



**WHITEPAPER**

**BC'S CYSN SERVICE DELIVERY  
TRANSFORMATION**



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# LAND ACKNOWLEDGEMENT

BCACDI and our member organizations acknowledge that we are on the traditional territory of many Indigenous Peoples, who have lived on this land for thousands of years. We are grateful for their stewardship of the land and strive to build respectful relationships with the Indigenous peoples in all areas of this province in which we live, work, and play. It is a privilege to work alongside the Inuit, Metis, and First Nations people of BC.

# THE BC ASSOCIATION FOR CHILD DEVELOPMENT AND INTERVENTION (BCACDI)

Since the 1970s BCACDI has roots in supporting community based not-for-profits that deliver services to children, youth, and families with support needs. In the 1970s there were strong local grassroots movements dedicated to transitioning children and youth with support needs out of institutionalized care and back into community. Citizens across BC created local non-profit organizations, typically called Child Development Centres, that built teams of professionals to support children and families in their communities. In the 1980s when the government started providing funding directly to CDCs via contracts, two non-profit associations were formed: the Child Development and Rehabilitation Network (CDRN) which was a provincial network of CDC Executive Directors, and the BC Association of Child Development Centers (BCACDC) which was a provincial network of CDC Board representatives. In 1996 these two organizations amalgamated to form the BC Association for Child Development and Intervention (BCACDI).

The Association's Mission is to advocate for quality child development and therapy services which are inclusive and accessible to all children and families and to provide member agencies with a forum for communication, information sharing and problem solving. The Association's Vision is for all children and youth requiring extra support and their families to have timely access to the most effective services that help them achieve their true potential.

Membership with BCACDI is voluntary, and as of January 2024 the Association had 41 member agencies with representation in each region of the province including rural, northern, and urban settings. All of our member organizations are community based not-for-profits that contract with the Ministry of Children and Family Development and other funding sources to deliver services and programs to children and youth with support needs. Collectively, BCACDI member agencies support over 30,000 children, youth and families across BC, and have hundreds of thousands of hours of experience in the sector.



# EXECUTIVE SUMMARY

In the current system, high-level, core-funded CYSN supports are primarily being provided by proven, long term, charitable service providers in a highly efficient and effective manner. However, decades of under-investment in services and supports for children, youth and families in the province has resulted in unacceptable wait times, fragmented service delivery in many communities, and some families not able to access the services they need. Family challenges have increased in complexity, with mental health challenges combining with a rise in basic needs such as food security and housing. The situation is exacerbated by a lack of adequate human resources, and a lack of transparency and understanding regarding the level of investment required to ensure all children, youth and families in BC have access to the services they need in a timely manner.

Reports and research in the sector have highlighted the challenges, but also provided an understanding of solutions moving forward. Family-centred care; cross-sector collaboration and connection; coordination of services; sufficient, equitable, and accountable funding; customized services; and staff training are key components of how services can be more effective. Fortunately, BC has an existing infrastructure of community-based not-for-profit organizations with the experience and expertise to deliver services in this manner, and this paper outlines BCACDI's Way Forward that will strengthen this existing infrastructure to meet the challenges facing the system today.

The system requires a transparent funding formula that is sufficient and equitable; a consistent suite of services available for all children, youth, and families; a system that is accountable to families and the public; procurement that is need-based and doesn't disrupt existing services for families; different funding models that focus on an equity lens and are complementary; and a robust human resources strategy that effectively supports the solutions above. The following is BCACDI's proposed [Way Forward](#) for the system of programs and services for children and youth with support needs and their families. We look forward to sharing our vision and continuing the conversation.



# CURRENT STATE – BRIEF SUMMARY OF COMMUNITY BASED CYSN SERVICES TODAY

## Foundational Programs

The majority of services for children and youth with support needs are delivered via government created foundational programs. There are a variety of programs designed to support caregivers in their child's first few years of life (e.g. Infant Development Program, Aboriginal Infant Development Program), support children to participate in childcare settings (Supported Child Development, Aboriginal Supported Child Development), and rehabilitation therapies (Early Intervention Therapies, School Age Therapy) to optimize health and developmental outcomes and quality of life for children and youth. More information regarding these programs can be found [here](#). These programs are needs-based, meaning that no formal diagnosis is required. If a parent/primary caregiver or community member in a child's life (e.g. – family doctor, early childhood educator, community nurse, teacher, etc.) has a concern regarding a child or youth's development, they can simply refer the family to the local community organization that delivers the appropriate foundational program. Caregivers can also self-refer.

The BC Ministry of Children and Family Development contracts with an organization to deliver a particular foundational program, and the majority of such contracts are held by

local community-based non-profit agencies. Community-based non-profits that contract with MCFD are required to be Accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). Every 3 years accreditors from CARF visit the community-based agency to review policies and procedures, approaches to service delivery, health & safety, quality, outcome measures, and much more. This is an intensive review every 3 years, in addition to the ongoing operational quality assurance measures that individual agencies put into place. This process provides an accountability framework for the significant amount of resources the government is transferring to the non-profit community-based sector.

## Diagnosis Specific Services

There are two primary diagnosis specific services: Autism Funding Program and the Fetal Alcohol Spectrum Disorder Key Worker Program.

### [Autism Funding Program \(AFP\)](#)

Children and youth with a diagnosis of autism spectrum disorder (ASD) are eligible to apply to the AFP for Individualized Funding (IF). IF is a system whereby public funds are provided directly to families, and the family purchases services to help support their child/youth.

The amount of funding is a set amount depending on the age of the recipient (6 and under; or over 6 and up to 19 years of age). Families can decide where to purchase their services from, depending in part on the availability of professionals and programming in their community.

### [FASD Key Worker Program](#)

The FASD Key Worker program is a support developed specifically for children and youth with a confirmed or suspected diagnosis of FASD or other complex developmental behavioral condition (CDBC). A community-based organization will contract with MCFD to deliver the program. Families with a child or youth with a diagnosis of FASD will be referred to this local community organization to connect with this program and receive support from a Key Worker.

