

Children and Youth with Support Needs

ENGAGEMENT REPORT 2023-2025



Ministry of
Children and Family
Development

This report was produced on the territories of the ləkʷəŋən People, known today as the Songhees and Esquimalt Nations. The Province acknowledges the territories of First Nations around B.C. and is grateful to carry out work on these lands.



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Minister's Message

I am pleased to present this report as part of the Province's commitment to strengthening the system of supports for children and youth with support needs. This represents a significant piece of learning that will help inform how B.C. can better ensure that services are equitable, accessible, and responsive to the needs of children, families, and communities across British Columbia.

This public engagement report reflects the perspectives and experiences of families, service providers, First Nations, Indigenous peoples, and others with lived experience who participated in a province-wide engagement process. Their contributions have provided valuable insights into the current challenges within the system and identified priorities for improvement. For this I am very grateful.

I want to acknowledge also that, in alignment with the Declaration on the Rights of Indigenous Peoples Act and the Truth and Reconciliation Commission's Calls to Action, the Ministry of Children and Family Development remains committed to working in full partnership with Indigenous peoples to advance culturally appropriate, community-driven services.

The findings of this report will help inform the next phase of system redesign, ensuring that future services are developed collaboratively, reflect the diversity of children and youth with support needs, and are grounded in principles of equity, inclusion, and cultural safety.

I personally want to extend my appreciation to all who contributed to this engagement process. If you are a contributor who is reading this, please know that your input will be integral to the development of a system that better meets the needs of children and youth with support needs and their families, now and into the future.

The Honourable Jodie Wickens
Minister of Children and Family Development

Acknowledgements

The Province is deeply grateful to everyone who shared their perspectives and experiences through engagement on Children and Youth with Support Needs (CYSN) programs and services. What was heard during engagement will help inform the path forward to improve CYSN services in B.C.

The Province is also grateful for each person and community who participated in the First Nations Rights and Titleholders engagements and for sharing their thoughts, suggestions and stories. The honesty, vulnerability, time, and energy contributed by the individuals who engaged with the Province will also be integral to creating a positive path forward for improving supports and services for First Nations children and youth with support needs.

Listening to the feedback and perspectives shared by Indigenous participants in engagement made it clear that significant work remains to address the ongoing and harmful effects of colonization in the context of families with support needs.

While this report does not capture the full depth or nuance of all that was shared during the First Nations Rights and Titleholders engagement sessions, the recommendations and experiences shared with the ministry will be used to inform the Province's work with First Nations to improve CYSN services for First Nation families and communities.

Finally, we would like to extend our appreciation to the community partners who have supported this engagement process and contributed valuable insights into how CYSN services can better serve families across B.C.

Executive Summary

Throughout 2023 and 2024, the Ministry of Children and Family Development (the ministry) engaged with the public to understand what is needed in a system of supports and services for children and youth with support needs.¹ This work included engaging with parents and caregivers, First Nations Rights and Titleholders, Indigenous Peoples, experts, practitioners, advocates and others with lived experience throughout the province.

As part of the Province’s commitments under the Declaration on the Rights of Indigenous Peoples Act (Declaration Act), the ministry adopted a distinctions-based approach to engagement.² The ministry engaged directly with First Nations Rights and Titleholders to understand the unique needs and priorities of First Nations communities. Funding was provided to First Nations communities to support their capacity to engage with the ministry and others on their priorities and the unique support and service needs of children and youth in their communities. The ministry also contracted Reciprocal Consulting Inc., an Indigenous research firm, to engage with Métis and urban Indigenous people on behalf of the ministry in a culturally safe way.

Reciprocal Consulting Inc. also engaged with underrepresented groups, including families where English is a learned language, as well as immigrant, refugee, BIPOC, and 2SLGBTQIA+ families.

Partner organizations who are active in the child development sector and/or who provide support needs services were also provided funding to engage directly with their communities and share their findings with the ministry. The ministry is deeply grateful for the work of these Nations and organizations and the information they shared to contribute to this report.

In 2018 and 2019, the ministry engaged in a similar way on Children and Youth with Support Needs (CYSN) services. However, changes within the service landscape, including the enactment of the B.C. Declaration on the Rights of Indigenous Peoples Act in 2019 and complications related to the COVID-19 pandemic, shifted public priorities and needs. In 2022, the Province decided to re-engage in deeper consultation with the public to provide greater transparency and clarity in what the B.C. public is saying about how services for children and youth with support needs can be improved.

This report focuses on the reoccurring themes and recommendations that emerged from our engagement with British Columbians between 2023 and 2024.

