

Select Standing Committee on Children and Youth

CHILDREN AND YOUTH WITH NEURO-DIVERSE SPECIAL NEEDS



LEGISLATIVE ASSEMBLY
of BRITISH COLUMBIA

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To the Honourable
Legislative Assembly of the
Province of British Columbia

I have the honour to present herewith the report of the Select Standing Committee on Children and Youth on children and youth with neuro-diverse special needs, as unanimously approved by the Committee.

Respectfully submitted on behalf of the Committee,

Nicholas Simons, MLA
Chair

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Composition of the Committee

Members

Nicholas Simons, MLA	Chair	Powell River-Sunshine Coast
Michelle Stilwell, MLA	Deputy Chair	Parksville-Qualicum
Sonia Furstenuau, MLA		Cowichan Valley
Rick Glumac, MLA		Port Moody-Coquitlam
Joan Isaacs, MLA <i>(to February 12, 2019)</i>		Coquitlam-Burke Mountain
Ronna-Rae Leonard, MLA		Courtenay-Comox
Ellis Ross, MLA <i>(from February 21, 2019)</i>		Skeena
Rachna Singh, MLA		Surrey-Green Timbers
Laurie Throness, MLA		Chilliwack-Kent
Teresa Wat, MLA		Richmond North Centre

Committee Staff

Jennifer Arril, Committee Clerk
Karan Riarh, Committee Research Analyst
Katey Stickle, Committee Researcher

Terms of Reference

On February 14, 2018, and February 21, 2019, the Legislative Assembly agreed that the Select Standing Committee on Children and Youth be appointed to foster greater awareness and understanding among legislators and the public of the BC child welfare system, including the specific needs of Indigenous children, youth, families and communities, and in particular to:

1. Receive and review the annual service plan from the Representative for Children and Youth (the “Representative”) that includes a statement of goals and identifies specific objectives and performance measures that will be required to exercise the powers and perform the functions and duties of the Representative during the fiscal year;
2. Be the committee to which the Representative reports, at least annually;
3. Refer to the Representative for investigation the critical injury or death of a child;
4. Receive and consider all reports and plans transmitted by the Representative to the Speaker of the Legislative Assembly of British Columbia; and,
5. Pursuant to section 30(1) of the *Representative for Children and Youth Act*, S.B.C. 2006, c. 29 complete the comprehensive review of the Act or portions of the Act by February 28, 2018 to determine whether the functions of the representative described in section 6 are still required to ensure that the needs of children and young adults as defined in that section are met.¹

In addition to the powers previously conferred upon Select Standing Committees of the House, the Select Standing Committee on Children and Youth be empowered to:

Appoint of their number one or more subcommittees and to refer to such subcommittees any of the matters referred to the committee and to delegate to the subcommittee all or any of its powers except the power to report directly to the House;

- a. Sit during a period in which the House is adjourned, during the recess after prorogation until the next following Session and during any sitting of the House;
- b. Conduct consultations by any means the committee considers appropriate;
- c. Adjourn from place to place as may be convenient; and
- d. Retain personnel as required to assist the committee;

and shall report to the House as soon as possible, or following any adjournment, or at the next following session, as the case may be; to deposit the original of its reports with the Clerk of the Legislative Assembly during a period of adjournment and upon resumption of the sittings of the House, the Chair shall present all reports to the Legislative Assembly.

¹ This mandate was not included in the Terms of Reference adopted by the Legislative Assembly on February 21, 2019 as the Committee’s work with respect to a review of the Act was concluded by the February 28, 2018 deadline.

Foreword by the Committee

The Select Standing Committee on Children and Youth has a unique responsibility to raise awareness of the challenges and issues experienced by some of our most vulnerable populations – children and youth and their families. This past year, the Committee undertook a special project on children and youth with neuro-diverse special needs.

We express our sincere appreciation to all family members and caregivers who shared their journeys, experiences, challenges, successes and hopes with us. We thank and honour all family members, friends and individuals who care and advocate for children and youth with neuro-diverse special needs. The pressures and challenges families face in supporting children and youth with special needs are significant. Recognizing that these pressures may limit the ability of some individuals to advocate and share their issues and concerns, we acknowledge that there are many voices we were not able to hear from. We also sincerely thank all service providers, professionals and organizations dedicated to helping children and youth with neuro-diverse special needs.

We recognize that each child's journey and needs are different. The system serving children and youth with neuro-diverse special needs includes a complex range of health and social programs and services which are often challenging to navigate and access. We understand that the system requires significant changes to better meet the needs of children and youth with neuro-diverse special needs and their families. In making our recommendations, we looked for opportunities to make a meaningful difference to children, youth and their families now, while recognizing that broader transformations and overall simplification is needed in the long-term.

Executive Summary

On November 22, 2018, the Select Standing Committee on Children and Youth (the “Committee”) agreed to undertake a special project on children and youth with neuro-diverse special needs with a focus on eligibility and assessment processes. Committee Members began their project with briefings on the current system of supports and services for children and youth with neuro-diverse special needs and their families. The Committee heard from the Ministry of Children and Family Development, the Representative for Children and Youth, the Ministry of Health and the Provincial Health Services Authority, the Ministry of Education, Community Living BC, and the Office of the Advocate for Service Quality.

The Committee held a public consultation from April 15, 2019 to June 7, 2019 which included eight public hearings and opportunities to share input via a written or video submission. Committee Members heard from parents, caregivers, service providers, and community organizations from across the province. The Committee carefully considered all input in making 16 recommendations to improve eligibility and assessment processes for children and youth with neuro-diverse special needs. This report summarizes the experiences, observations, ideas and priorities shared throughout the consultation, and the Committee Members discussions and recommendations, and is organized thematically.

Committee Members recognize that each child has unique gifts and needs and every family’s journey through assessment and eligibility processes is different. The Committee heard repeatedly about challenges families experience in trying to understand and access the system of assessments, services, and supports involving different ministries and organizations, sometimes with varying criteria. Parents and caregivers face barriers navigating this system while also experiencing emotional and financial strain and challenges with accessing respite. Some families face additional barriers due to cultural or socioeconomic factors or a history of personal or family trauma. The Committee recommends that government create family navigator positions and a comprehensive, multilingual website to help families navigate this complex system, as well as increase access to respite care across the province.

Timely identification and assessment of children and youth with neuro-diverse special needs is also a challenge. Committee Members emphasize the importance of early identification of children and youth as many families, caregivers and organizations stressed the significant positive impact of early intervention in the long-term. Members highlighted this issue in their deliberations and recommend enhancing universally accessible screening of children at the age of 18 months, as well as exploring opportunities for additional universally accessible screening between the age of 18 months and five years to improve early identification of neuro-diverse conditions. The Committee also recommends a public awareness campaign on the full range of neuro-diverse conditions. The campaign should work to improve recognition of neuro-diverse conditions, and awareness of and access to services and supports, as well as reduce stigma and promote an environment of inclusion amongst all British Columbians.

Throughout the consultation, families, caregivers and organizations pointed to long waitlists for assessments and services as a major barrier. Families find the assessment process to be complex, often involving multiple referrals and appointments with different medical practitioners. Committee Members discussed opportunities to reduce waitlists and streamline the assessment process, and recommend allowing speech-language

pathologists to refer for assessments. The Committee also recommends requiring ministries and other publicly funded organizations and service providers to set benchmarks for reducing assessment and service wait times and to report on outcomes on an annual basis.

Some families, caregivers and organizations also noted that there are high caseloads for service providers or a lack of sufficient service providers, particularly in rural, remote, and northern communities. Committee Members agree that a labour market review for professionals serving children and youth with neuro-diverse special needs should be conducted, and that based on this review, access to occupational therapy and speech-language pathology services should also be increased and expanded. They further recommend the provision of incentives and/or rural-based post-secondary programs to increase the number of service providers in rural, remote and northern communities so that families do not have to travel for services. They also recommend that government expand the use of telehealth.

Another key issue that emerged from the consultation is that the provision of and funding for many services is based on diagnosis. Children and youth with certain diagnoses may receive or be eligible for higher levels of funding and supports than children and youth with other diagnoses, even though the functional need and ability of these children and youth may be similar. Members agree that the provision of services should be based on functional ability, rather than diagnosis. A service model based on functional ability will ensure supports are appropriate and address need. The Committee also heard about challenges with service provision within the school system and the importance of promoting a positive learning environment. Committee Members recommend ensuring the Ministry of Education's inclusion policy is observed and that children with neuro-diverse special needs are fully supported in the school community while accessing individualized education.

The Committee heard from families and service providers about challenges with transitions and information sharing. The transition from community-based support to the school system, as well as transitions between grades, is particularly difficult for children with neuro-diverse special needs. The Committee agrees that planning and communication should be improved and recommends creating a single health record for children with neuro-diverse special needs that can be accessed by service providers. They also suggest providing the flexibility to delay kindergarten entry by one year, beginning transition planning earlier, and implementing transition planning between community-based therapy teams and school-based therapists.

Special Project Overview

The Select Standing Committee on Children and Youth is appointed by the Legislative Assembly to foster greater awareness and understanding of BC's child welfare system, including the specific needs of Indigenous children, youth, families and communities. In addition to considering reports of the Representative for Children and Youth, the Committee may undertake special projects on aspects of the child and youth-serving system. On November 22, 2018, after considerable reflection, the Committee agreed to undertake a special project on children and youth with special needs.

The Committee received initial briefings from the Ministry of Children and Family Development on programs, services and supports for children and youth with special needs and the Representative for Children and Youth on January 21, 2019. In these briefings, Committee Members heard that pathways, assessments, service provision and challenges are different and particularly profound for children and youth with neuro-developmental disorders and their families and caregivers. The scope of the special project was therefore refined to children and youth with neuro-diverse special needs, such as Autism Spectrum Disorder (ASD), Fetal Alcohol Spectrum Disorder (FASD) and developmental delay, with a focus on eligibility and assessment processes.

The Committee also heard about the Ministry's work on the development of a service framework for Children and Youth with Special Needs (CYSN) programs and services. This included a consultation with families and service providers regarding access, quality and coordination, and will guide improvements to the provision of and funding for programs and services provide by the Ministry.

Additional briefings were received on March 26, 27 and 28, 2019 from the Ministry of Children and Family Development and the Representative for Children and Youth, as well as the Ministry of Health and the Provincial Health Services Authority, the Ministry of Education, Community Living BC, and the Office of the Advocate for Service Quality. These briefings provided Committee Members with further information on the existing eligibility and assessment processes for children and youth with neuro-diverse special needs, as well as associated challenges and considerations.