### **Gated Services and Supports**

The BC MCFD provides additional services and supports for CYSN that are ‘gated,’ meaning that eligibility is determined by the government. Many of these additional services and supports are provided through what is now known as the At Home Program. Children and youth with more severe and complex health needs may be able to access the At-Home program to access funding for home equipment, medical supplies, respite, and additional therapy if the child/youth is school aged.

### **Provincial Services**

Local community-based services are supported by a number of Provincial Services, including those provided by BC Children’s Hospital Sunny Hill Health Centre (e.g., seating clinic, feeding clinic, complex developmental behavioural conditions, assistive technology and augmentative alternative communication), Autism Assessment Clinics, and Provincial Services supported by some of our member agencies such as the BC Family Hearing Resource Society, and the BC Centre for Ability’s provincial community brain injury rehabilitation program. This is just a short list of the many Provincial Services available to families.



# CURRENT STATE – STRENGTHS OF THE CURRENT SYSTEM

In the current system, high-level, core-funded CYSN supports are primarily being provided by proven, long term, charitable service providers in a highly efficient and effective manner. They bring added value to their CYSN contracts through their decades of experience providing complex support to the sector, their highly experienced and knowledgeable staff, and their 16+ years of accreditation.

The current system has faced significant challenges over the years. Austerity measures put into place during the 2008/2009 financial crisis resulted in a freeze on base contract funding for many years. Over the past decade there have been occasional contract increases related to collective bargaining agreements, but little to no increases for service development and expansion. Throughout this period, we have seen a significant increase in referrals, children with greater health complexities surviving and needing support in the community and higher complexity in our families including new Canadians, refugees, mental health and behavioural challenges, single parent homes, financial stress and other needs requiring intensive wrap around services and supports. Despite historical under-funding of the current system, it has persevered and brings with it many strengths:

## **1. Not for Profit**

The majority of services are delivered via contracted not-for-profit agencies; thus, the focus is on service delivery, meeting contract requirements and balancing revenue and expenses. Organizations are led by volunteer boards, not shareholders. There is no focus on profit generation, and any excess revenue goes directly back into service delivery.

## **2. Accountable**

Organizations contracting with the government for amounts in excess of \$500,000 are required to go through an intensive Accreditation process every 3 years. This process is an additional level of accountability beyond an organization's own quality assurance program, to ensure policies and procedures are in place to facilitate effective, quality services. Organizations also go through annual financial auditing which is reported on publicly.

## **3. Community-Based**

Local non-profits are led by local citizen board members who are residents of the community the organization serves. Many have been in operation for decades and have extensive local networks and partnerships. Local organizations have the ability and experience to adapt and evolve services to better meet the needs of their community and have benefitted from years of volunteer supports, donations, and fundraising campaigns.



#### **4. Multi-Disciplinary Team Based Approach**

The majority of organizations deliver multiple programs. This facilitates a team-based approach where professionals serving the same client can more easily collaborate and support the intervention plan, easing navigation and communications for families. These organizations also host other complimentary services on behalf of Government including Foundry, Integrated Child and Youth teams, family preservation and foster support, and housing allowing for seamless and integrated services for clients and families in the community.

#### **5. Family Centred Service Delivery Model**

Service delivery recognizes and values the central role of primary caregivers in the development of their child or youth. True family centred practice involves families in the decision-making process ensuring the intervention plan is led by their perspectives and addresses their priorities and needs. There is no one way of providing family centred services. The relationships that are formed with parents are central to understanding each family's circumstances, priorities, and preferences in how to engage with a program or service.

#### **6. Network of Organizations**

BC has a network of non-profit community-based organizations in all regions of the province, in both urban and rural settings. These organizations learn from each other and support one another. New models of intervention, and professional development

and training can be more efficiently disseminated through such a network. Professionals benefit from informal and formal communities of practice and champions models.

#### **7. Needs based access (i.e. – low barrier, open referral) for most children, youth and families**

The majority of existing services and programs are needs-based; thus, families do not require a formal diagnosis or referral to access. Families can self-refer, or a large range of professionals and supports that may already be engaged with a family can refer them to their local non-profit delivering CYSN services.

#### **8. The People**

The individuals who choose to work or volunteer at community-based not-for-profits are passionate and caring citizens devoting their careers to trying to improve the lives of others. Wages and benefits are lower than similar work in any other sector, caseloads are large, resources are scarce, and the work is incredibly complex. Yet the dedication of the staff and volunteers in this sector is relentless. The people working in this sector are unique, and have the training and expertise to deliver highly complex health and social services in community rather than families having to access this support exclusively from a traditional healthcare facility. That allows services to be tailored, relevant and accessible in a setting that's more convenient and appropriate for the child/youth/ family while not taking away or adding additional burden to the acute care setting.

## 9. Evidence Informed

Services at these organizations are rooted in evidence and best practices in early intervention therapy and child development. Organizations are required to gather data on outcomes, and develop quality improvement plans and initiatives to address areas for continuous improvement. The network of providers through BCACDI are supported to lead and participate in national and international research projects, engage in ongoing professional development and have close relationships with leading academic institutions in our field including the University of Victoria, UBC, McMaster and McGill. Staff at these organizations teach, mentor students, provide clinical support and supervision to new grads, participate in communities of practice, lead and participate in research, write and present locally, nationally and internationally and host international delegations of child development and therapy services organizations who visit to learn more about the progressive and creative work happening in this sector in BC.