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1 Children and youth with support needs refers to children and youth who are experiencing, or at risk of, developmental delay or disability and require support beyond that required by children in general. The developmental delay or disability may be in one or more of the following areas: physical, cognitive, social, emotional, communicative, or behavioural. Children and youth may be experiencing, or at risk of, developmental delay or disability as a result of neurobiological factors (such as genetic, metabolic, or other biological factors) or as a result of social/environmental factors.

2 Definition of a *distinctions-based approach*

Common recommendations from families, Indigenous peoples, advocates, leading researchers and others, such as the Representative for Children and Youth (RCY), in terms of what is needed in an improved system of supports include:

- Greater funding for CYSN services to support child and family well-being
- The maintenance and expansion of direct funding (e.g., Autism Funding) to additional children and youth with disabilities, based on need, with greater flexibility in how that funding can be used by families
- A shift in how the needs of a family are understood and measured
- Intervention to address long wait times for diagnostic services
- The separation of CYSN services from the ministry responsible for child protection
- A streamlined approach to services under one ministry
 - » The Ministry of Health was most often cited as the ideal ministry to hold responsibility for services
 - » Including a way to address silos between mental health services and support needs services to support an integrated approach to service delivery
- The strengthening of the community-based service sector through
 - » Funding enhancements and streamlined policies
 - » Integrated family support, behaviour supports and mental health supports through community-based service sector providers
- A response to regional inequities experienced by families and service providers in rural and remote areas
- Improved access to inclusive child care and supports through the school system

Over the two years that the ministry did this work, front of mind of all participants has always been the urgency with which progress needs to be made for this population of children and youth and their families. This report expands on these recommendations, providing more info about what the Province has heard in more detail. In addition to this engagement report, an evaluation of a pilot approach to CYSN service delivery that includes family connection centres (FCCs) in four communities in B.C. will also inform future CYSN services, among other inputs.

The Ministers of Children and Family Development and Health are committed to working together with Indigenous peoples, key partners and people with lived experience, to realign and improve services for children and youth with support needs and mental health needs.

Introduction

“There have been 12 reports since 2007 with a total of 50 recommendations specific to children and youth with disabilities. No substantive change within that period.” – Reciprocal Consulting Inc., Community Engagement Report on the Development of a System of Services for Children and Youth with Support Needs (Community Engagement Report)

It is well-established that children and youth who are experiencing, or have an increased likelihood of experiencing, developmental delay or disability require support as early as possible to optimize their development, functional abilities and quality of life. In B.C., many families of children and youth with support needs face significant challenges with accessing timely supports and services.

The ministry provides Children and Youth with Support Needs (CYSN) services through three different pathways: CYSN Specialized Provincial Services, Family Support Programs and Foundational Programs. The ministry also provides services to children in care with support needs.³ CYSN services and supports are intended to promote children’s healthy development, maximize their quality of life, assist families in their role as primary caregivers and support full participation in community life.

The Province heard from the public, First Nations and Indigenous Peoples, the Representative for Children and Youth (RCY), partners and others about the urgent need to address gaps in services. These calls highlighted the critical need to make sure that all children and youth with support needs are provided necessary and timely resources to thrive.

The Province recognizes that the current structure of CYSN services is unable to meet the contemporary challenges that many families face. The RCY has called on the Province to address these gaps in services to children and youth with support needs by adopting an all-of-government approach with child and youth well-being at the centre.⁴ To develop a more informed understanding of how CYSN services can be improved to best serve all children and youth with support needs and their families, the Province asked the public to share their experiences, opinions and ideas.

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³ *Information about CYSN services on gov.bc.ca*

⁴ *Representative for Children and Youth. (2025). Too Many Left Behind: Ensuring Children and Youth with Disabilities Thrive.*

Overview of the Engagement Process

Public engagement

From 2023 to 2024 the Province engaged in a comprehensive consultation to inform how the system of CYSN services can be improved. Learning about diverse and unique lived experiences was key to developing a deeper understanding of the barriers, challenges and potential solutions to improve services to children and youth with support needs.

The Province worked closely with sector partners, First Nations Rights and Titleholders, Indigenous peoples, CYSN advisory committees, and other partners to create an engagement process that was culturally safe, trauma-informed, accessible and inclusive of diverse perspectives and experiences. This learning will be incorporated into future engagement projects. The ministry acknowledges that while the timeline, process, and accessibility of the engagement worked for some individuals and groups, they may not have worked for everyone.

The ministry developed several engagement streams and heard from over 5,000 British Columbians about what they envision for the future of services for children and youth with support needs and their families. In addition, the ministry worked collaboratively during the engagement process with the Ministry of Health and the Ministry of Education and Child Care to understand a foundation for employing a cross-ministry, all-of-government approach to supporting children and youth with support needs going forward.