The Committee held a public consultation between April 15 and June 7, 2019, inviting British Columbians to share their input and experiences at a public hearing (in-person or via teleconference) or by providing a written or video submission. Public hearings were held between May 21 and June 4 in Terrace, Fort St. John, Prince George, Kelowna, Castlegar, Nanaimo, Victoria, and Surrey. In addition to distributing provincial and regional media releases, the consultation was promoted on the Legislative Assembly's social media accounts. The Committee also reached out directly to stakeholder groups, including service providers, advocates, parent organizations, community organizations, workforce associations and academics. To encourage participation, the following guiding questions were provided:

- Briefly describe your experience with children and youth with neuro-diverse special needs. Are you a parent or caregiver of a child with neuro-diverse special needs? A service provider?
- What is your experience with how children and youth with neuro-diverse special needs are identified, monitored, and referred for services? How could this be improved?

- 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?
- How does support change from early years to school age and from school age to Community Living BC? What are the challenges with these changes? How could processes and supports at these stages be simplified and improved?
- What changes could be made to eligibility and assessment processes for children and youth with neuro-diverse special needs that would have the most positive impact?

In total, the Committee heard 87 presentations and received 137 written and video submissions. Committee Members carefully considered input received from all sources during their deliberations. A list of all participants is available in the appendices.

Meeting Schedule

The Committee met on the following dates for the purposes described below.

Third Session, 41st Parliament

October 16, 2018	Special project planning
November 22, 2018	Special project planning
January 21, 2019	Initial briefings: Representative for Children and Youth; Ministry of Children and Family Development
	Special project planning

Fourth Session, 41st Parliament

February 28, 2019	Organizational meeting
	Special project planning
March 26, 2019	Briefings: Ministry of Children and Family Development; Representative for Children and Youth
March 27, 2019	Briefings: Ministry of Health and Provincial Health Services Authority; Ministry of Education; Community Living BC
March 28, 2019	Briefing: Office of the Advocate for Service Quality
May 21, 2019	Public hearing: Terrace
May 22, 2019	Public hearings: Fort St. John and Prince George
May 23, 2019	Public hearings: Kelowna and Castlegar
May 24, 2019	Public hearing: Nanaimo
June 3, 2019	Public hearing: Victoria
June 4, 2019	Public hearing: Surrey

July 9, 2019	Deliberations
July 10, 2019	Deliberations
July 16, 2019	Deliberations
September 20, 2019	Deliberations
October 7, 2019	Deliberations
	Adoption of report

Meeting documents, transcripts and minutes are available on the Committee's website:
www.leg.bc.ca/cmt/cay

Background

The provision of supports and services for children and youth with neuro-diverse special needs from early years to adulthood spans the social services, health and education sectors, and involves multiple ministries and authorities. Accordingly, the pathways associated with identification, assessment and service eligibility for children and youth with neuro-diverse special needs are complex and can make it difficult for families and caregivers trying to access the supports and services they require. In particular, gaps in early identification and developmental monitoring, lengthy waitlists for assessments and services, issues with diagnostic versus functional assessments, case coordination and inter-agency communication, and differences in eligibility criteria, all pose significant challenges for families and caregivers.

Early Years

The Ministry of Children and Family Development is responsible for providing foundational and early years programming which are organized as follows: foundational and early intervention programs, specialized provincial services, and family support programs.

Foundational and early intervention programs are provided to children under the age of six with no formal diagnosis required to access services. Families can self-refer or access these programs through family or community referral, or through formal mechanisms such as a public health nurse or general practitioner. These programs are delivered exclusively through contracted community agencies, including child development centres; no Ministry social worker is assigned. Examples of foundational and early intervention programs include the Supported Child Development Program, Infant Development Program, Early Intervention Therapies, and the Aboriginal Supported Child Development Program.

Specialized provincial services are provided to specific populations and require a formal medical or psychological assessment and diagnosis. These services include the At Home Program's medical benefits, autism funding, the Community Brain Injury Program, and Provincial Deaf and Hard of Hearing Services. To access autism funding, families connect with a CYSN social worker to determine eligibility and apply for funding. This funding is renewed annually regardless of the child's needs and provided until the child reaches 18 years old. The amount of funding provided is \$22,000 per year per child up to the age of six, and then \$6,000 per year per child between the ages of six and 18. Autism funding follows an individualized funding model whereby the parent or guardian receives the funding directly, and manages and has oversight of services; however, eligible equipment and services must be approved by the Autism Funding Branch and therapeutic services must be selected from the Registry of Autism Service Providers. Autism funding also enables eligibility for CYSN family support services.

Family support programs provide supports for families of children and youth with a diagnosis of intellectual disability (confirmed by a registered psychologist, registered psychological associate or certified school psychologist), ASD or who are eligible for the At Home Program. Supports in this area include respite, in-home support services and specialized supports, and are coordinated through a CYSN social worker.

School Age

When a child becomes school age, funding and supports generally shift from families and caregivers to the education system, primarily to support children within the classroom setting, on the understanding that school is where a child spends a significant proportion of their time. The Ministry of Education is responsible for policy development and providing funding for inclusive education to school boards who are then responsible for service delivery, including determining resourcing and staffing, and providing assessments and supports.

To receive inclusive education funding (which is in addition to the base allocation) from the Ministry of Education, a child needs to be assessed and have a medical diagnosis, be designated into one of 12 categories, and have an individualized education plan (IEP). Each of these designations has specific criteria and funding attached with school boards funded according to the number of children within each of these designations; funding does not flow directly to the individual child. In their presentation, the Ministry noted that a funding model review is underway.

Adulthood

Community Living BC is the provincial Crown Corporation responsible for funding supports and services to adults (aged 19 and older) with developmental disabilities. To receive services, an individual with a developmental disability must have a significant impairment in intellectual functioning (i.e. an IQ of 70 or lower) or impairments in adaptive functioning that are so severe that intellectual functioning is comparable to a person with an IQ less than 70. The onset of this impairment must have occurred before the age of 18 for an individual to be eligible for services.

Through the Personalized Supports Initiative, Community Living BC also provides services to adults with a diagnosis of ASD or FASD who have significant limitations in their adaptive functioning and therefore require help with daily tasks. Eligibility for Community Living BC services requires an assessment by a qualified psychologist. As Community Living BC is one of nine government agencies and ministries involved in planning supports and services for young people, there are transition planning protocols in place with the Ministry of Children and Family Development as well as other ministries.

Identification and Assessments

Children and youth with neuro-diverse special needs may be identified and assessed at different stages of their lives. Parents and caregivers are often the first to recognize something atypical about their children; however, many are not aware of the signs of neuro-diverse conditions or normalize them, and some are unable to identify such behaviours in their children. This can delay formal identification, assessment and diagnosis which is often required for accessing services and supports. A lack of understanding and awareness on the part of various service providers and health professionals may also contribute to a delay. Even when children have been identified and referred for assessments, gaps in assessment frameworks as well as barriers to accessing assessments, particularly long waitlists, may lead to further delays in accessing supports and services.

Awareness and Identification

Parents, caregivers, and organizations emphasized to the Committee the importance of early identification; the earlier a child is identified, the sooner they can receive appropriate services which has a significant positive impact on their long-term development. However, there are many barriers to early identification including a general lack of awareness regarding neuro-diverse conditions. This is especially true for the many neuro-diverse conditions which are “invisible” and for children who do not display well-known neuro-diverse symptoms or behaviours. Kootenay Family Place indicated that some parents and caregivers normalize their children’s behaviour or are unaware of the early signs.

Dr. Margaret Newbury Jones observed that sometimes symptoms are viewed as behaviours resulting from poor parenting which can affect whether a child is referred for diagnosis. A number of parents and caregivers indicated that a particular lack of awareness and understanding of FASD, Attention Deficit Hyperactivity Disorder (ADHD) and gifted children translates into fewer supports for the families of these children. Parents, caregivers, and organizations, including the Kermode Friendship Society, noted that teachers often view conduct associated with FASD as “bad behaviour.” They indicated that more education and understanding of the full range of neuro-diverse conditions would enable earlier identification.

In addition to issues of awareness, many parents, caregivers, and organizations, including the Canada Fetal Alcohol Spectrum Disorder Research Network, identified challenges with the perceived stigma of having a child with neuro-diverse special needs, particularly with respect to FASD. The FASD Okanagan Valley Assessment and Support Society emphasized that stigma is a barrier to identifying youth with FASD as there is often a reluctance to confirm alcohol use during pregnancy; this is particularly challenging if they have been adopted or in foster care as confirmation is difficult to obtain in these circumstances. The Surrey District Parent Advisory Council noted that stigma may also influence a parent or caregiver’s willingness to recognize their child’s special needs. One parent shared that fear of stigma in a small elementary school was one of the reasons why the family did not pursue an assessment earlier. In addition, Inclusion BC observed that communities facing cultural, financial and social adversity require more education and awareness of neuro-diversity to help de-stigmatize disabilities and the need for help. Some parents also noted that while the Ministry of Children and Family Development has the job of providing services for children and youth

with special needs, it is also responsible for child protection. This acts as a barrier for families who fear their requests for help may become a child protection issue.

The Committee also heard about a gap between standard immunization appointments at 18 months and kindergarten entry (at age four or five) during which time families may not be connected to any health providers at all. The Port Alberni Association for Community Living explained that children who do not attend preschool, particularly in small communities, have even fewer opportunities for early identification. Occupational therapist Susan Stacey, and psychologists Erin Knudsen and Judith Magrill noted that when children's needs are not identified before they start school, it delays opportunities for intensive early intervention. Organizations such as First Call: BC Child and Youth Advocacy Coalition pointed out that a universal early screening process could help identify more children earlier.

Sometimes children are misdiagnosed or misidentified, especially in cases where there are multiple conditions existing simultaneously. One parent noted that the education system did not recognize their child's ADHD or learning disability, and attributed his difficulties to a lack of effort and cooperation. Another parent explained that his daughter was very quiet in elementary school so she was not a priority and was therefore identified and assessed quite late whereas his son, who was disruptive in class, was diagnosed with ADHD quite early. Misidentification and misdiagnosis may be more common when the child's first language is not English; for example, Vivian Ly of Autistics United Canada shared that signs of her own ASD were dismissed when she was a child as they were attributed to English being her second language. AutismBC observed that awareness and services for children with dual or multiple diagnoses is also lacking, particularly in terms of the intersection with mental health.