# RECENT REPORTS RELATED TO CYSN SERVICES

Decades of underfunding has unfortunately led to some tragic and concerning outcomes in the Children and Youth with Support Needs sector. This has led to several reports and research in response, outlining the challenges experienced by both families and service providers. Several of these reports helped for the basis for this white paper, and are referenced here:

## [1. Toward Inclusion: The need to improve access to mental health services for children and youth with neurodevelopmental conditions](#)

This report highlighted the very high prevalence of mental health disorders amongst children and youth with neurodevelopmental conditions, specifically those with Autism Spectrum Disorder (ASD), Fetal Alcohol Spectrum Disorder (FASD) and Intellectual Disability (ID). It also highlighted effective mental health interventions such as parent training programs and social skills training.

## [2. Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family](#)

Alone and Afraid is a RCY investigative report that describes the tragic story of “Charlie,” a 12-year-old boy with autism who wasn’t able to access services to address his special needs, rarely attended school and had no access to other socialization.

Many recommendations resulted from this report, including the need for a review of existing service levels, improved access, and better integration between the Ministries of Health, Education, and Children and Family Development.

## [3. Select Standing Committee on Children and Youth: Children and Youth with Neuro-Diverse Special Needs](#)

This report was a special project by the Select Standing Committee on Children and Youth that had a focus on eligibility and assessment processes for children and youth with neuro-diverse special needs. Recommendations included the setting of benchmarks for assessment and service access wait times, ensuring services are based on need and functional ability, and improve access to respite services.

## [4. Key Components of Service Delivery for Children and Youth with Support Needs and their Families](#)

This report commissioned by the RCY attempted to address 3 key questions: What are the key components of effective, family-centred service delivery systems for children and youth with support needs (CYSN) and their families? What additional components are required to address the mental health needs of CYSN? And, what additional components are required to effectively deliver services to Indigenous CYSN and their families?

Eight key components were revealed from this work, further detail of each and how they link with existing not-for-profit community-based services are outlined on page 14 of this document.

#### [5. Left Out: Children and youth with special needs in the pandemic](#)

This report commissioned by the RCY demonstrated the failure of an under-resourced system to effectively meet the needs of families during the pandemic. Recommendations called for more equitable access and a needs-based approach to service delivery, streamline processes to improve access, explore virtual service delivery options, and provide flexible financial supports to families.

#### [6. Kid's Can't Wait: The Case for Investing in Early Childhood Intervention Programs in BC](#)

A collection of provincial advocacy organizations, service providers, and families came together in 2016 for a summit on early childhood intervention services. The group reached consensus on the need for increased investments into the sector, provincial standards for wait times, and expanded supports during periods of transition (i.e. - into Kindergarten, into adulthood). Further, there was a call for improved collaboration between Ministries, investing in relationships between Indigenous communities and service providers, and improved child and family centred practice. Recruitment and retention of professionals was also discussed, with a recommendation for expansion of the training programs for the professionals needed in the sector.

Key themes emerging from these reports:

### **1. Significant prevalence of associated mental health challenges in children and youth with support needs**

Mental health challenges within the population of children and youth with support needs are prevalent, yet in the current system of service delivery intervention services and mental health services are not well integrated. Although there are efforts to improve this, the implementation of such programming is slow (i.e. Pathways to Hope) and/or supported through unsustainable funding (e.g. – community based not-for-profit developed programs supported through donations or foundation funding).

The mental health of primary caregivers/ parents is also an increasing concern. Mental health counselling needs to be accessible through child-focused organizations. There is a need to create greater connections between pre/post natal and maternal health services for improved continuity of care.

*The Way Forward will address this existing gap in service through a sustainable and integrated model of care.*





**2. The actual need for CYSN services across BC and the current capacity to meet those needs are not clear.**

It is not clear what funding formula is being used to determine resource allocation across the province, nor is it clear the level of funding we should be striving for. There needs to be an assessment of the true need for CYSN services across BC, the existing capacity of the current system, and the investments required for the system to expand to meet the true need.

*The Way Forward will include a transparent funding model and clear targets for ideal resource levels.*

**3. Wait times are unacceptable**

Wait times are a significant challenge, both for diagnosis and for service access. The province and service providers should collaborate to publicly set benchmarks for reducing assessment and service wait times, and publicly report on outcomes on an annual basis.

*The Way Forward will have clear and transparent wait time benchmarks for both assessment and service access, and public scorecards outlining key performance indicators.*

**4. BC Needs to Develop the Labour Force for Children and Youth Services**

Labour challenges are an issue in all sectors; however, in children and youth services it is of particular concern. The research on early intervention demonstrates the positive return on investment when children can access services during this critical developmental period of their lives. Staffing shortages negatively impact the ability for families to access the services they need to achieve their full potential and pass on future costs to society. Further, the education of professionals in this sector needs to emphasize relational skills in order to engage with families who would benefit the most.

*The Way Forward will have a robust human resources development strategy to address the staffing and training challenges in the sector.*

## 5. Navigating the Current System can be a challenge, and families need more support

The social services sector suffers from an identity crisis, in that communities in general aren't aware of the services provided until they or someone in their family would benefit from them. Healthcare (i.e. hospitals) and Education (i.e. schools and universities) have strong representation in people's minds, but community-based not-for-profits operate without the same degree of public acknowledgement or awareness despite supporting some of our province's most marginalized citizens. This, along with the complexity of contracts and multiple organizations delivering services, can result in significant navigation challenges for families.

Parents and caregivers of children and youth with support needs are heroic, often having to set aside careers and make countless other sacrifices as they step up to provide the best possible parenting for their child. The intensity of caregiving for a child or youth with support needs requires respite, and the special circumstances raising a child or youth with support needs makes it challenging to find formal or informal respite opportunities other parents may be able to easily access. Currently, formal respite is challenging to qualify for, and hard to find.

*The Way Forward will have a system that is easier to navigate, support for navigation for those families that need it, and responsive respite programming that is easy to access.*





# KEY COMPONENTS OF SERVICE DELIVERY FOR CHILDREN AND YOUTH WITH SUPPORT NEEDS AND THEIR FAMILIES

British Columbia has an existing network of community-based non-profit organizations with the skills, staff, and expertise to effectively support children and youth. However, over the past 15 years this existing network has been starved of resources, leading to many of the challenges the system faces today. As the complexity of challenges faced by families has grown, the necessary investments into the existing infrastructure to support them has simply not matched the need.