This engagement represented a deeper approach to previous discussions held with the public in 2018 and 2019 regarding service needs of children and youth with support needs and their families. Additionally, it is reflective of the Province's continued commitment to enhancing CYSN services to best serve all children and youth with support needs.

Engagement website

The engagement website served as the main portal to access all engagement opportunities, including an online feedback form, discussion forum, registration for a virtual symposium speaker series, written submission instructions, engagement learnings from sessions with First Nations and grant funding application information. Information about engagement opportunities facilitated by partners was also available on the website.⁵

First Nations Rights and Titleholders engagement

The Province connected with 63 First Nations communities and organizations across B.C. This included participation through virtual engagement sessions, individual meetings, and written feedback via email and community report submissions.

The virtual engagement sessions were attended by 81 individuals from a variety of backgrounds including Elders and Knowledge Keepers, frontline support workers, researchers and policy analysts, parents and family members of children and youth with support needs and community members. The ministry did not limit or determine who should attend as a First Nation Rights and Titleholder and recognizes that individuals did not necessarily

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5 *Engagement website*

attend on behalf of their Nation or community, rather as distinct individuals with unique views. Representatives from 18 Nations that received provincial funding to conduct their own engagement attended a ministry-led virtual engagement session.

Funding for B.C. First Nations

Provincial funding of \$25,000 was available to all B.C. First Nations communities to help support their capacity to engage with the ministry and others on their unique needs in the context of supports and services for children and youth with support needs. 47 First Nations accessed this one-time grant.

Community engagement

Reciprocal Consulting Inc. was contracted by the ministry to support engagement with various communities across B.C. Reciprocal Consulting Inc. led focus groups with underrepresented populations, including:

- Urban Indigenous and Métis families
- English-as-a-learned-language, immigrant, refugee, BIPOC, 2SLGBTQIA+ families
- Families caring for children who are deaf or hard of hearing
- Families caring for children who are blind or partially sighted
- Families caring for children with complex needs

A total of 281 people participated through virtual and in-person focus groups, virtual interviews, and an online survey.

Partner-led engagements

The ministry provided funding to partners that have established relationships with different communities to help facilitate engagement and elevate diverse perspectives and experiences of currently underserved groups.

PARTNERS:

- Attention Deficit Hyperactivity Disorder (ADHD) Advocacy Society of BC
- BC Complex Kids Society
- BC Disability Collaborative
- BC Association of Child Development and Intervention
- Community-Led Collaboration Project (BC Association of Aboriginal Friendship Centres; The Federation of Community Social Services of BC; Inclusion BC; BC Association for Child Development and Intervention)
- Down Syndrome Resource Foundation
- Family Support Institute
- Health Sciences Association of BC
- Inspire Kids Fetal Alcohol Spectrum Disorder (FASD) Support Society of BC

Advisory committees

MINISTER'S ADVISORY COUNCIL FOR CHILDREN AND YOUTH WITH SUPPORT NEEDS

The Minister's Advisory Council for Children and Youth with Support Needs (Minister's Advisory Council) was formed in 2021 and met 26 times over four years, offering a platform to foster collaborative relationships, communication and engagement. These meetings saw discussions on key issues related to the planning and delivery of the full range of CYSN services, supporting the ministry's efforts to enhance the system for children and youth with support needs, while ensuring that families remained at the forefront.

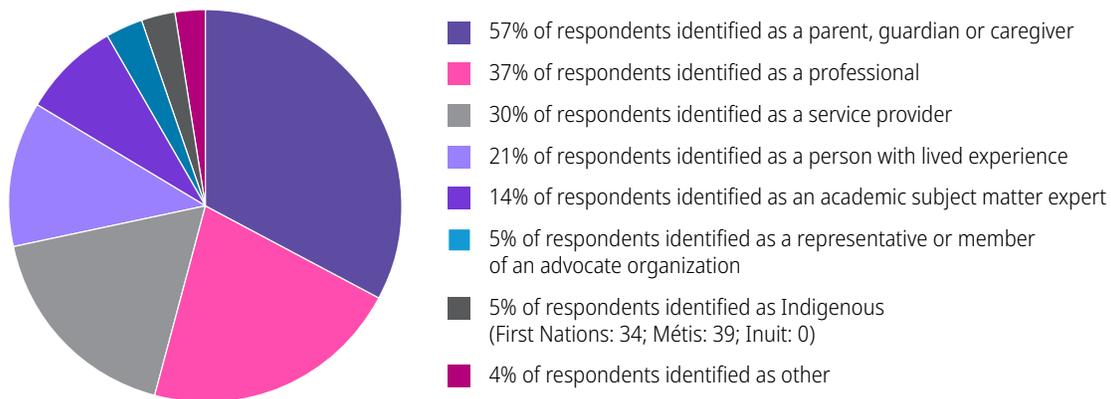
INDIGENOUS CHILDREN AND YOUTH WITH SUPPORT NEEDS ADVISORY CIRCLE

Since September 2021, the Indigenous Children and Youth with Support Needs Advisory Circle (Indigenous Advisory Circle) met to discuss issues related to services for Indigenous children and youth with support needs, offering guidance to the ministry before and during engagement.