Referrals

After a child has been identified as displaying tendencies suggestive of neuro-diverse needs, parents and caregivers often seek an assessment which, according to many parents, requires a referral from a general practitioner to see a pediatrician. This referral process can be complicated and often involves waitlists of six months to one year for an appointment with a pediatrician. Psychologists Erin Knudsen and Judith Magrill stated that reliance on pediatricians as the only referral source for diagnostic assessments may contribute to a lack of access to support services.

Parents, caregivers, and organizations also observed that many physicians are unsure of when they should be making a referral to a pediatrician. The Port Alberni Association for Community Living noted that the referral process is especially challenging because of variations in process, service providers working in silos, and a lack of awareness of services. A number of parents, caregivers, and organizations, including Belmont Park Pre-School Society, expressed concern that some medical practitioners adopt a "wait and see" approach before making referrals, suggesting that a child might outgrow a behaviour. This could lead to children being identified later and missing early intervention services.

Gaps in Assessment Frameworks

Once parents and caregivers obtain an appropriate referral, they move on to the assessment process. The Committee heard repeatedly about the need for functional assessments which according to the BC Psychological Association, better capture the needs of neuro-diverse children as they focus on each individual child's functioning rather than diagnostic labels. However, many assessments, and the corresponding provision of funding and services, are based on diagnostic criteria rather than functional need or ability. As

Gareth Williams at Kinsight Community Services described, a focus on the functional skills of the child in various settings helps to build a stronger profile of support needs. At the same time, Joel McKay and several other parents discussed the value in receiving a diagnosis as it helps families understand and come to terms with the challenges their child may have.

Assessment frameworks do not always consider the child's complete circumstances, including the home environment, and socioeconomic and cultural factors. For example, the Belmont Park Pre-School Society noted that one of the biggest challenges for children with ASD is social interactions; however, the assessment process does not take this into account. Others, such as Rick FitzZaland of the Federation of Community Social Services of BC, observed that assessments often take place later than they should, they are often rushed, and the required re-assessments may not happen at all. Many parents shared that their assessment appointments were very quick and in their opinion did not provide the opportunity for assessors to fully understand their child's needs.

Assessment appointments can also be very difficult for families; for example, Laranna Androsoff described the assessment for the At Home program as one of the hardest assessments to go through as a parent because the focus is on the child's perceived weaknesses. Similarly, one parent shared that assessment forms leave families "feeling like failures" when it comes to describing what their kids can and cannot do.

Dr. Margaret Newbury Jones argued that abuse, trauma, or adverse childhood experiences (ACEs) can impact significantly on a child's behaviour so screening for these factors should be an initial step in all assessments. Parents Lori Bell and Meghna Haldar referred to a study on ACEs which found that the more negative events a child experienced, the higher the likelihood of an array of health and behaviour problems in adulthood.

Several parents expressed concern about a lack of appropriate assessment tools and techniques for children with ADHD, gifted children and families from non-Western cultures. Carrier Sekani Family Services explained that most assessments are conducted using Western models of diagnosis which impact the ability to obtain accurate and culturally appropriate diagnoses. According to Erin Davies, a special education coordinator at a First Nations school in Port Hardy, the use of norm-referenced tests does not accurately represent Indigenous children's experiences. She added that the historically poor relationship between government service providers and Indigenous people often acts as another barrier.

The Committee also learned that researchers are increasingly aware that ASD, ADHD and other neuro-diverse conditions present differently depending on gender. One parent noted that girls are more likely to hide or camouflage their symptoms. Another parent observed that this may lead to many girls being misdiagnosed. For example, DeAnna Wry, who presented on behalf of the Dawson Creek Support Group for Parents of Children with Special Needs, shared that her daughter's assessor missed signs that were common of females on the spectrum during the appointment. Vivian Ly from Autistics United Canada stated that autistic women, non-binary autistic people and racialized autistic people are often underdiagnosed or misdiagnosed.

The Committee further heard that given the complex needs of children, youth and their families, few providers have the knowledge to properly assess them. For example, one individual noted that ADHD in particular is very difficult for medical professionals to diagnose as it can co-exist with many other conditions while another parent stated that some doctors are unwilling to make definitive diagnoses of ADHD prior to children starting school. According to SHARE Family & Community Services Society, some assessors may feel the need to repeat medical histories or are reluctant to begin treatment until they are sure of a diagnosis. Other providers, including school-based teams, school psychologists, speech-language pathologists,

behaviour specialists and teachers, often have important information about a child's behaviour which can be valuable for assessment and diagnosis; however, this information is not always taken into consideration.

Many children do not receive assessments until they reach school. The British Columbia Association of School Psychologists and school psychologists from School District No. 57 (Prince George) explained that comprehensive school assessments enable families to advocate for their children's needs beyond the education system and can supplement assessments made outside of the school system. Conversely, some submissions noted that school psychologists do not necessarily have the specialized training to assess children with profound intellectual disabilities. The Gifted Children Association of BC observed that districts often have insufficient funding to perform the necessary number of assessments. In addition, the Coalition of Neighbourhood Houses Capital Region and Sooke Family Resource Society explained that if a child does not present with challenging behaviours in the classroom, the child is not a priority for assessment. This was illustrated by one parent who shared that the school would not recommend her daughter for a psycho-educational assessment as other children had more severe needs and the school did not observe the same behaviours at school that the family saw at home.

With respect to transitioning to adulthood, school psychologists from School District No. 57 (Prince George) explained that Community Living BC has its own set of criteria and requires an up to date assessment even though it is presumed that intellectual disabilities are lifelong. School psychologists are often called upon to reassess these students who clearly have significant needs in order to satisfy Community Living BC criteria, with an inter-ministerial protocol in place to ensure this service is provided. These reassessments can make up a significant portion of the caseload for school psychologists, limiting the time available to assess other students in need. Other submissions specifically discussed Community Living BC's Guide to Support Allocation (GSA) assessment tool. Judy Hoffman stated that the GSA cannot be relied upon to determine an appropriate level of funding, especially for individuals with mental health issues, physical disabilities or complex care needs. She added that clients are not uniformly funded due to the reliance on subjective judgement of analyst staff who might not even meet with the individuals being assessed.

Some submissions also discussed the recognition of diagnoses from other jurisdictions. One parent noted that when her family moved to BC they had to undergo a verification of diagnosis process with a psychologist even though her son had been diagnosed with ASD in Ontario. Another parent shared that after moving back to BC from the United States, her family was told their daughter's testing and diagnosis was not valid and that they needed to get a BC diagnosis for ASD.

Barriers to Accessing Assessments

There are several barriers to accessing assessments, with one of the most common being waitlists. Several organizations, parents, and caregivers shared that long waitlists for assessments mean that many children do not receive a timely diagnosis and access to services in the important early intervention stage. Delays in early intervention then affects the services provided in schools and contributes to difficult transitions for children who enter school without a diagnosis. The Developmental Disabilities Association observed that children who do not receive a formal diagnosis before starting school may enter the education system unprepared with little or no additional supports or resources for them or their caregivers.

Many families explained that they turned to private assessments because waitlists for public assessments are lengthy; however, they noted that only some families are in the financial position to be able to afford this option as private assessments can cost between \$2,000 to \$3,000. In some cases, there are waitlists for

private assessments as well, although these are generally shorter than public assessments. Organizations, including Kids First Pediatric Therapy and the Developmental Disabilities Association, noted that some private clinics make diagnoses and then recommend private therapy at their agency which may be a conflict of interest.

The availability of assessments and wait times vary greatly across the province. Waitlists are particularly long in northern BC where there are fewer outreach clinics and professionals available to perform assessments. For example, the Kitimat Community Development Centre shared that clients may wait anywhere from 18 to 24 months to access an assessment from the Northern Health Assessment Network. The Kermode Friendship Society also observed that travel expenses for families in rural areas are a major barrier to assessment. Training of assessors may also be an issue with some submissions recommending increasing diagnostic capacity across BC.

One factor that may contribute to long waitlists for assessments is that there are not enough psychologists to fill available publicly-funded positions. According to the BC Psychological Association, two-thirds of psychologists are working in private clinics. They explained that BC trains many psychologists at the doctoral level; however, there is a requirement to pursue a pre-doctoral residency which tends to be available out of province. In addition, according to the Association, the compensation for publicly-funded psychologists in BC is comparatively lower than private practice and other provinces.

Conclusions

The Committee acknowledged the critical importance of early identification and intervention to ensure children receive impactful and effective supports, focusing their discussions on issues related to awareness and recognition, assessments and wait times. Members observed that intensive, appropriate support in the early years leads to better outcomes for the child and the family, as well as cost savings and less pressure for the child and youth-serving system in the long run. They noted opportunities and touch points for identification by ensuring families are connected to community services and focused on suggestions for enhancing the screening process during immunization appointments, and exploring additional screening opportunities between the ages of 18 months and five years, which could help with identification and addressing stigma.

Committee Members also discussed the range of barriers children and families face in accessing assessments. They were concerned about lengthy wait times, particularly with respect to diagnostic assessments as these are often required to be eligible for funding and services. Waiting for an assessment may delay much-needed interventions during critical early intervention windows, compounding developmental challenges and creating more issues in the long-term. They noted that wait times are impacted by the referral process as families experience wait times for each referral appointment. Members explored opportunities to streamline the assessment process including the possibility of allowing speech-language pathologists, who may be the first point of contact for families, to refer for assessments. The Committee also discussed other avenues to reduce wait times including setting benchmarks for assessment and service wait times and allowing registered pediatric psychologists to bill MSP directly, thereby increasing access to psychologists. Members also identified regional variations in the availability of assessment services as a barrier and recognized that families experience further waits when they have moved from out of province and need to have their diagnosis verified to meet BC standards. The Committee further acknowledged the frustrations associated with having to undergo reassessments to be eligible for Community Living BC services.

Another area of interest to Committee Members was public awareness and education about neuro-diverse conditions, particularly those that are not obviously symptomatic. Members agreed on the need to raise awareness and understanding of neuro-diversity, with a focus on cultural sensitivity, to reduce stigma, acknowledging that parents may feel blamed or fear being labelled, as well as the need to work on prevention and awareness of FASD across the province. They discussed targeting awareness to new parents, caregivers, and service providers within the system as a means to improve recognition.