The report commissioned by the Office of the Representative: Key Components of Service Delivery for Children and Youth with Support Needs and their Families, outlines the key components of effective, family-centred service delivery systems for CYSN and their families. These key themes strengthen the need to build off the existing network of community-based non-profit organizations:

## **1. Provision of family-centred care**

Family-centered care engages and involves families in the decision-making and care planning process. A family's perspective needs to be respected and should be reflected in a family-centered plan of intervention.

A team of professionals working together at an organisation are well positioned to provide this family-centred care approach. Indeed, this is common practice at community based not-for-profits, although there should be ongoing education, training, and evaluation to ensure intervention truly is family-centred. In particular, the sector as a whole would benefit from ongoing training on engaging with families who find the system hard to reach, cultural safety and humility, trauma and violence informed care, and relational approaches to intervention.

## **2. Cross-sector collaboration and connections to community networks and resources**

BC has a long and rich history of community-based not-for-profit organizations supporting their communities. Decades of operation in a local community strengthens local partnerships and increases the awareness of existing services and supports. Boards of directors consisting of local citizens and volunteers assisting with the ongoing operations of an organization, both serve to weave an organization into the fabric of a community.

Communities see the value of these local organizations, evidenced by the millions of dollars in donations contributed by community to help agencies better serve their clientele. Long serving organizations, such as those represented by BCACDI membership, have the existing relationships for effective cross-sector collaboration and connections to other local resources.

### **3. Coordination of services across therapies**

Community-based not-for-profits are well positioned to facilitate coordination of services across therapies. When programs and services are contracted with an organization, multiple professionals involved in the intervention plan for a child or youth can more easily communicate and coordinate care when they are all working for the same organization. Consistent team meetings, the ability to integrate colleagues' goals into the care plan, and utilizing the same case management software are all facilitated by a global contract with a local community-based not-for-profit.

### **4. Sufficient, accountable funding, equitable funding allocation, and sufficient resources**

Community based not-for-profits have a deep understanding of the communities they serve. The referrals they receive, and the caseloads of their staff provide a measure of how sufficient the existing level of funding is. The rigorous accreditation process they go through, in addition to their own internal quality improvement processes, provides a standard level of accountability not found in smaller organizations or individual practitioners.

Funding allocation across the province should be reviewed, and standards need to be set in terms of FTE allocation and expected wait time for service to assist with equitable funding distribution. BCACDI is currently undergoing work in this regard for our sector. Sufficient resources is also currently an area that needs to be reviewed. Contracts are typically for service hours only, and organisations aren't on a level playing field in terms of donor bases to assist with the administrative resources necessary for effective service delivery.

### **5. Services customized to meet individual needs (intensity, quality)**

This is where the decade plus of under investment in the sector has had its largest impact. Increasing complexity of children and youth requiring support, coinciding with inadequate resources and no significant increases in contracts to allow more hiring of staff, have created an environment of scarcity. Waitlists and high caseloads have resulted in massive challenges to customize services to meet individual needs. Clinicians are forced to implement treatment plans that don't have the level of service intensity their professional judgment deems necessary for effective outcomes. The expertise to ensure services are customized to meet individual needs is there, all that is required is effective resource allocation to make it happen.



## **6. Staff training related to the service delivery model**

Training and professional development are critical components of an effective system of care and support. When emerging research demonstrates effectiveness with a particular approach, it is crucial to efficiently translate this new knowledge to the staff supporting a child, youth, and family. The existing network of community based not-for-profits provides an efficient mechanism for delivering training across the province. Staff from different disciplines can be educated together, helping further build the rapport required for a multi-disciplinary team-based approach to supporting a family. BCACDI has several examples of cost-effective and efficient training for staff at community-based not-for-profits in areas such as cultural safety and the F-words.

In the research report commissioned by the Office of the Representative, there were two additional components identified as key for effective mental health service delivery: Wraparound services and ease of referral and access

## **7. Wraparound services**

In many cases the local non-profit organization delivers more than one program, and is thus able to support a child, youth, and/or family in multiple ways to help meet their goals and needs. Teams of professionals with different training and delivering separate programs all working for the same organization are in a better environment to collaborate and provide wrap-around services and supports. Teams will help implement their colleagues' goals into their own intervention plans, and if one professional establishes a strong rapport with a primary caregiver then they can be the main source of contact to ease the navigation and communication



challenges when multiple services are involved. Many community based not-for-profits will have a family support worker role to further assist with service navigation, access to resources such as child care, housing, food security and other aspects of the primary caregivers life that increase the complexity in accessing services.

### **8. Ease of referral and access**

The majority of existing CYSN services are needs-based and have ease of referral. Families can self-refer, or an organization may receive a referral from a physician, community nurse, teacher, early childhood educator, etc. This should be expanded to include behavioural support services and other specialized programming for children and youth who are suspected of having Autism or FASD but do not have a diagnosis. Ease of access will improve with sufficient funding for the sector.

The report noted two additional components for effective CYSN services for Indigenous children and families:

### **9. Embed Indigenous Culture, Values, and Practices; “Two-Eyed Seeing”**

Community-based not-for-profit organisations are on a journey to improve culturally safe service delivery to Indigenous children and families. Accreditation and quality assurance requires cultural safety plans, but more importantly, team training in areas such as the impact of colonization and culturally safe practice assist an organization as a whole to acknowledge just how much there is to learn and facilitate a culture shift within the programs and services delivered.