Online feedback form

From September 2023 to December 2024 members of the public were able to share their perspective on the future of services for children and youth with support needs. Respondents were asked a series of closed-ended questions about what topics and programs interested them and a single, open-ended question about what is most important to them for a new system of services for children and youth with support needs.

1,047 people completed the online feedback form:



Topics of the most interest:

- 47% of respondents were interested in therapies for school aged children
- 37% of respondents were interested in individualized autism funding
- 28% of respondents were interested in early intervention therapy
- 24% of respondents were interested in Supported Child Development
- 19% of respondents were interested in direct funded respite

Online discussions

Between January and December 2024, the Province posted four open discussions on important topics related to CYSN services through an online engagement portal. All British Columbians were welcome to share their thoughts and perspectives raised in these discussions. 103 individuals participated in the discussions outlined below.

DISCUSSION TOPICS:

- Parents and Professionals Plan (a policy plan submitted to the ministry by a group of parents, caregivers and professionals that work with and care for children and youth with support needs)
- Increasing behavioural complexity and needs of children and youth with neurodevelopmental disorders
- BC Association of Child Development and Intervention's (BCACDI) Service Delivery Transformation proposal
- Ministry of Education and Child Care's Inclusive Child Care Strategy

Written submissions

From September 2023 to December 2024, all British Columbians, including families, service providers, organizations, professionals, and Indigenous communities were invited to submit their ideas in a comprehensive written format for what a new, effective system of CYSN services should look like in B.C. The Province received a total of eight written submissions. Two of these submissions were proposals from community partners on the future of CYSN service delivery.⁶

Symposium speaker series

In November and December 2023, the Province launched a symposium speaker series to enhance co-development of a new, effective system of CYSN services. The series was open to everyone and provided a unique opportunity to foster collaboration and sharing among families, professionals, service providers and interested parties. It encouraged inclusive discussions and provided a platform for sharing insights, best practices and research findings.

TOPICS:

- Trends related to children and youth with medically complex support needs
- Key components of an effective system of services
- Individualized funding: a review of the international research literature
- Mental health needs of children and youth with support needs
- Inclusion, quality of life and community networks of support
- Increasing behavioural complexity and needs of children and youth with neurodevelopmental disorders

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⁶ BC Association of Child Development and Intervention and "Parents and Professionals" submitted proposals on the future of CYSN services.

Analysis and reporting

The ministry's project team reviewed and compiled the qualitative data gathered during engagement to inform the findings presented in this final report. Qualitative data was collected and used for this analysis and report to provide deeper understanding about the service needs and diverse lived experiences of children and youth with support needs and their families. The data was analyzed using NVivo data analysis software.

The project team used qualitative analysis to identify key themes within the data. This involved observing re-occurring ideas and themes in what was shared during engagement. Each comment was "coded" to its relevant theme with sub-themes created to reflect specific feedback. This led to the identification of 12 overarching themes which structure the results section of this report.

This engagement process and report is reflective of the ideas and opinions shared with the ministry. While this report captures the current needs and experiences of many individuals, families, and communities across B.C., it is not intended to provide a complete or fixed perspective of all individuals with support needs. We recognize that no report can provide a complete picture of the complexity and diverse experiences of every individual.

Key Principles

Across the province and through all streams of engagement the following key principles arose and were consistently touched on by participants.

A family-centred approach

Participants expressed the importance of a family-centred approach to service provision. It was reported that many families experience burnout and stress from self-advocacy and navigating a complex system of supports. Families want help that is holistic and looks at the well-being of the whole family, including parents, caregivers and siblings. This means providing wraparound supports with consideration for each family's unique experiences, strengths and needs, using trauma-informed, culturally safe and sensitive practices.

A child- and family-centred approach is seen as flexible, empowering families by placing their voices at the centre of decisions about care planning and the supports they receive. It allows for personalized services that meet the diverse needs of each family, unlike a one-size-fits-all approach that might not work for everyone. This approach recognizes families as experts of their lived experiences and ensures their choice and agency are valued and respected.