The Committee also discussed the potential of moving to functional assessments, as well as the use of preliminary assessments, as a way to reduce wait times and improve access to services. They particularly acknowledged gaps and challenges with respect to language and cultural barriers, and differences in how neuro-diverse conditions present across genders which may lead to a child not being identified, going undiagnosed or misdiagnosed, as well as barriers for receiving an FASD diagnosis which requires confirmation of prenatal consumption of alcohol. Committee Members noted the importance of ensuring assessments are comprehensive in taking the needs of the whole child and family into account, and the value of conducting assessments in natural environments such as the home.

RECOMMENDATIONS

The Committee recommends to the Legislative Assembly that the provincial government:

1. Enhance universal screening during 18 month immunization appointments, and explore opportunities for additional universally accessible screening between the ages of 18 months and five years, to improve early identification and long-term outcomes of children with neuro-diverse conditions.
2. Allow speech language pathologists to directly refer children for assessment of neuro-diverse conditions to support early identification.
3. Require ministries and other publicly funded organizations and service providers to publicly set benchmarks for reducing assessment and service wait times and publicly report on outcomes on an annual basis.
4. Conduct a public awareness campaign on the full range of neuro-diverse conditions with a focus on reducing stigma, and improving access to assessment and services.
5. Perform a cost-benefit analysis of allowing registered pediatric psychologists to bill MSP directly.

Eligibility and Services

Eligibility and the provision of funding and services varies based on age, diagnosis, and program. Parents, caregivers, and organizations shared a number of frustrations and issues with the way services and funding are determined, as well as issues with access, capacity, resourcing, and staffing.

Diagnosis-based Eligibility and Funding

The Committee heard repeatedly from parents, caregivers and organizations about gaps and inequities with eligibility for funding and services, particularly with respect to the use of diagnoses to determine eligibility. Many highlighted that children with ASD receive funding for supports and services while children with other diagnoses and conditions, including FASD, ADHD and gifted learners, do not receive similar levels. As such, families are often anxious to pursue and receive specific diagnoses such as ASD to trigger funding. The Developmental Disabilities Association reported that psychologists sometimes diagnose a child who has intellectual disabilities or mental health disorders with ASD so the family can receive funding for necessary therapies or other assistance. Dr. Kyle Burns, a psychiatrist with Vancouver Coastal Health, noted the challenge of tying funding to a diagnosis from a medical perspective, explaining that diagnoses can be subjective and that research has shown a diagnosis of ASD is about 86 percent reliable, meaning that there is an 86 percent chance that someone with similar training would also diagnose the same condition.

A few submissions noted that some children may have challenges with functional abilities but not fit a specific diagnosis. Furthermore, focusing on diagnoses does not take into consideration severity and variation in needs nor comorbid conditions. Susan Stacey, an occupational therapist, indicated that this is an issue for children with ASD as well as children with other neuro-diverse needs since the same level of funding is provided to every child with ASD regardless of a child's level of functional ability. As a result, some families do not feel it necessary to use their full funding allocation as their child does not require that level of services while others could benefit from additional support. Moreover, funding is not indexed to inflation.

Several parents, caregivers, organizations and service providers also discussed limitations as to what services and interventions families are eligible to receive. They emphasized that the needs of each child and family vary, and that the families should be provided with flexibility to pursue and access interventions that best meet their needs. Brenda Lenahan pointed out that CYSN programs were all created at different points in history in response to the needs of the time and that the system has not been updated, resulting in a patchwork of services that serve some families in some ways and exclude others.

The Committee also heard about different approaches to eligibility and funding processes in other jurisdictions. One family described their experience when they lived in Germany where their child was referred for and received services free of charge based solely on a pediatrician's recognition that early intervention was required; no diagnosis was needed. When the family returned to BC, their daughter had to be assessed before receiving services. Jennifer Newby similarly shared her family's experience in California. Within two months of a referral, the local Regional Center, which provides services to individuals with developmental disabilities and their families, sent a speech-language pathologist to the family's home and provided their child with weekly speech sessions, a full occupational therapy assessment and an Applied Behaviour Analysis

program. These services were provided based on the recognition of developmental delays, without a formal assessment or diagnosis.

Access and Capacity Challenges

The value of early intervention was emphasized to the Committee; providing supports during a critical window in a child's development, such as the higher level of autism funding for children under six, help to improve outcomes. Unfortunately, lengthy waitlists for assessments, as well as waitlists for services, delay access and can result in children not receiving these interventions before they begin school. Parents, caregivers, and service providers, including the Sooke Family Resource Society, reported especially long wait times for therapeutic interventions such as speech-language therapy, occupational therapy and physical therapy, as well as waitlists for access to pediatricians and child psychiatrists. For example, the Child Development Centre Society of Fort St. John and District noted that their waitlists for speech therapy and the infant development program are 137 and 92 children respectively.

The Nanaimo Child Development Centre indicated that many specialized programs for children and youth with neuro-diverse special needs do not have adequate resources to meet demand. Families may turn to private services as their finances allow, resulting in unequal access to services; however, as Speech and Hearing BC pointed out, waitlists for private services are growing as well. First Call: BC Child and Youth Advocacy Coalition indicated that the individualized funding model for autism supports has created a growing market of private therapists for whom pricing is unregulated, leading to high fees.

The Coalition of Neighbourhood Houses Capital Region reported that long wait times for therapeutic services often result in families being sent to community services for support where staff are not equipped to deal with complex issues outside their scope of practice. Families may also be directed to education and consultation group programs which do not meet the needs of children requiring higher levels of intervention. The Sooke Family Resource Society similarly indicated that recent shifts in the delivery of therapeutic services to be more consultative and educational present challenges for parents and caregivers who do not have the capacity to do therapy and exercises with their children, leading to families seeking additional support from community-based services that are not intended to provide therapeutic services.

Several service providers highlighted high caseloads as contributing to a lack of capacity to support children and youth with neuro-diverse needs. Those who assist and work with these children and youth, including therapists, early childhood educators, education assistants and social workers, require adequate time, resources and knowledge to address complex needs and improve outcomes. High caseloads for specialized services and social workers result in a lack of adequate supports and challenges for families, as well as burnout for service providers and social workers. For example, Speech and Hearing BC indicated that a caseload of 24 to 40 children is recommended for a full-time speech-language pathologist; however, approximately half of all speech-language pathologists in BC who work with children have caseloads over 80. Dina Zanet Costa, a program manager at Kootenay Family Place, reported that School District No. 20 (Kootenay-Columbia) has one occupational therapist with over 200 children on her caseload. Cynthia Lockrey stated that private speech-language pathologists in the Cowichan Valley are not accepting school-aged children due to high caseloads and that the local school district has one part-time occupational therapist with a caseload of over 400 children.

Parents, caregivers, and organizations also highlighted disparities in the provision of services by geographic location, with many families in rural, remote and northern communities experiencing acute challenges with

accessing supports and services. Several organizations, including AutismBC, shared that rural communities often lack local providers, including speech-language pathologists, pediatricians and key workers. Pacific Autism Family Network cited transportation as part of the issue and suggested increasing support for families who have to travel or incentivizing providers to travel to families. DeAnna Wry pointed out that autism funding can only be spent in BC which delays services for families in border communities such as Dawson Creek where Alberta service providers are more accessible and available.

A lack of sufficient supports for children with FASD was another common theme. Natascha Lawrence, a registered clinical counsellor who provides counselling services to individuals with FASD, shared that she decided to go into private practice because she observed that the public system did not recognize the needs of individuals with FASD. She highlighted that the key worker program lacks adequate funding and that BC lags behind other provinces such as Alberta, Manitoba and Saskatchewan with respect to policies and programs for FASD. The Canada Fetal Alcohol Spectrum Disorder Research Network indicated that the key worker program is essential to helping families support children and youth with FASD and advocated for increasing the number of key workers as well as support for ongoing training and supervision. Their Family Advisory Committee emphasized that the key worker program alone is insufficient for addressing the needs of children and youth with FASD and that funding for intervention services is required.

The Committee also heard from parents and caregivers about challenges with access to respite services. They highlighted that parents, caregivers, and family members are subject to stressors on a day-to-day basis and many require respite services; however, even when funding is available, the availability of respite is often inadequate and is dependent upon where one lives. Eligibility criteria for respite may also be restrictive or funding may be insufficient to provide families with the level of respite required. BC Parents of Complex Kids particularly highlighted challenges with respite under the At Home program, including eligibility criteria and long waitlists. They noted that the basic amount of respite funding provided by the program of up to \$2,800 annually has not increased since 1989 and lengthy waitlists persist. Diana Salcedo explained that the respite benefits she receives from the At Home program are only enough for 2.5 hours of respite per week while Catherine Nash shared that she waited for two years to get access to respite through the At Home program, at which point she had given up on it.

Eligibility and Services in Schools

Many families and organizations, including Special Olympics BC, reported that the level of support and services, particularly with respect to publicly-funded assessments and therapy services, drops significantly when children enter the school system and is insufficient to meet needs. A number of parents indicated that the Ministry of Education's guidelines, designations and definitions result in many children with neuro-diverse needs, including those with ADHD and FASD as well as gifted learners, not receiving the required level of supports. The BC Confederation of Parent Advisory Councils highlighted gaps and barriers resulting from reporting. They noted that only one designation is reported to the Ministry of Education, even though students may present with more complex needs or with comorbid diagnoses and conditions. As a result, complex conditions are not understood and managed, and services therefore fall short.

Parents, caregivers, and organizations stated that it is not uncommon for children who receive interventions in the early years to then fall outside of the education system's definition of special needs or be required to meet new criteria to receive supports. They shared that supports for kindergarten children may be delayed as they may need to be reassessed. Children may also enter school without a diagnosis which is required to qualify

for inclusive education funding. Others may not be recognized as having neuro-diverse needs until they begin school and even if they receive a diagnosis by the end of kindergarten, they may not have received the necessary supports in the interim.

According to a number of parents and caregivers, supports and resources in the school system are limited, and only children with the most severe needs or children who exhibit disruptive behaviours are seen. Jeanine Demmler noted that while the needs of neuro-diverse children may change throughout their childhood, these needs do not disappear. For children and families accessing autism funding, the amount provided to them decreases from \$22,000 per year per child to \$6,000 per year per child when the child turns six and begins school. Furthermore, children are no longer eligible for foundational and early years programs once they enter the school system. Many individuals and organizations pointed out that these changes in supports and funding at age six are particularly problematic for those families who have not benefited from intensive early intervention services due to a delay in receiving a diagnosis.