Organizations are learning from each other on other practices to better support Indigenous families, including partnerships with local Indigenous organizations, the establishment of Indigenous Advisory Circles, and increasing staff and board member diversity. There are examples within BCACDI membership of our member agencies working with Indigenous organizations to help each other build capacity to support local Indigenous communities, and transitioning a service contract from a BCACDI member agency to a local Indigenous organization. We acknowledge there is significant potential for further growth and improvement in the embedding of Indigenous culture, values, and practices into the existing service delivery models of community-based not-for-profit organizations, and the sector welcomes this challenge.

### **10. Support the Whole Family**

This is where community-based multi-service organizations with multiple programs and services excel. With effective resources so that critical roles such as Family Support Workers are in place, and the knowledge and training to ensure a culturally safe approach, an organization delivering multiple programs has the ability to truly wrap services around the child, youth, and family.

# PARENT VOICES

BCACDI deeply values the lived experiences of families. Our member agencies are guided by a family and child centred approach, which means that families are empowered and supported to develop their own goals based on their priorities. Services and supports are then developed and guided by the unique strengths and needs of each child and their family. We have an incredibly diverse population in British Columbia, including refugees, IBPOC, families experiencing mental health and substance use challenges, families living in extreme poverty and more.

One family's journey truly is just one family's journey and no path forward will be successful if the voices of families and their unique lived experiences aren't at the centre of any potential future service delivery model(s). To that end, we thought it would be important to include some family stories in this paper. While they do not encompass every experience, we are hopeful that they capture a range of experiences. Family and any other identifying information has been removed to ensure confidentiality.

## **Family #1 - Lives in the Thompson-Okanagan area**

### **Family Description and Services Received:**

We are a family of six. Husband and wife, 3 daughters (ages 21, 17, and 13) and one son (age 19).

All of our kids have autism. They were diagnosed at different ages. One was diagnosed at 3 years old, one at 4 years old, another at 10 and the last at 13 years old.

We received services through a community based not-for-profit organization (CBNP) starting with our son. He could not talk so we reached out for Speech language therapy when he was 2.5 years old. Once he was diagnosed with Autism, he was placed immediately into services provided by our CBNP. He had daily behavior intervention as well as weekly speech therapy and occupational therapy. Once he entered elementary school, his time with our CBNP was reduced to one or two afternoons per week. Then, as he got a bit older, he attended his autism intervention sessions once per week, until he reached the age of 14. At which time, we withdrew him as he was flourishing in social and daily activities.

Our middle daughter started receiving services through our CBNP before the age of two, for occupational therapy as she "bum-scooped" but didn't know how to crawl. She attended at least twice a week for awhile, then once she caught onto crawling, the next step was walking. She began doing so independently at 20 months but continued sessions due to low core strength. As well, she began Speech Therapy on a weekly basis due to not being able to pronounce certain letters properly.

She was diagnosed with autism one month after her 4th birthday. She began working with behavior interventionists at our CBNP on a daily basis until she entered school. She attended her intervention therapy until she was 12 years old. She flourished in her social and communication skills. She's also very academically inclined.

Our oldest daughter was diagnosed with autism at 13 years old. She didn't attend our CBNP for intervention, however, she did attend our CBNP when she was five years old due to her sensory and delicate fine-motor skills. She did some occupational therapy a couple times per week until she turned five years old. She learned how important it was to strengthen her core and crossover her body with activities. This helped tremendously with her ability to hold a pencil properly.

Our youngest daughter attended our CBNP very young. In fact, she began occupational therapy at the tender age of three months old due to the lack of muscle-strength in her neck. We continued her sessions with the occupational therapist well into her first years. As well, she began Speech Therapy on a weekly basis for a few months due to her inability to connect words and make sounds. She continued with speech until she turned five years old. She was diagnosed at 10 years old with autism. Which really wasn't a surprise because it seems to be genetic within our family.

### **How did the services received help our family:**

I don't think our children would be who they are today without the help of CBNP. Especially where our son and our middle daughter are concerned. Our son is a fully-functioning adult who maintains a full-time job at a grocery store. He interacts with shoppers and staff on a regular basis. He has a wonderful yet slightly sarcastic sense of humor, and he is one of the kindest people you'll ever meet. Our middle daughter is very creative both with words and through her art. She helps any student at school who needs some assistance, whether it be needing a partner in class or help getting through an assignment. She is a straight-A student and has many goals that she wants to accomplish in life.

We still keep in touch with staff from our CBNP and attend the annual autism walk.

### **How did we find a CBNP:**

Literally-speaking, we found our CBNP through recommendations from our family doctor, pediatrician, and the preschool instructor that our oldest daughter had when she was little. They offered all the services we needed in one place, which helped a lot considering the amount of emotion a parent goes through when receiving news that their child/children have some speech/motor/social delays or issues. Thankfully, we were directed to our CBNP and never looked back.



## Family #2 - Lives in the Lower Mainland

### Family Description and Services Received:

Our Family has lived in the lower mainland for over 25 years. My husband and I have been married for over 20 years and we have an 18 year old and a 14 year old. Our 18 year old has Autism Spectrum Disorder and was diagnosed at the age of 4. He has received both centred-based and home-based therapy services since the age of 4 and has done incredibly well. I am grateful for all of the intervention that he has received and absolutely know, without a doubt he would not be as independent as he is without the incredible work of the Behaviour Analysts, Speech and Language Pathologists, and Interventionists that have been in our lives.

I was incredibly concerned with the government announcement around the loss of Individualized Funding (IF) as I know how much it has helped my child. That said, I have also been exhausted and frustrated with IF and the fragmented and complex navigation required to keep quality services going for my child. I am a parent with an incredible support system, resources, education and while my child has needs, he is not complexed and responds very well to intervention. I have watched family, friends and acquaintances struggle incredibly trying to utilize their IF, while their child receives no support whatsoever. I've even been asked to help newcomer families navigate using IF and it is absolutely heartbreaking to see some of those families be taken advantage of, not receive adequate or evidence based services, and struggle more than I can imagine.