“This approach recognizes that parents must be equal partners on the care team, with their voices being integral to decision-making. Family driven care ensures that family priorities and strengths are driving care planning processes.” – BC Complex Kids Society, Beyond Survival: Recommendations for Transforming Support Systems for Children & Youth with Medical Complexity and Their Families in British Columbia (Beyond Survival)

Participants noted that CYSN policies should be updated to reflect a family-centred approach to supporting families. For example, participants spoke about how individualized funding should be provided to families based on needs rather than just diagnosis. It was shared that the functional needs of a child and the socio-economic circumstances of the family should be considered when determining the level of funding provided to families. Additionally, participants shared that the decision-making process about individualized funding should also account for how a family's situation and needs may change over time.

Equity and inclusion

Suggestions were made to broaden eligibility for CYSN services to create more equitable and inclusive access for all children, youth and their families. Concern was raised about how the current system of services leaves many children and youth without supports, such as those with medical complexity, Down syndrome, FASD, ADHD, dyslexia, children and youth who are blind or partially sighted, deaf or hard of hearing, and those who are undiagnosed or awaiting a diagnosis.

Many participants expressed the need for equitable access to individualized funding, respite, child care and education. Building equity into CYSN service delivery requires a seamless and inclusive system where barriers that prevent access to services are addressed both within and across ministries. This necessitates a review of how 'need' is defined within the family context, understanding who has access to what services and when. Other examples in considering equitable access include understanding how service delivery can be restructured to reduce the wait times for services such as diagnostic services and inclusive child care.

To create more inclusive communities where children, youth and their families can thrive, participants called for neuroaffirming practices centred on social relationships and community connections. Participants expressed how increasing awareness along with adequate training and education on neurodiversity to those designing and delivering services to children and youth with support needs would help to reduce stigma and prejudice and create more inclusive environments.

Intersectionality

During engagement it was shared how intersectional factors, such as gender, sex, age, ethnicity, race, disability, income, geographic location, digital literacy, network access, culture, and language create unique challenges and experiences. These factors combined with a lack of adequate supports and services create inequity and systemic barriers to CYSN services when not addressed.

For instance, gender-based biases were reported to create delays in ADHD assessments and misdiagnoses for girls due to the misconception that ADHD is more typical among boys and presents similarly. In other cases, it was reported that transgender individuals struggle to access health care and ADHD diagnoses.

Newcomer families where English is a learned language or where a child or youth is deaf or hard of hearing, may encounter difficulties in accessing information and resources. These families require unique supports, like interpretation, translation and American Sign Language (ASL) services. In addition, single-parent households and families with limited financial resources are disproportionately impacted by financial challenges and may require extra resources to support family well-being.

Many families require tailored supports to access essential services like education and child care in order to fully participate in the wider community. Without considering the complexity of a child or youth and their family's experience, their ability to engage and benefit from community opportunities may be severely limited. Participants said tailored services and supports to address these multiple layers of identity and circumstance will be essential for fostering a more equitable and accessible system for all families.

It was shared that enhancing the use of data and analyzing the outcomes of future CYSN services will be helpful in assessing and monitoring whether policies, programs and services are effectively serving diverse families. This in turn will provide information that helps the Province to continue to identify and address gaps in programs, deliver effective services and take action to address systemic racism.⁷

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7 *Anti-Racism - Province of British Columbia*

Rights-based

Participants stated how equitable supports should be available to all children, youth and families based on their rights. Throughout engagement there was a call for services for children and youth with support needs to uphold commitments and responsibilities outlined in:

- United Nations Convention on the Rights of the Child
- United Nations Convention on the Rights of Persons with Disabilities
- United Nations Declaration of the Rights of Indigenous Peoples; Truth and Reconciliation Commission of Canada: Calls to Action (TRC); the Declaration Act and Declaration Act Action Plan
- B.C. Human Rights Code
- Accessible B.C. Act

The Province is dedicated to upholding the rights of children, youth and their families to support good quality of life and well-being. This includes ensuring service delivery design for early intervention and support services is non-discriminatory, in the best interest of children, youth and their families, and supports the lives and development of children and youth equally.

Relationships and trust

Engagement highlighted that trusting relationships and social connection provide families with a support system. Families find value in community connection, social and recreational programs and support groups. It was suggested that participation in child care, school and recreational activities within the community offer children and youth with support needs the opportunity to develop social skills and build meaningful relationships with peers. Parents and caregivers who are able to connect with other families through parent support groups exchange emotional and practical support.

“Across communities, families voiced a strong desire for more local, community-based support networks and peer support groups. Connecting with other families experiencing similar challenges would provide essential emotional and practical support.” – *Family Support Institute & Canadian Institute for Inclusion and Citizenship, The Family Voices Project: Helping Shape the Future of CYSN Services (The Family Voices Project)*

Many participants shared how community agencies are an integral part of service delivery. These agencies are often well-established within communities, suggesting they possess a strong understanding of the local context and are in an ideal position to establish trust and build relationships with community members.