The Committee also heard concerns about funding levels and allocations in the education system and about accountability and oversight with respect to how the funding is expended. School districts are provided inclusive education funding based on individual designations to supplement the base allocation; however, not all children who have neuro-diverse needs have been identified, have a diagnosis or are designated. In addition, some children with neuro-diverse conditions may have higher needs than others. As such, school districts may use their funding envelope to provide services to children who have not received a designation to ensure more children receive some level of support or may provide interventions to students with the most significant challenges. As a result, funding may not reflect the actual level of need and may be inadequate to provide appropriate supports. The BC Teachers' Federation reported that most school districts spend twice the amount of money on special education services than they receive from the Ministry of Education. As such, school trustees and boards of education have to choose how to reallocate funding to ensure students with neuro-diverse special needs receive adequate support. Accordingly, the BC Teachers' Federation, along with the Kermode Friendship Society, suggested increasing the level of funding for students with neuro-diverse special needs to better meet actual need, while several parents suggested directly linking funding to the individual child or providing the funding directly to parents or caregivers.

The BCEdAccess Society indicated that schools do not have the capacity or resources to implement the systems, services and accommodations that are effective for children with neuro-diverse needs, and further, that parents experience difficulties in being heard regarding programs and services for their children. The BC Teachers' Federation stated that staffing challenges, such as failure to fill vacant teaching positions, are leading to special education and English Language Learner teachers being pulled from regular assignments to teach grade classrooms, resulting in students with special needs losing out on accommodations and supports. According to the BCEdAccess Society, as well as a number of parents, this lack of capacity, resources and staff to support students with neuro-diverse needs leads to children being excluded from the classroom or sent home altogether; between September 2018 and June 2019, the BCEdAccess Society recorded over 3,000 instances of children being excluded from school across the province.

As it relates specifically to staffing, the BC Teachers' Federation indicated that many teachers who work with special needs students are close to retirement and challenges with recruiting new staff may create gaps in the provision of specialized accommodations and services for students with neuro-diverse needs. The BCEdAccess Society noted a shortage of school psychologists and suggested increasing post-secondary positions and recruitment, as well as facilitating the cross-jurisdictional transfer of qualifications. The Society also pointed

out that education assistants do not work full-time or year-round making it challenging for them to be a part of the school team. A couple of parents expressed concern that there is no regulatory body or standardized training for education assistants while another shared that education assistants have the lowest level of pay and least opportunity for further training, yet they work with the most complex and vulnerable students.

Parents and caregivers, including Laura Offley and Leona Kampman, pointed out that if appropriate supports and services are in place, more students with neuro-diverse needs could complete academic courses and graduate with a Dogwood certificate, rather than being pushed into Evergreen (completion) programs. In a presentation to the Committee, Sierra Irving stated that students with different abilities who receive completion certificates are not able to go post-secondary education and therefore are unable to get good jobs and support themselves.

A number of parents and caregivers also expressed frustration with individual education plans (IEPs). Some reported discrepancies and inequities across school districts in how they are managed while others stated that IEPs are out-of-date, incomplete or ineffective with no accountability or enforcement to ensure they are implemented. Several parents and caregivers were of the view that schools do not set aside enough time for meaningful consultation with parents and that teachers do not have the time to review files to understand students' individual needs.

The Committee further heard that a lack of supports and services in the public school system leads to parents and caregivers moving their children to distributed learning programs, independent schools, private schools or home-schooling. These alternative programs and schools tend to provide smaller class sizes, more specialized supports and more flexibility for supporting their child's education. For example, Melissa Giles shared that distributed learning allowed her family to work at home around sickness and therapy time. She found that this model allowed her to guide which services are most helpful for her children and has helped them become honours students. Another parent, Ginette Dube, referred specifically to the SelfDesign Learning Community which she notes has met her daughter's needs in a way that a traditional school could not.

Representatives from Vancouver Coastal Health also shared information about two needs-based programs that they currently offer for school-aged children and youth as potential models. The Boundaries program provides therapy to young children who exhibit sexualized behaviour to help them understand and modify their behaviour. Counsellors also work with families and other caregivers to help them problem solve, create safety plans and manage behaviours. Dr. Kyle Burns noted that about 75 percent of the children in this program have either ASD, FASD or an intellectual disability and the other 25 percent have ADHD. The Boundaries program does not require a diagnosis but rather is designed to treat a specific behaviour which can then sometimes lead to diagnoses. Another example is Tupper Nova, a day treatment program run in partnership with the Vancouver School Board that provides services to youth, 13 to 18 years of age, who have serious mental health concerns and are unable to attend their neighbourhood school. The program provides a full range of mental health services, as well as educational programming, and is based on the individual needs of each student.

Recruitment and Retention

The Committee heard about shortages of qualified professionals across the public system, including clinical psychologists, school psychologists, speech-language pathologists, behaviour interventionists, education assistants, teachers, occupational therapists, physiotherapists and pediatricians. Parents, caregivers, and

organizations, including Speech and Hearing BC, attributed this shortage to inadequate compensation, particularly in comparison to other jurisdictions or the private sector.

Recruitment and retention challenges faced by school districts, child development centres, community service providers and other organizations in rural, remote and northern communities were also highlighted. For example, the Terrace Child Development Centre reported that Terrace will have been without physiotherapy services for almost a year. They pointed to the BC student loan forgiveness program, under which 33 percent of the BC portion of student loan debt was forgiven in exchange for working in underserved communities, as beneficial for attracting staff.

Training and Education

Parents, caregivers, and providers were of the view that some service providers who work with children and youth with neuro-diverse needs do not have sufficient training, expertise and understanding of the population they are working with, and therefore, are not equipped to provide effective interventions. One submission stated that teachers could benefit from additional training and education on how to work with students with neuro-diverse conditions. The BC Teachers' Federation noted that the nine teacher education programs around BC do require some coursework at the university level around inclusion of students with special needs, but these courses vary from program to program. The Canada Fetal Alcohol Spectrum Disorder Research Network highlighted a lack of knowledge, awareness, and standardized training regarding working with children and youth with FASD. They shared that training in this area is paramount for individuals and families to receive appropriate services and reduce negative impacts. There is also a lack of standardization for key workers regarding education, training and service offerings.

Eligibility and Services into Adulthood

Funding supports and services for adults (ages 19 and older) are provided by Community Living BC. However, a number of organizations, including the British Columbia Association of School Psychologists and the Centre for Child Development of the Lower Mainland, highlighted that Community Living BC eligibility criteria are restrictive. In particular, they indicated that many youth with neuro-diverse special needs do not qualify for services as their IQ is too high even though they require supports. The criteria are particularly problematic for those without a formal FASD diagnosis. This then impacts access to the Services to Adults with Development Disabilities, a program that helps with navigating transitions, as eligibility is based on Community Living BC criteria. Organizations recommended reviewing and broadening eligibility criteria, while one parent suggested extending respite and other adult supports to neuro-diverse individuals who do not meet Community Living BC eligibility requirements.

Several parents, caregivers, and organizations further highlighted the change in supports and funding when shifting into adulthood. This includes a general lack of flexibility, consistency and options, as well as the end of direct funding for youth with ASD. As Helen Engel-Gray noted, youth with neuro-diverse needs are reaching a major transitional point in their lives for which additional support would be beneficial; she suggested continuing autism funding after the age of 19 and creating more community supports to assist with the transition while others recommended providing more flexibility in the provision of supports and services. Therapy Hub suggested allowing therapy services to continue during the transition into adulthood, rather than ending at the age of 19.

Conclusions

The Committee identified the current diagnosis-based framework as a key issue contributing to gaps and inequities within the provision of funding and services. They noted that many children do not qualify for funding or services unless they have a diagnosis of ASD even though they may present with similar or more acute needs than some children with ASD. Moreover, the autism funding structure of an annual allowance does not reflect the individual needs of each child with ASD. Members heard that some families pursued multiple assessments and private assessments in order to obtain an ASD diagnosis as it would enable them to access funding.

The Committee recognized that neuro-diversity, regardless of diagnosis, exists on a spectrum, and as such, each neuro-diverse child is unique and requires their own intervention plan which best supports the child and their individual needs. Accordingly, Committee Members expressed support for re-examining the current diagnosis-based approach and shifting to a needs-based model that identifies, acknowledges and addresses the functional abilities of each child with neuro-diverse needs regardless of clinical diagnosis. They also noted that the current framework does not adequately take into consideration coexisting conditions or family capacity and need. They were further interested in potentially providing additional flexibility for families in the choice of eligible services, such as those on the Registry of Autism Service Providers list.

Committee Members expressed appreciation for teachers, education assistants, therapists and all service providers who are doing their best to support children and youth with neuro-diverse needs. They noted that child development centres and similar agencies could be centralized or better funded to increase and simplify the provision of supports to families and children in the early years when supports and services are so critical.

They also acknowledged issues within the public school system while recognizing the responsibility and challenges the school system has in managing the education and care of all children. The Committee observed gaps with the system of designations, which are again based largely on diagnosis, and the importance of ensuring appropriate supports are in place for children based on actual need. Members particularly focused on issues of isolation and exclusion, as well as inclusion to ensure all children with neuro-diverse special needs are supported as part of the school community. They also discussed the possibility of expanding the flexibility of learning supports, including for distributed learning programs, as well as providing teachers additional training on neuro-diverse conditions during professional development days.

As with assessments, Committee Members expressed concern about wait times for services and the impact this has on early intervention, and agreed that service wait times need to be monitored and measured with benchmarks to track progress (see Recommendation #3). Members observed labour gaps in many professions, including speech-language pathologists and occupational therapists across BC, and that these gaps are particularly acute in rural and northern communities. They also reflected on challenges with accessing services for families in rural and remote communities who may have to travel for appointments. Members noted that travel costs are a significant barrier for many families and extend beyond the cost of transportation to include accommodation, the cost of child care for siblings, as well as time lost from work, and stress for both caregivers and children. Given the reported gaps, they discussed the value of conducting a labour force review to ensure BC has a sufficient number of professionals serving children and youth with neuro-diverse needs and address wait times. The Committee also supported the provision of incentives and rural-based post-secondary programs to recruit professionals to live and work in rural, remote and northern communities, as well as incentives for professionals to travel and provide services to families in these communities and the expansion of telehealth.