### How did we find a CBNP:

My son's very first Speech and Language Pathologist was at a CBNP, that we were connected to through our family doctor, and was the very first person to support us on our journey. She flagged autism, helped me advocate for an assessment and supported me during a time that was stressful and scary. I will never forget her, and I really don't know where we would be today without her. We need more universally accessible services for families in this province. I believe that there is a path forward that builds upon the strengths of our system but it needs to work for all families, not just those who are the most privileged.

## Family #3 - Lives in the North

I was first introduced to the Child Development Centre when my 2-year old had only a few words and we were brand new to town. Our doctor recommended we go see the folks at the CDC to assist with our concerns, I was able to walk through the doors and self-refer for services. I felt an instant sense of relief with the welcoming environment and the staff's willingness to listen to me as a somewhat frightened and confused parent. My son started speech services and from there he received an autism diagnosis. Sixteen years later, I cannot adequately express my gratitude for the CDC and their holistic, family centred approach to care. Throughout our time at the centre, we accessed occupational therapy, infant development therapy, speech language therapy, and respite to address sleep, speech, sensory diets, classroom integration, and social supports.

They provided care for our whole family including my husband and two other children. These supports were provided within the organization and in our home which was a definite benefit when it was challenging to travel to the centre. I can truly say that the adult I'm so proud of today is a direct result of all of the efforts of our team at the CDC.

As a young parent, it's easy to feel overwhelmed with your desire to do the best job you can. This is even more true when you have a neurodiverse child in your family. The team at the CDC treated us like we were part of the solution, not just a passive observer of their wisdom. They empowered us as a family to know better and do better at every turn. In an effort to give back to the Centre, I volunteered on the board of directors for a few years and there I truly understood the magnitude of care that CDC's offer to families just like mine. Over the years I have watched caseloads increase and waitlists eclipse them. I am deeply worried about the next generation of families struggling to advocate for care for their children while balancing work commitments, care for their families, and the increasing pressure of the cost of living. We know that intervention for children 0-5 not only improves outcomes for families but also reduces the strain on education and health care systems going forward. I understand that funding is not infinite, however these families deserve our investment; we know better, and it's time we did better. Families should not be required to advocate for services (or even just a spot on a waitlist) in order to provide their children their best possible outcomes. Adequate staffing and funding formulas that are equitable and transparent are important to ensuring developmental outcomes for all children and families that need it.



# THE WAY FORWARD

BCACDI's vision of the way forward for services for children and youth with support needs draws from the countless hours of experience and expertise from community based not-for-profits, lived experiences of the families our member agencies serve, principles of early investment in the early years, and a rights-based approach to service access. Starting with Nobel Laureate James Heckmann's work (Heckman, 2008), there is clear evidence that strong and supportive early years programs, particularly with a focus on disadvantaged children, result in substantial positive effects on a range of cognitive and noncognitive skills, including achievement in school and social behaviors, long after the early interventions have ended. To leverage these findings, society needs to commit to long-term investments in our children, rather than short-term cycles influenced by elections.

Through an equity and child's rights based approach (Article 23, UN Convention on the Rights of the Child; Article 7, UN Convention on the Rights of Persons with Disabilities), services and supports require an infrastructure with a lens on equitable access for families regardless of where they live and the challenges they face.

**1. Goal: Provide a sufficient and equitable level of funding for the existing infrastructure of community-based not-for-profit (CBNP) organizations to meet the needs of their communities.**

Insufficient funding levels force CBNPs to focus on high priority families only, limiting the customization of services that can be provided, decreasing service intensity, and providing less access for other families with still important but relatively lower levels of need. Insufficient funding also inhibits other important work that should be taking place such as building community partnerships with other stakeholders in the community, evolving service delivery models to meet the changing needs of the families served, and ensuring staff have the training and support they need to do the best job possible.

Sufficient funding will decrease wait times and access issues for all children and families, ensure customized services of the appropriate intensity, the ability to build improved community partnerships, increase cross-sector collaboration, and improve service delivery to our most vulnerable populations.

## **How We Get There:**

The information exists for the Province to establish sufficient and equitable funding levels; however, the system currently does not have a procedure in place to gather and analyze this data. Community population statistics and prevalence of developmental disability data can be used to determine an estimate of the number of children and youth that will likely require services and supports.

Existing workload data, such as caseload sizes and existing funded staffing levels, can be utilized to determine if current funding levels are sufficient and where the Province has the biggest gaps in investment. This information can be supplemented by other sources such as UBC HELP data (e.g. - EDI to help determine neighborhoods requiring increased investments) and community demographic information (e.g. - rural, percentage of marginalized populations) so that the Province knows where enhancements need to be made.

The information and data exist, all that is required is for the Province and the sector to get together and develop a transparent funding model with ideal targets for staffing and resources.

*The Way Forward will include a collaborative and transparent funding model and clear targets for ideal resource levels (e.g. a defined number of FTEs based on population) to ensure a sufficient and equitable level of funding for the existing infrastructure of community-based not-for-profit (CBNP) organizations to meet the needs of their communities. Contracts will include additional resources for relationship building and development between community based organizations and other stakeholders in the community (e.g. - libraries, recreation centres), to help ensure families are connected to additional resources that will improve their quality of life.*

## **2. Goal: Consistent suite of services available in each community in BC, and accessibility of services across the pediatric lifespan (0-22).**

The needs of families have evolved and changed since the existing foundational programs were developed. Families face increasingly complex challenges, including poverty, food insecurity, and expensive and hard to find housing. More and more children and youth present with multiple physical and mental health related conditions requiring a wrap-around multi-service team-based approach. The existing system is delivered via multiple contracts that aren't always delivered by the same organization, aren't always funded by the same Ministry, and aren't always available in each community.

Families, children, and youth in BC deserve an integrated system of services and supports, with enhancements during key points of transition (e.g. - school entry, transition to adult services).