Participants emphasized that building and maintaining strong relationships with service providers and professionals, such as therapists, takes time and requires trust. Once trust in relationships is established, the continuity of these relationships is foundational for ensuring high-quality care for children, youth and their families.

“The development of a trusting therapeutic relationship is essential to the success of therapy. In my experience such relationships take time to develop. My pediatrician has advised... six months is the minimum amount of time that it would take to build a trusting therapeutic relationship before therapy can expect to have any positive benefits.... changing therapy providers would be detrimental to my children’s long-term mental health and development.”
– Parent, online feedback form

Accountability

Participants reported a desire for greater accountability and transparency from government. Accountability was emphasized as a key component of building trust, placing families and communities at the centre, and supporting families in meeting their needs and maintaining quality of life.

There were recommendations made to create monitoring and reporting measures to hold ministries accountable for their commitments and track the effectiveness of services and supports. Participants shared that evidence-based and data-informed processes are necessary to demonstrate transparency and accountability not only around allocation of resources, but also policy decisions, such as who gets what services and why, and service design and delivery metrics. It was also highlighted how strengthening accreditation processes in service delivery can support accountability, improving the consistency and quality of services provided to children, youth and their families.

“The system must be held accountable toward its aims in order to ensure that the needs of people with disabilities, their families, and their family cultures, are always at the centre.”
– BC Disability Collaborative, *A family-driven model of care: Setting the table right for disability rights in BC (A family-driven model of care)*

“Seamless, cross-ministerial collaboration to create transformative system change and accountability.... [using] metrics, reporting and appeals processes based on family-defined outcomes to build trust and track system impact.” – BC Complex Kids Society, *Beyond Survival*

Co-creation

Participants emphasized the importance of co-creating with communities, partners, Indigenous people and those with lived experience, ensuring decisions regarding the design and delivery of services and supports for children and youth with support needs are inclusive, centred on families and communities and responsive to their lived experiences.

“This change is [government’s] to co-create with us, reflecting the disability community’s Call to Action: ‘Nothing about us without us’.” – BC Disability Collaborative, *A family-driven model of care*

Emergent Themes

Barriers to accessing services

Throughout engagement participants shared that they experience challenges with accessing services. Participants identified long wait lists for diagnostic assessments and early intervention services; complicated administrative processes for direct funding, medical equipment and supplies; and narrow eligibility criteria as barriers to services for children and youth with support needs.

It was mentioned that support from the ministry has not kept up with the evolving understanding of what services make up core ‘intervention services.’ For example, core intervention as it was conceived 20 years ago aligned with a medical model perspective focusing on physiotherapy, occupational therapy, speech therapy and developmental services (e.g., infant development services). Today, increasing shifts towards a blended medical and social paradigm have expanded the concept of core intervention services to include family supports, behavioural intervention, mental health and social supports.

The outcome of not keeping pace with the evolution of disability or demand for services is that many families are left feeling unsupported. Families would like to see their children supported in timeframes consistent with developmental stages. This includes care planning across the lifespan and supporting children and youth with important transitions, such as transitions into adult services and supports. Additionally, many families expressed needing better access to financial support and are calling for more flexible options for services to reduce barriers to accessing the supports they need.

“Ultimately, giving up custody of the child is the last resort for parents - but the support system is so deficient in this area - that parents are left with no-choice” – Service provider, online feedback form

DIAGNOSTIC ASSESSMENTS

Families reported experiencing multiple hurdles in accessing what their children need. Many participants shared that they waited years for diagnostic assessments in the public system. Since diagnoses are currently a key component for determining eligibility for some supports and services for children and youth with support needs, participants shared that children, who are unable to receive a diagnosis miss out on valuable supports and services during important developmental stages.

Many families resort to private assessments due to the long waitlist for public assessments. However, private assessments also involve a waiting period due to the limited availability of practitioners who can provide them. It was shared during engagement that private assessments are often costly and require families to pay out-of-pocket. Participants spoke about how this creates a two-tiered system, where families with financial means get help sooner than those who cannot afford the additional costs of private assessments. This places undue pressure on families and others supporting children in their daily lives.

“The current system in place is also a very inequitable two-tiered system. Families with money can get a diagnosis in half the time of a family with meagre means or lack of social supports. Absolutely unfair and wrong.” – Participant, online discussion

“Waits for assessments are months or years which leaves early childhood educators to wear multiple hats and juggle excessive safety concerns if they continue to provide care during the waiting period.” – Service provider, online feedback form

ACCESS TO EARLY CHILDHOOD INTERVENTION SERVICES

Access to early childhood intervention services, such as speech and language pathology, occupational therapy, physical therapy, Infant Development /Aboriginal Infant Development, as well as Supported Child Development/ Aboriginal Supported Child Development, are a central concern for many families. Participants shared how children and youth are not able to access supports and services during important stages of their development due to waitlists for early childhood intervention services. The long waitlists are exacerbated by a shortage of practitioners and the unequal distribution of services across the province. For example, participants shared that there are less practitioners available in rural and remote communities and that they often have to travel outside of their communities to access services in urban centres.