RECOMMENDATIONS

The Committee recommends to the Legislative Assembly that the provincial government:

6. Ensure services and supports in the early years and within the school system are based on need and functional ability and provided prior to diagnosis.
7. Promote a positive learning environment for all children by ensuring that the Ministry of Education's inclusion policy is observed and enables children with neuro-diverse special needs to be part of the school community while accessing individualized education.
8. Conduct a labour force review of all professions serving children and youth with neuro-diverse special needs, including examining open positions, service wait times, compensation and post-secondary training.
9. Based on data from the labour force review, increase and expand access to occupational therapy and speech-language pathology services.
10. Provide incentives and/or rural-based post-secondary programs to attract early childhood educators, speech-language pathologists, pediatric therapists and other professionals to rural, remote, and northern communities and to those professionals willing to travel to provide services in these communities.
11. Expand the use of telehealth to reduce travel and improve access to services for families.

Coordination and Transitions

The Committee heard from many caregivers and organizations about the difficulties experienced during transition periods between early years, the school system and adulthood, and continuity of care. Many children also experience difficult transitions upon moving from one school or grade to another. Given that many services are provided by different agencies and ministries, inter-ministerial communication and collaboration were identified as priority areas.

Age-Based Gaps

The Committee repeatedly heard about gaps in services as a result of age-based eligibility in the early years and the transition to kindergarten. Gareth Williams at Kinsight Community Services described age as an arbitrary line based on a chronological metric rather than a developmental one. They argued that aligning systems and supports based on developmental trajectories rather than age-related criteria could improve experiences and outcomes for children.

There is also a gap between when youth graduate and leave the school system at the age of 17 or 18 and the age of 19 when they are eligible for services from Community Living BC. As the Kitimat Community Development Centre describes, there are no services to replace being at school for 30 hours a week and the gap is a long time for families to go without services. Juliana Becker and Nancy Nixon referred to practices in other provinces where support services are not separated between children and adults but rather structured as a continuum of care, reducing barriers and paperwork for families to access services.

Several organizations and individuals advocated for flexibility with respect to when children enter the school system, with corresponding sustained child development supports and services. Speech and Hearing BC highlighted data from the University of British Columbia's Human Early Learning Partnership which found that approximately one-third of children in BC are not ready to learn when they reach kindergarten and this learning readiness gap follows them their entire life. The Pacific Autism Family Network shared that some children with neuro-diverse needs may not be ready to enter the school system at age five, particularly since long waitlists mean children may have received little or no services prior to entering school. The Port Alberni Association for Community Living indicated that in their local school district, if a child is not ready for kindergarten, a parent can opt not to enroll the child that year; however, the child must then proceed directly to grade one instead of entering kindergarten the following year. Regarding graduation from school, Catherine Adlam suggested that allowing students with neuro-diverse special needs to stay in school until the age of 21 may enable them to earn their Dogwood diploma.

Continuity of Care

Some parents and caregivers highlighted the importance of consistency of support workers and service providers during transition periods. Changes at different stages within a child's life, upon starting and leaving school or moving from one grade to the next can be stressful as different providers may have different methods, philosophies or strategies for various interventions. In addition, it takes time for a new provider to get to know the child and for the child to adjust to the new provider. Many parents reported frustration with

the inability to continue with existing service providers as their child enters kindergarten and with their child having different education assistants or learning assistants throughout their school experience. One parent specifically pointed to staffing based on seniority which limits the ability of parents to request and retain the same staff to work with their children in school. The Canada Fetal Alcohol Spectrum Disorder Research Network focused on the challenges children with FASD have with transitions, and how it is helpful to have the same educational assistant stay with a student throughout their school years, rather than having different assistants every year.

Communication and Collaboration

Another theme was challenges and inconsistencies with communication and collaboration between parents, caregivers, agencies, programs and services. The BC Government and Service Employees' Union indicated that those who provide specialized assistance to coordinate services and funding options for families are challenged by staffing shortages, high caseloads and poor organizational capacity. Many parents, caregivers, and organizations observed issues at transition points where information is not shared or gets lost from one provider to the next. The Coalition of Neighbourhood Houses Capital Region described struggles that both families and professionals face in trying to maintain an understanding of the various systems and services, and the challenges professionals face in being able to transfer knowledge. They noted that regulations, such as those related to privacy, often act as a barrier to sharing relevant and important information, and parents and caregivers find themselves having to repeat their history and experiences, which creates frustration and exhaustion. The Committee received repeated calls for improving coordination, collaboration and communication across ministries, health authorities and service providers to ensure seamless transitions.

Data and Definitions

Communication, collaboration and transitions are also hampered by differences with respect to definitions and criteria held by different agencies for similar presenting needs and diagnoses which can lead to a delay or refusal of services. The British Columbia Association of School Psychologists pointed out that the education, health and child and youth-serving systems each have different criteria and definitions that do not necessarily correspond to one another. Sandra Marquis highlighted that inconsistent definitions also limit data and research on people with developmental disabilities, emphasizing that research and data is critical for informing the development of policies, programs and services, and for monitoring the well-being of people with disabilities. Erin Knudsen and Judith Magrill suggested aligning definitions and requirements to facilitate more effective transitions between service providers and more efficient access to needed support services.

Conclusions

Committee Members noted that services and supports for children and youth with neuro-diverse special needs appear to be siloed across the ministries and organizations that provide services from early years through to adulthood. They identified issues with communication and collaboration, as well as a lack of continuity in service providers, as contributing to difficult transitions for children and families, particularly as children begin school and move from community-based services to school-based services and when they move from elementary to middle school, and high school to adulthood.

Members discussed creating an electronic health record that service providers could access as a child moves from community-based supports to the school system as a means to improve transitions and information

sharing. They further noted that the transition to kindergarten could improve with better collaboration and planning between service providers. They were also of the view that parents and caregivers could be provided with the flexibility to delay entry to kindergarten by one year. The Committee observed that some parents and caregivers choose to keep their children in school until the age of 19 due to the gap in supports between high school graduation and the provision of Community Living BC services; however, they noted that not all families are aware of this option or of the eligibility for the Persons with Disabilities designation and associated supports which is available to youth at the age of 18.

The Committee discussed the importance of taking a child and family-centered approach to improving communication, information sharing and planning prior to and during transitions to ensure this process is more seamless. They also discussed the possibility of integrating and streamlining services to move away from hardline transitions.

RECOMMENDATIONS

The Committee recommends to the Legislative Assembly that the provincial government:

12. Create a single electronic health record for children with neuro-diverse special needs that can be accessed by service providers (such as child development centres) throughout the child's life.
13. Improve transitions to school by beginning transition planning earlier and providing families with the flexibility to delay their child's kindergarten entry by one year.
14. Implement transition planning involving both community-based therapy teams and school-based therapists during the transition to school.

Child and Family Centered Support

A number of submissions and presentations addressed the impact that caring for children and youth with neuro-diverse special needs can have on families. Navigating the system of assessments and supports emerged as a major theme as many parents and caregivers spoke about their struggle to find appropriate services for their children. This is especially difficult for vulnerable families who face additional cultural, economic, or other barriers. These submissions emphasized the importance of remembering that the child is at the centre of the journey and that each family's experience is different.

Family Impact

Many families cited financial barriers and difficulties in having to pay out-of-pocket for needed therapies, services, and medications. This is compounded for families who have more than one child with neuro-diverse needs. One parent noted that an entire salary may be required to pay for child care, therapists and required equipment. Another parent shared that her family plans to re-mortgage their house to pay for their son to attend private school where he will have access to additional resources. Some families found that their income levels were too high to receive publicly-funded supports but too low to afford services and equipment.

Another common issue was missed time at work due to a lack of sufficient support and services, particularly for children with neuro-diverse needs other than ASD, and needing to keep up with appointments and assessments. Organizations such as Inclusion BC observed that many families make the decision to have one parent leave the workforce to be able to fully support a child or children with neuro-diverse special needs. This adds to existing financial challenges in paying for needed supports and services, as well as emotional strain, and makes it difficult to keep pace with the cost of living. For example, one father decided to leave a full-time job to work part-time on evenings and weekends so that he could be the stay-at-home parent for twins with severe ADHD. Similarly, Joel McKay stated that either he or his wife will have to quit their job to care for their daughter who has ASD because she is unable to attend daycare without a support worker for whom there is currently a long waitlist at the child development centre. The Developmental Disabilities Association observed that families are expected to homeschool or pay for specialized education when children are sent home from school because they do not have adequate supervision, or they demonstrate challenging behaviours. Those who cannot afford private school may feel pressed to quit their jobs to look after their child.

There is a lot of responsibility placed on parents to become experts, managers, educators, financiers, therapists and many other roles, rather than just being parents.

Parents and caregivers shared that they are responsible for filling many roles in caring for their children, which can lead to burnout. Waiting for assessments and managing services and care for a child with neuro-diverse special needs often impacts the mental health of the entire family. Organizations including ARC Programs Ltd. observed that many families break down due to the emotional and financial stress they experience. One

parent explained that she and her partner coped with their child's diagnosis in different ways and ended up separating. In addition, the FASD Okanagan Valley Assessment and Support Society emphasized that the stigma surrounding many neuro-diverse special needs, in particular FASD, can lead to families being ostracized from communities and isolated from support. While peer support groups can be helpful, many parents spoke about how difficult it is to find them.

In some cases, challenges with accessing and affording services can lead to children being placed in the care of the ministry. One parent shared that the Ministry of Child and Family Development asked if her family wanted to put their children in voluntary foster care as there are more supports, such as respite services every second weekend, offered to foster families.

Managing Care

Organizations, including the Children's Therapy and Family Resource Centre, and Fresh Steps Behaviour Consulting, emphasized the administrative burden that is placed on families in managing services for their children. Parents and caregivers must manage multiple appointments and assessments in addition to keeping track of paperwork which is often difficult to complete. For example, one family shared that they attended weekly appointments over a period of 17 years during which time they saw more than 40 experts. Other parents and caregivers experienced requests to resubmit documents and re-tell their stories, or to complete different application processes to access different supports and services.

Not only were they dealing with the stresses and difficulty of raising a child with this challenge-but also had the challenge to become a "business" in order to find and pay for the services he required.

In addition to the administrative burden of managing care, many families must also travel for medical assessments, appointments and services, especially when they do not live in urban centres. Several individuals and organizations, including the Terrace Child Development Centre, spoke about the expenses and challenges of traveling with a child who has neuro-diverse special needs who may require two caregivers to travel with them. One parent from northern BC, Ashley Seltenrich, shared that traveling for appointments with a child with ASD can be traumatic for the child and stressful for the parent. Other families described the process of having to take a ferry for counselling services and other appointments, which resulted in missed time at work for the parent and missed time at school for the child.