### **How We Get There**

The Province should leverage the existing network of CBNPs and their experience with multi-service, team-based, needs-based support and provide sufficient resources via global contracts that aren't siloed into narrow scope programs. CBNPs already have the foundation of multiple professionals with a broad range of expertise, and in the vast majority of cases all that would be required is the addition of a profession or two to expand services into other non-traditional areas such as more intensive mental health services and supports. Contracts with increased flexibility will allow resources to be shifted around



to enhance the services most needed in a community to ensure the right service at the right time is available. Flexibility in contracts would also allow for the innovative solutions required for supporting rural and remote communities, newcomers to Canada, Indigenous communities, and any other unique environments and challenges impacting service delivery. Further, early intervention services should be expanded to ensure support through and several years beyond school entry to ease challenges created during that critical transition period. Youth ‘aging-out’ of services and entering adulthood should have expanded supports as well, and not be unceremoniously ‘cut-off’ once they turn 19 from the services they rely on and are familiar with and would facilitate a successful transition to adulthood.

*The way forward will provide a consistent suite of services available in each community in BC, and accessibility of services across the pediatric lifespan (0-22).*

### **3. Goal: A service that is accountable to the families served, the funding source, and the citizens of BC**

The sector and the province have all sorts of data regarding service delivery, but no established mechanism of sharing this information publicly and ensuring the data is valid and reliable. Improved data collection standards and public sharing of this information will improve the accountability of the system as a whole.

### **How We Get There**

Community based not-for-profits undergo a rigorous accreditation process every 3 years resulting in, amongst other accountability measures, effective quality assurance processes such as outcome measures and tracking client access (i.e. - wait times). The province should leverage this data and in collaboration with families and service providers co-create a reporting system with benchmarks for key performance indicators. This would be similar to how the Ministry of Health tracks wait times for various surgeries, and has benchmarks they are striving to meet. For example, in BC we could have a benchmark of 3 months wait time or less for when a referral is received by an organization to when that child/youth has an initial appointment. Such key performance indicators would be made available to the public, and be reported on quarterly and annually.

*The Way Forward includes key performance indicators (e.g. - wait time to access service, achieving family goals, family satisfaction with service), developed in collaboration with government, families, and service providers, that are made available to the public and reported on in a consistent manner.*

#### **4. Goal: Procuring services in a manner that acknowledges and values the experience and expertise of existing service providers, and doesn't significantly disrupt services to children, youth and families**

Procurement of services such as those that support people needs an approach that is vastly different from procuring other government services. The wealth of local experience and expertise, community relationships, existing complement of staffing, and local organizational infrastructure should not be lost through a traditional request for proposals process. Further, broad-based procurement approaches (i.e. - provincial wide) disrupt services in communities where there are effective supports and services working well, with often irreparable damages to existing relationships between community partners.

#### **How We Get There**

Local experience and expertise, existing community relationships, complement of staffing, and local organizational infrastructure are factors that should be heavily weighted in a proposal scoring process, as these are components that mitigate the disruption of services and supports to families during times of change. Further, procurement approaches should be on a community by community basis, as the need for change and the amount of change required will vary significantly depending on a community's existing resources. Procurement should be implemented when a service needed in a community doesn't already exist, and only for that respective service. When procurement is required, existing service providers within a community should have the time and

resources to have the sometimes difficult conversations necessary to collaborate on a solution that best meets the needs of their community in a way that is least disruptive to existing services. Any transition needs to take the time to learn about other procurement approaches with a focus on what is the least disruptive for families, and any roll-out of a new approach requires a transparent multi-year plan co-developed by families, service providers, and MCFD.

*The Way Forward includes a procurement approach that is community specific and community driven, acknowledging the strengths of existing service providers, only done when necessary for the service necessary, and resulting in minimal service disruption for families*

#### **5. Goal: Individualized funding that complements publicly funded not-for-profit services**

Individual funding has been in place in BC for children and youth with Autism for almost two decades, and is also available for some families of school aged children that qualify for certain programs. BCACDI acknowledges that for some this model works well, and doesn't believe in taking anything away from families currently accessing funding in this manner. However, the current model of IF funding in BC is not an equitable way of accessing services for many families, is typically quite challenging to utilize in rural and remote communities, contributes to staffing challenges in the not-for-profit sector,

lacks an accountability framework, and has the potential to lead paediatric therapy services into a two-tiered system of care (a private vs. public paediatric rehabilitation system of healthcare). Individualized funding models such as the NDIS in Australia assumes that: Parents and caregivers can choose who supports their child, the services they receive, and when and where they are delivered. This assumes that there are ‘choices’ of services readily available in the families’ geographical location and that a parent (typically mother) has the time, capacity and self-efficacy to navigate these ‘choices’ which may include multiple service providers.

### **How We Get There**

Since 2018, BCACDI has been advocating for a hybrid model of services for children and youth with Autism. This model would maintain IF funding for those families of children and youth with Autism that choose this format (with an enhanced accountability framework in place), while implementing needs-based behavioural support services via contracts with community based not-for-profits. BC already has several agencies with robust behavioural support programs in place, and hundreds of families choose to utilize their IF funds to purchase services from these programs. However, community-based not-for-profits are not designed to deliver services via an IF payment model, and it creates significant challenges that has resulted in program closures and threatens the viability of remaining programs. A needs based behavioural support program contracted to a community based not-for-profit would leverage the strengths of such organizations, and facilitate the team-based wrap-around

service delivery approach that is necessary to support BC’s more complex families.

*The Way Forward implements a hybrid model of service delivery for children and youth with Autism, strengthening behavioural support services by introducing behavioural support contracts across the network of community based not-for-profit organizations across the province.*

### **6. Goal: Development of a robust human resources strategy for the CBNP sector**

This sector does not have the general public awareness of the critical work we do, thus professionals with the potential to work in this sector often are not even aware that opportunities exist. Further, the acute healthcare sector tends to drive human resource development in our province, and the needs of acute healthcare do not align with the needs of community based not-for-profit paediatric rehabilitation. Due to these challenges, this sector requires a unique and dedicated approach to human resource development.