“The need for in-person therapies is high. Therapies offered from urban areas want to do mostly virtual sessions, which is difficult. – The expectation is that people have good and reliable internet but that is a challenge for families. Do they have access to the network and phone, computer that they need? – That in-person touch is needed.” – Member of the Indigenous Advisory Circle

COMPLICATED ADMINISTRATIVE PROCESSES

A recurring theme across engagement is that many families and professionals find it challenging to navigate the information and resources for direct funding and services for children and youth with support needs. Additionally, lengthy and complicated administrative processes for the approval of direct funding, medical equipment, and supplies create barriers to services and supports that families need.

Participants raised concern over how ministries provide services and supports that are uncoordinated and often siloed, making it difficult for families to find the supports they need and then coordinate them. Additionally, the uncoordinated and complicated administrative processes force families to retell their stories and complete multiple applications to access the services.

“Approvals can take months. We applied to get a new seatbelt for his [my child’s] wheelchair. By the time we got the approval and got the seatbelt it no longer fit [them].” – Reciprocal Consulting Inc., Community Engagement Report

CHALLENGES OF DIAGNOSIS-BASED CRITERIA

Engagement highlighted the challenges of the existing structure of the eligibility criteria for services and supports. For instance, it was shared that assessments based on diagnosis are inequitable with arbitrary criteria, are invasive for families, and often impose extended timelines that are incompatible with child development.

While participants stated that a diagnosis is important and helpful, participants throughout the engagement highlighted how diagnosis-based assessments are inequitable. For example, participants shared that the diagnosis-based criteria for direct funding excludes some children and youth from receiving the developmental and social supports they need. It was shared that participants felt the criteria for direct funding, supports and services do not reflect the needs of children, youth and their families.

“My child has high IQ, ADHD, anxiety, no autism diagnosis, violent and aggressive behaviours. The system has failed my child. He is excluded from school, we can no longer work, because of his high cognitive functioning and lack of autism diagnosis, there is no program he is eligible for....well, let me tell you, this is a full-time job...the behaviour is extreme and impacting every part of his/our lives.” – Parent, online feedback form

Participants expressed frustration over diagnosis-based assessments, stating that a particular diagnosis does not capture all of the unique needs and experiences of a child or youth. Many participants feel that strictly diagnostic assessments can be invasive, often are deficit-based and do not accurately reflect their child or family's needs. Parents commented that assessments often focus on conventional presentations of diagnoses and some parents and caregivers are waiting for up to two years for assessments, only to be told their child doesn't qualify for supports because they do not meet eligibility criteria.

“You have to basically talk about your child in the worst way sometimes to get what you need. You have to talk about your child's absolute worst days to get what you need. And even that brings up such a huge amount of grief, reliving these really terrible times. And I think sometimes as a parent, you want to see some of the good stuff, but when you're constantly reminded to tell them about the awful things that you're going through as a family just to get funding for something, it feels awful.” – Parent, Family Support Institute & Canadian Institute for Inclusion and Citizenship, The Family Voices Project

“CYSN system to be more based on functional characteristics rather than stereotypes about what a child's diagnosis will mean for their everyday life,” – Respondent, online feedback form

FLEXIBLE OPTIONS TO ACCESS SERVICES

Families are calling for more flexible and timely access to the supports they need. For example, many participants spoke about how access to services can be strengthened by creating more flexibility in the way services are provided. This includes creating more entry points to services and supports, like through schools, in homes, online and in communities to provide different options for children and youth who may require different types of supports. Participants shared ideas about how services can be streamlined across government which are discussed in this report under the *Streamlined services* section.

Several adaptations were suggested to the ministry to create more accessible supports and services to children, youth and their families:

- Improve access to publicly funded diagnostic assessments to get children timely support
- Address shortages of qualified professionals to deliver early intervention services
- Streamline access to information and services to alleviate administrative burden on families
- Base direct funding to families on child and family need instead of diagnosis

Service delivery approach

INDIVIDUALIZED FUNDING

Many participants expressed a preference for individualized funding for children and youth with support needs. Generally, individualized funding refers to funding that is allocated directly to a child, youth and their family to provide the assistance necessary to meet support needs. Under this funding model the amount of funding allocated to families is based on specific needs and aspirations of a child and their family, where the family determines how the funds are used to meet those needs.⁸

Families value this funding model for its ability to provide families agency and flexibility, enabling them to choose the types of services they receive, select their preferred service providers and professionals, and decide when and where they access these services. Participants reported that being able to tailor their supports allows them to better meet their families' needs.