Another aspect of managing care is the difficulty of finding child care spaces for neuro-diverse children. One parent explained that staff requirements for child care are based on neuro-typical children. Organizations highlighted a lack of trained staff due to recruitment and resource challenges within child care settings to support children with neuro-diverse special needs. As well, child care and preschool programs are experiencing growing numbers of children with self-regulation challenges who are waiting for assessment. One parent, Susan Doran, informed the Committee that her child cannot go back to daycare without a support worker, so she does not know how she will be able to manage care. In addition, Erin Davies explained that often children with FASD or other neurodevelopmental disorders are not accepted at daycares due to challenging behaviours, and many are either cared for by relatives or are unsupervised after school.

Advocacy was another common theme amongst parents and caregivers. Many noted that it is often left to parents, families and caregivers to advocate to get their children assessed or to find them services. Nadia Crawford and Jaandi Roemer noted that many parents do not have the time or capacity to do this. As Tina Patterson emphasized, leaving families to advocate for services for their children makes access to service inequitable. Parents also often feel that their voices are not being heard, especially by doctors and service providers; for example, Michelle Boshard stated that the advice parents share about how to reduce behaviours and support a child with special needs is often ignored.

Raising a child with special needs is a full-time job. We are tired. We don't have time to write letters. We don't have time to go to the media. We don't have time to protest. A lot of the parents of kids with special needs are barely hanging on.

Vulnerable Families

A number of parents, caregivers, and organizations pointed to potential challenges and barriers due to cultural, socioeconomic and other factors. Immigrant and refugee families may face barriers due to limited English, a history of trauma or cultural stigma. One parent shared her experience as an immigrant who fled violence and explained that it was difficult to overcome language and cultural barriers in accessing services. Some organizations, including the Centre for Child Development of the Lower Mainland, highlighted the impacts that trauma can have on assessment and services. William Tsai drew attention to the stigma in the Chinese community associated with having a child with special needs.

A number of organizations, including the Secwepemc Child and Family Services and Tillicum Lelum Aboriginal Society, noted that there is a lack of culturally appropriate and trauma-informed services for Indigenous families and many have been treated unfairly when looking for services outside of Aboriginal agencies. Some shared that assumptions about Indigenous parents and children can lead to inappropriate or inaccurate assessments. Therefore, Indigenous children are overrepresented among those without a diagnosis and many families are not aware of the services and supports available to them.

Parents of children with neuro-diverse special needs may also have neuro-diverse needs themselves which impacts their ability to navigate the system. The Children's Therapy and Family Resource Centre stated that these parents may have had negative experiences with school and the medical system when they were young. In addition, Vivian Ly from Autistics United Canada noted that it may be difficult for parents who have ASD, ADHD or disabilities themselves to recognize developmental challenges and navigate services for their children.

The BC Psychological Association spoke to the availability of public versus private services and how lower income families are not able to afford to pay for more timely private assessments, supports and services. Clinical counsellor Michelle McElroy observed that some families are marginalized due to race or poverty; they may not drive or have access to a vehicle, or their children have never attended preschool where their neuro-diverse special needs could have been identified. Several parents and caregivers emphasized the difficulty faced by marginalized and impoverished families in advocating for their children. Dr. Margaret Newbury Jones remarked that caregivers who are living in poverty, working multiple jobs or who have experienced trauma may not have the resources to seek out help for a neuro-diverse child, and when they do, they are often turned away. Single parents or caregivers may also struggle to find adequate support.

Navigation

Navigation was a major concern for parents and caregivers regarding both the assessment process and service provision. The Tillicum Lelum Aboriginal Society and Dina Zanet Costa, a program manager at Kootenay Family Place, shared that parents and caregivers often find the assessment process overwhelming. Shaunah Majcher explained that there are multiple and diverse paths for how families arrive at a diagnosis as the process of identification, monitoring and referral for services is inconsistent. Some families noted that after receiving a diagnosis they were sent home with forms and pamphlets but never received any follow-up.

A family's current journey for an assessment consists of frustration and disconnection amongst the various child and family serving systems, limited psychologists and pediatricians, travel to urban centers, financial burdens, lack of transportation and additional stress.

Families also repeatedly noted that they do not receive adequate information or guidelines for finding services and that they do not know who to call for assistance. They highlighted the lack of a central information resource or hub to help parents navigate the system of supports which includes the health, education and social services sectors. When information is provided to families it can be overwhelming, and caregivers are left to go through extensive lists of providers which are sometimes out of date. Tia Krogstad noted that her family missed out on some funding and other supports as a result of having to piece together resources and tools without assistance. Tracey Vrecko, president of Autism Okanagan, noted that dozens of parents contact the organization everyday looking for help navigating programs and services.

It felt like a confusing maze trying to piece the system together.

Many families spoke about the value of child development centres in connecting them with resources and services. An example of a particularly successful model is the Family Advocate role at the Comox Valley Child Development Centre. This role was developed to support children and families in accessing necessary services as quickly as possible. The Family Advocate can make a preliminary assessment of a family's concern and either initiate the intake process for services or link the family to a more appropriate service. The Centre shared that sometimes a conversation with the Family Advocate is all the family needs to put their concerns to rest and they do not go on to access any other service. They have found the role to be helpful in ensuring that the Centre's specialized services are maximized. Since establishing this role, the waitlist for speech therapy has gone down from one year to four months.

Conclusions

One of the central issues emphasized by the Committee was the need for a child and family-centered model of care that recognizes each child's and each family's unique circumstances and works with families to determine and provide appropriate, wrap-around supports and services. They reflected on the experiences families shared about constantly having to advocate to receive referrals, assessments or services, and the emotional, mental and physical impact this has on the whole family. They also acknowledged that many families do not have the capacity to connect and advocate within the system due to socioeconomic, cultural, language and other barriers, which may lead to children not receiving the supports and services they need.

The Committee expressed concern for vulnerable families who may have experienced trauma, speak limited English or have socioeconomic barriers, recognizing that they may face additional challenges to accessing assessments and services.

Members noted that there are multiple paths to referral, diagnosis and services which are difficult for families to navigate and acknowledged requests for family navigator positions to help address this. They pointed to the example of the Family Advocate position at the Comox Valley Child Development Association as a potential model, observing that it had helped reduce the wait for speech-language services. Committee Members noted that a face-to-face navigator could not only assist families with understanding the system, and providing support and direction on what to do, but could also help connect families in the same area for support and the bundling of services. At the same time, the Committee acknowledged that the need for a family navigator stems from the complexity and fragmentation within the system, recognizing that this complexity stems in part from trying to serve children and families with diverse needs requiring diverse services. They were of the view that a navigator could address urgent issues while broader changes are undertaken to simplify and streamline services.

To further assist families in navigating the complex system of services and supports, Committee Members discussed the possibility of creating a comprehensive website, in multiple languages, as a central source of information for families on potential pathways and services available in each community. Members also considered the role of CYSN social workers in helping families to navigate the system, noting some families either do not have access to a social worker or are not comfortable approaching them due to the Ministry of Children and Family Development's role in the provision of child protection services.

Committee Members observed the need for greater family consultation in providing services and for more follow-up after a diagnosis or assessment. The Committee noted the importance of peer support while acknowledging that many families may not have time to participate in these groups, do not have access to this support in their community or are unaware that support groups are available. Committee Members also reflected on the ways in which organizing and managing care for children with neuro-diverse needs affects families who may experience emotional and financial strain and negative impacts on their health. They highlighted the need for increased access to respite services for families as providers can be difficult to find even when funding is in place.

RECOMMENDATIONS

The Committee recommends to the Legislative Assembly that the provincial government:

15. Establish community-based family navigator positions, in child development centres where they exist, and a comprehensive website in multiple languages to help families navigate assessments, supports and services, including helping to identify next steps, connecting them to providers, peer support groups and other families and facilitating contracted group services.
16. Provide more funding for, and increase access to, respite care across the province.

Summary of Recommendations

Identification and Assessments

1. Enhance universal screening during 18 month immunization appointments, and explore opportunities for additional universally accessible screening between the ages of 18 months and five years, to improve early identification and long-term outcomes of children with neuro-diverse conditions.
2. Allow speech language pathologists to directly refer children for assessment of neuro-diverse conditions to support early identification.
3. Require ministries and other publicly funded organizations and service providers to publicly set benchmarks for reducing assessment and service wait times and publicly report on outcomes on an annual basis.
4. Conduct a public awareness campaign on the full range of neuro-diverse conditions with a focus on reducing stigma, and improving access to assessment and services.
5. Perform a cost-benefit analysis of allowing registered pediatric psychologists to bill MSP directly.

Eligibility and Services

6. Ensure services and supports in the early years and within the school system are based on need and functional ability and provided prior to diagnosis.
7. Promote a positive learning environment for all children by ensuring that the Ministry of Education's inclusion policy is observed and enables children with neuro-diverse special needs to be part of the school community while accessing individualized education.
8. Conduct a labour force review of all professions serving children and youth with neuro-diverse special needs, including examining open positions, service wait times, compensation and post-secondary training.
9. Based on data from the labour force review, increase and expand access to occupational therapy and speech-language pathology services.
10. Provide incentives and/or rural-based post-secondary programs to attract early childhood educators, speech-language pathologists, pediatric therapists and other professionals to rural, remote, and northern communities and to those professionals willing to travel to provide services in these communities.
11. Expand the use of telehealth to reduce travel and improve access to services for families.

Coordination and Transitions

12. Create a single electronic health record for children with neuro-diverse special needs that can be accessed by service providers (such as child development centres) throughout the child's life.
13. Improve transitions to school by beginning transition planning earlier and providing families with the flexibility to delay their child's kindergarten entry by one year.
14. Implement transition planning involving both community-based therapy teams and school-based therapists during the transition to school.

Child and Family Centered Support

15. Establish community-based family navigator positions, in child development centres where they exist, and a comprehensive website in multiple languages to help families navigate assessments, supports and services, including helping to identify next steps, connecting them to providers, peer support groups and other families and facilitating contracted group services.
16. Provide more funding for, and increase access to, respite care across the province.

