her English or work because she has to be ready to pick her daughter up when called by the school. The family has no access to respite or other types of support or therapy because their daughter does not qualify with her current diagnoses. MCFD is involved due to a child protection investigation. This family is not eligible for services through Children and Youth with Special Needs, even though they are in desperate need at this time.

How could K-12 education be improved?

Recommendations:

- **Ensure early identification and assessment. Cross-Ministerial (Education, Health & MCFD) collaboration is necessary to provide early identification, assessment and intervention services so that all students will receive the support they need once they enter Kindergarten or at the time they are identified.**
- **Eliminate wait-times for psycho-educational assessments throughout the K-12 system.**

Kids Can't Wait

This submission is meant to be supplemental to the December 2016 Report Kids Can't Wait, which was co-authored by Richmond Society for Community Living, Inclusion Langley, The BC Association for Child Development and Intervention, BC Centre for Ability and the Family Support Institute of BC. Collectively as advocates, service organizations and families, we came together to build the case for investing in Early Childhood Intervention programs in British Columbia. Despite recent investments, the challenges outlined in this report prevail and the solutions, from our perspective, still hold true.

Transition to Adult Services

The following section was prepared by Inclusion BC.

What is your experience with how children and youth with neuro-diverse special needs are identified, monitored, and referred for services?

By the time families of youth with neuro-diverse special needs approach graduation, many are overwhelmed by years of case management, navigating the maze, and fighting for services. Unfortunately, and far too often, this period of transition is one of further upheaval, stress and uncertainty.

Recognizing this stressful time, the province introduced the STADD (Services to Adults with Developmental Disabilities) program several years ago. STADD has recently moved into MCFD and we are hopeful this presents a new opportunity.

The purpose was to help support youth (ages 16-24) make the transition to adult services and connect with their communities. However, access to STADD is currently attached to Community Living BC (CLBC) eligibility. This is a limiting factor of the program, especially considering the number of youth with neuro-diversity who do not qualify for CLBC support.

Even with the early transitional support provided by STADD, an individual and their family will not find out which CLBC services are available to them until after they have been assessed through CLBC's assessment tool, the Guide to Support Allocation (GSA). This tool cannot be applied for until after a person turns 18.

As a result, despite early transition planning and person-centred approaches, people are often waiting for services long after they transition from high school.

CLBC's Assessment Tool: The Guide to Support Allocation (GSA)

Those who qualify for CLBC are not guaranteed the supports they need to live a good life in the community. Developed in response to inadequate funding, the GSA is unfortunately used as a cost-savings tool and is not an accurate description of a person's support needs.

The CLBC website states that, "because CLBC can only approve services within available funding, these tools make sure that those who need the most help right away receive the services they need, and that as many people receive services as possible." The assessment tool is essentially a mechanism used to deny families and individuals the services they need.

In reality, this means that individuals families who need, for example, 25 hours a week minimum community support end up with an assessment score that gives them \$233 a month in respite funding. And those families who are unable to find a respite provider receive no support at all.

The family is expected to provide the support their child needs. For years we have been hearing from families that this is the most exhausting and stressful time of their lives. These are families who have navigated systems and waited for service after service from the time their child was an infant, through the school years. CLBC's assessment tool should provide accurate information about a person's needs with the intention of meeting those needs, not managing the expectations or denying their rightful access to a good life in their community.

Transition to Adult Services (continued)

In January 2010, the Guidelines for Collaborative Service Delivery for Adults with Developmental Disabilities was developed between CLBC, Regional & Provincial Health Authorities, Ministry of Health and Ministry of Social Development. The purpose was to develop guidelines and policy to meet the health-related needs of people with developmental disabilities in an integrated and sustainable manner. The agreement included (at the time) mental health services for ages 14 and above.

Integrated and sustainable mental health assessment and support continues to be a gap for many transitioning youth with neuro-diverse special needs. In many areas of the province, the wait time to see a psychiatrist can be more than 8 months and predominantly offered in the Lower Mainland of BC. People only have access to Development Disability Mental Health (DDMH) for 18 months. Counselling is not covered by benefits, so if you don't have money, you can't see a counsellor; much less one that specializes in neuro-diversity and intellectual disability. For most, once a person is in crisis the only support available is going to a hospital emergency, or calling the police. Considering people with intellectual disabilities experience mental illness at twice the rate of the general population this is an area that requires immediate attention and investment.

How could the transition to adult services be improved?

Recommendations:

- Expand the mandate of STADD to allow Navigators to support a broader population of youth with neuro-diverse special needs.
- Ensure the GSA is used for the purpose of providing support with accurate information about the support requirements for youth with neuro-diverse special needs.
- Improve collaboration among CLBC, Ministry of Health and Regional and Provincial Health Authorities to improve the way we support youth with neuro-diverse special needs.
- Eliminate geographic barriers to mental health assessments and support for youth with neuro-diverse special needs by regionalizing assessments centres.

Thank you for the opportunity to provide a submission. Inclusion BC offers our support to implement all the recommendations as an ally to government and strong community partner.



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