### **How We Get There**

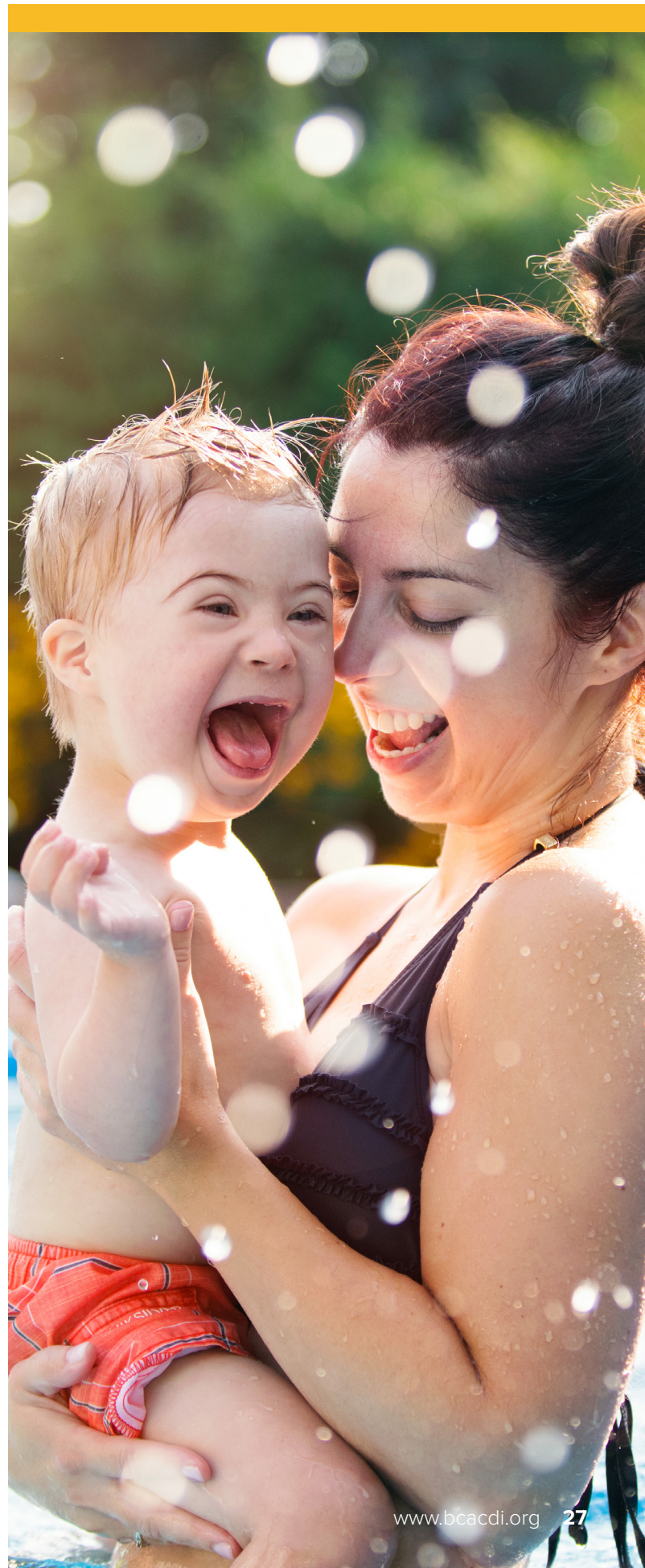
Other sectors (e.g. - Education, Health) have dedicated recruitment departments with the ability to reach out and connect with potential applicants. The CBNP sector deserves the same, a dedicated provincial recruitment lead with a budget to engage with training programs across the country and professionals working in other sectors.



The lead could create partnerships with post-secondary institutions to facilitate student placements in CBNP environments, and put into place innovative new strategies for our sector such as student led clinics and supported rural/remote practicums.

BC needs to increase the number and location of training opportunities for both Speech-Language Pathologists and Occupational Therapists, the two professions with the largest and longest vacancy demands. Incentives to introduce new models to encourage the appropriate use of support personnel would also help address sector HR needs. Lastly, there are significant discrepancies between public sector agreements and public vs. private sector wages. Efforts should be made to standardize public sector agreements so that there aren't such significant differences based on whether a professional works in the Health, Education, or CBNP sector. Private sector professionals who benefit from the availability of public funds should have reasonable rate limits in place to prevent the private market system from escalating fees to the point where it negatively impacts family services and/or creates a significant difference in a professional's earning potential between the public vs private sector.

*The Way Forward includes a dedicated office for the recruitment of professionals to work in the CBNP sector, an increase in the number of training seats for Speech-Language Pathologists, Occupational Therapists, and Behaviour Analysts, and efforts to standardize wage grids across the various sectors employing paediatric rehabilitation professionals.*





# CONCLUSION

Thank you for taking the time to read this document. BCACDI has the privilege of representing 41 community based not-for-profit organizations with decades of experience delivering services and supports to children, youth, and families. These organizations do incredible work, have teams of professionals dedicated to improving the lives of those they serve, and do this work in innovative and effective ways informed by the latest evidence and research. There are several other community-based not-for-profits who are not members of BCACDI doing this work as well, providing an existing infrastructure of publicly funded organizations across our Province already doing great work supporting children and families.

Our way forward focuses on providing this existing infrastructure with the tools and resources to make these services more accessible and even more effective. A transparent funding formula that is sufficient and equitable; a consistent suite of services available for all children, youth, and families; a system that is accountable to families and the public; procurement that is need-based and doesn't disrupt existing services for families; different funding models that focus on an equity lens and are complementary; and a robust human resources strategy that effectively supports the solutions above. This is how the Province can improve services for children and youth with support needs.

We look forward to sharing our vision and continuing the conversation.



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