Appendix A: Public Hearing Participants

Shawna Adams (3-Jun-19, Victoria)
Catherine Adlam (4-Jun-19, Surrey)
Laranna Androsoff (23-May-19, Castlegar)
ARC Programs Ltd., Emma Cuell, Julie Robinson (23-May-19, Castlegar)
Aspies On Mars, Tristan Sonntag (3-Jun-19, Victoria)
Melanie Atwell (24-May-19, Nanaimo)
Autism Okanagan, Tracey Vrecko (23-May-19, Kelowna)
Autistics United Canada, Vivian Ly (22-May-19, Fort St. John)
Victor Banman (22-May-19, Fort St. John)
Jennifer Barkman (4-Jun-19, Surrey)
BC Association for Child Development and Intervention, Jason Gordon (23-May-19, Kelowna)
BC Psychological Association, Dr. Kelly Price (3-Jun-19, Victoria)
BC Teachers' Federation, Glen Hansman (4-Jun-19, Surrey)
BCEdAccess Society, Tracy Humphreys (3-Jun-19, Victoria)
Lori Bell, Meghna Halder (4-Jun-19, Surrey)
Carolyn Braun (23-May-19, Kelowna)
Holly Breingan (24-May-19, Nanaimo)
Darcie Brown (4-Jun-19, Surrey)
Centre for Child Development of the Lower Mainland, Gerard Bremault, Karen Edwards, Dr. Brian Katz (4-Jun-19, Surrey)
Child Development Centre Society of Fort St. John and District, Tana Millner (22-May-19, Fort St. John)
Comox Valley Child Development Association, Joanne Schroeder (24-May-19, Nanaimo)
Nadia Crawford (3-Jun-19, Victoria)
Hazel Currie (3-Jun-19, Victoria)
Erin Davies (24-May-19, Nanaimo)
Dawson Creek Support Group for Parents of Children with Special Needs, DeAnna Wry (22-May-19, Fort St. John)
Jeanine Demmler (3-Jun-19, Victoria)
Susan Doran (22-May-19, Prince George)
Donna Douglas (23-May-19, Kelowna)
Cindy Elliott (24-May-19, Nanaimo)
Bonnie Fallowfield (22-May-19, Prince George)
Colin Farzan, Shelley McGarry (23-May-19, Kelowna)
FASD Okanagan Valley Assessment and Support Society, Bernadette O'Donnell (23-May-19, Kelowna)
First Call: BC Child and Youth Advocacy Coalition, Adrienne Montani (4-Jun-19, Surrey)
David Gerry (3-Jun-19, Victoria)
Sandra Goth (3-Jun-19, Victoria)
Shobna Gounder (4-Jun-19, Surrey)
Jennica Graham (22-May-19, Prince George)
David Gravells, Heather Hamlin Gravells (23-May-19, Kelowna)
Jodie Harris (4-Jun-19, Surrey)
Judy Hoffman (3-Jun-19, Victoria)
Janis Hoffmann (3-Jun-19, Victoria)
Home for Every Child Adoption Society, Amanda Preston (4-Jun-19, Surrey)
Inclusion BC, Dan Collins, Karla Verschoor (4-Jun-19, Surrey)
Sierra Irving, Adrienne Wicks (3-Jun-19, Victoria)
Nolee Jones (21-May-19, Terrace)
Leona Kampman (4-Jun-19, Surrey)
Kitimat Community Development Centre, Ceara Hutchinson, Brittany Mailloux (21-May-19, Terrace)
Kootenay Family Place, Gent Harrison (23-May-19, Castlegar)
Kootenay Family Place, Dina Zanet Costa (23-May-19, Castlegar)
Saydie Koral (3-Jun-19, Victoria)
Tia Krogstad (3-Jun-19, Victoria)
Cynthia Lockrey (3-Jun-19, Victoria)
Monique Malenfant (21-May-19, Terrace)
Naomi McCann (4-Jun-19, Surrey)
Michelle McElroy (22-May-19, Prince George)
Joel McKay (22-May-19, Prince George)
Shannon McLay (4-Jun-19, Surrey)
Mary Morris (3-Jun-19, Victoria)
Nanaimo Child Development Centre, Dominic Rockall (24-May-19, Nanaimo)
Catherine Nash (3-Jun-19, Victoria)
Jennifer Newby (4-Jun-19, Surrey)
Laura Offley (4-Jun-19, Surrey)
Kim O'Neill (23-May-19, Kelowna)
Tina Patterson (4-Jun-19, Surrey)
Wes Pidgeon (4-Jun-19, Surrey)
Marcus Pollard (3-Jun-19, Victoria)

Quesnel & District Child Development Centre, Bulkley Valley
Child Development Centre, and the Child Development
Centre of Prince George and District, Kerri Bassett, Lynn
Mathiesen (22-May-19, Prince George)

Jaandi Roemer (22-May-19, Fort St. John)

Maya Russell (4-Jun-19, Surrey)

Diana Salcedo (4-Jun-19, Surrey)

Kristen Sandborn (3-Jun-19, Victoria)

School District No. 57 (Prince George), Olivia Jaswal, David
Ki, Barb Nichols, Sarah van Leeuwen (22-May-19, Prince
George)

Secwepemc Child and Family Services, Tiesha Collins-
Newton, Emily Edmundson, Willow George, Nicole
Williams (23-May-19, Kelowna)

Ashley Seltenrich, Dawn Seltenrich (22-May-19, Fort St.
John)

Violet Shade (24-May-19, Nanaimo)

SHARE Family & Community Services Society, Claire
MacLean (4-Jun-19, Surrey)

Mary Souter (3-Jun-19, Victoria)

Special Olympics BC, Scott Howe (3-Jun-19, Victoria)

Speech and Hearing BC, Lynne Patrick (24-May-19,
Nanaimo)

Jocelyn Stanton (3-Jun-19, Victoria)

Surrey District Parent Advisory Council, Dean McGee
(4-Jun-19, Surrey)

Terrace Child Development Centre, Heather Callis, Fiona
Delorme (21-May-19, Terrace)

Tillicum Lelum Aboriginal Society, Tammy Aguilera
(24-May-19, Nanaimo)

Vancouver Coastal Health, Lizzie Ambler, Dr. Kyle Burns
(4-Jun-19, Surrey)

Margaret Warcup (21-May-19, Terrace)

Lisa Warnock; Ray Warnock (4-Jun-19, Surrey)

Nicole Zimmer (3-Jun-19, Victoria)

Appendix B: Written and Audio Submissions

Kathy Allaire
Kimberly Armstrong
Gary Robins, AutismBC
Jeff Ballou
Alice Barnes
Andrea Sinclair, BC Confederation of Parent Advisory Councils (BCCPAC)
Simon Kelly, BC Government and Service Employees' Union
Brenda Lenahan, BC Parents of Complex Kids
Aven Poynter, BC Pediatric Society
Juliana Becker, and Nancy Nixon
Darlene Manthorpe, Belmont Park Pre-School Society
Sarah Bianchini
Kim Block
Yvonne Blomer
Michelle Boshard
Breana Bowes
Alyssa Bollans, British Columbia Association of School Psychologists
Rachel Calder
Catherine Camley
Audrey McFarlane, Canada Fetal Alcohol Spectrum Disorder Research Network
Warner Adam, Carrier Sekani Family Services
Gaelene Askeland, Central Okanagan Journey Home Society
Christina Cheply
Toby Wendland, Children's Therapy and Family Resource Centre
Nicky Logins, Coalition of Neighbourhood Houses Capital Region
Andréa Coutu
Jacqueline Crummey
Sheila Curran
Alanna Hendren, Developmental Disabilities Association
Gina Dillon
Wayne Leslie, Down Syndrome Resource Foundation
Ginette Dube
Rosemary Eberle
Devon Eisenberger
Leesa Gilliland
Helen Engel-Gray
Dorothy Reid, Family Advisory Committee, CanFASD Research Network
Rebecca Ataya Lang, Federation of Community Social Services of BC
Richard FitzZaland, Federation of Community Social Services of BC
Maryam Foroughi
Danielle Freeman
Janis Joseph, Fresh Steps Behaviour Consulting
Cynthia Frostad
Amanda Fuller
Cara Gibson
Sherry H. Ghorbankhani, Gifted Children Association of BC
Melissa Giles
Mary Glasgow Brown
James and Michelle Glave
Darren Gregory
Jeff Hammerich
Alison Hampton
Kimberley Handley
Carrie Hartig
Juliet Henderson-Rahbar
Renee Hildebrand
Byron Hill
Michelle Hill
Ann Law, Jack and Jill Parent Participation Preschool
Christine James
Heather Johnston
Nicole Kaler
Amy Kazeil
Tanya Kemp
Danielle Lavoie, Kermode Friendship Society
Helen Ward, Kids First Parent Association of Canada
Deb Lightman, Kids First Pediatric Therapy
Gareth Williams, Kinsight Community Society
Erin Knudsen, and Judith Magrill
Candace Koch
Nicole Kranjc
Debbie (Chia Fang) Kuan
Jocelyn and Ulrich Laue
Natascha Lawrence
Suet man Lee
Brenda Lenahan
Fran Les
Natalie Lindsey Birchall
Camille Long
April Loughrey
Laura MacCormac
Annette MacGregor
Shaunah Majcher
Sandra Marquis
Brad McCandlish
Meaghan McLeod
Ivonne Montgomery
Kalindi Morgan
Kutrina Mosch
Mike Munro
Adrienne Yates, New Voice Speech and Language
Margaret Newbury Jones
Heather Ouellette, Northern Health Health Services for Community Living
Monica Nunes
Ron Jorgenson, Orca Healing Solutions
Sergio Cocchia, Pacific Autism Family Network
Emery Pakos
Samanta Palomino
Suzanne Pardoe
Courtney Phillips
Martin Phillips
Mary Phillips
Winona Phillips
Andrew Pilliar
Julie Wakefield, Port Alberni Association for Community Living
Meredith Keery, Provincial Outreach Program for FASD, B.C. Ministry of Education
Pete Quily
Sarah Reid
Gabriela Reynoso
Janelle Robb
Bryan Rowley
Harvey Ruddell

Maria S
Dr. Michelle Schmidt
Kim Seymour
Penny Shepherd-Hill
Sherry H. Ghorbankhani, Shining
Horizon Counselling Services
Daphne Raymond, Sooke Family
Resource Society
Antonia Tata, Sooke Family Resource
Society - Kingfisher Preschool
Sonia Spooner
Susan Stacey
Julia Stockhausen
Betty Tang
Antonia Tata
Rhoda Taylor
Reva May Pearson, Teddy Bear Day
Care
Jennifer Sexton, Therapy Hub
Chrissy Thom
Sandy Thon
Jill Crichton. Tri-Cities and New West
CDBC Programs; Andrea Carlson,
Tri-City CDBC Program
William Tsai
Kim Turkington
Gail van der Leek
Charlene Vanderkamp
Josephine Zahn
Crys Zimmer