In B.C., direct funding to families is not needs-based but the Autism Funding Program is considered an example of individualized funding. School Aged Extended Therapy benefits via At Home Program Medical Benefits and Direct Funded Respite could also be described as similar to an individualized funding model.

Participants often used the terms individualized funding and direct funding interchangeably and expressed a desire for direct funding through these programs to be increased and expanded to all children and youth with support needs. Additionally, participants said they would like to see more flexibility in the way direct funding can be used.

“Maintaining direct funding for families with children with disabilities is crucial to giving them the freedom to choose and quickly access programs best suited for them.” – Advocate and representative for children and youth with support needs, correspondence

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⁸ Stainton, T. (2008). Individualised Funding: An international review of approaches, outcomes and challenges

Needs-based funding and supports

During engagement many participants emphasized the value of a needs-based approach to assessments for direct funding, supports and services. It was suggested that needs-based assessments could better respond to a child, youth and family's needs than strictly diagnosis-based assessments. For example, some participants mentioned that the diagnoses and lived experiences of children and youth can vary significantly, resulting in unique needs.

It was shared that many children and youth without a diagnosis, waiting for a diagnosis, or who do not meet the eligibility criteria for services and supports, have a high level of need but are not able to access supports. Many participants discussed that functional needs and strengths should be considered in an assessment for direct funding, supports and services.

“There is so much more to what level of support a child needs than [their] diagnosis. Not to mention some kids don't ever get a clear diagnosis. The level of support you get has to be based on how much your diagnosis (or need without diagnosis) impacts your life...and I don't mean toileting, feeding, dressing, bathing. I mean, does the child with autism have trouble sleeping and making friends but is getting Bs at school...or does the child with [ADHD] have self-harming behaviours, or are they excluded from school [and] getting marks that barely pass at school... the diagnosis is not enough.” – Parent, online feedback form

There was broad recognition that the eligibility criteria for the At Home Program which includes an assessment of a child or youth's functional needs within activities of daily living (e.g., eating, dressing, toileting and washing) is generally a more equitable approach to service access compared to diagnosis-based eligibility. Despite this, participants often suggested that the At Home Program assessment, criteria, thresholds for eligibility and lack of transparency with the assessment criteria are concerning and creating unnecessary barriers to access. Participants indicated that broader needs beyond a child's functioning in the activities of daily living should be considered for eligibility.

“A more holistic approach when assessing a child's needs should be considered, and shouldn't be limited to self-care tasks [or activities of daily living]. Emotional well-being, mental health, and community integration should all be considered, which requires a multidisciplinary perspective” – Participant, online discussion

Participants mentioned that behavioural needs should be considered when assessing the amount of funding and the types and intensity of supports and services provided to a child or youth and their family. This is because behavioural needs can have a significant impact on children, youth and families' well-being and quality of life. For example, when a child or youth's behavioural needs go unaddressed, they can face barriers to participating in child care, school and the broader community. This can place undue pressure on parents and caregivers trying to balance work and caregiving.

“The functional impact of some of these children's [behavioural] needs results in a parent being unable to hold down a regular job due to their child being asked to leave Day Care and school.” – Participant, online discussion

Additionally, participants discussed how behavioural needs are complex and often linked to other challenges and unmet needs, such as difficulties with communication, mental health challenges or a response to a stimulus within the environment. Participants shared that accounting for behavioural needs within functional assessments allows for a more holistic approach to supporting the unique needs of children, youth and families in comparison to a diagnostic assessment. This is because the approach focuses on understanding and addressing the underlying root causes that contribute to behavioural needs.

“A deeper look into what is creating the conditions for behaviour (food and housing security, family dynamics, health, etc.) and using supports/interventions to meet those needs alongside any diagnosed or un-diagnosed conditions is vital to providing holistic supports and uplifting children and families.” – *Participant, online discussion*

“Funding for positive behaviour support must be provided to families with children with Down syndrome as needed.” – *Down Syndrome Resource Foundation, Engagement Project*

Participants emphasized that other factors, such as medical needs and a family's circumstances and capacity, should be considered, as these can influence the level of need for services and supports.

A concern echoed through engagement is that direct funding through the Autism Funding Program and benefits and supports through the At Home Program are not accessible to all children and youth with support needs. This results in an inequitable and two-tiered system of services. Participants said that some children have less access to supports and services because they are ineligible for direct funding. For example, participants expressed that many children and youth, such as those with Global Development Delay, ADHD, complex trauma, Developmental Coordination Disorder, FASD and Down syndrome are not able to access direct funding support through these programs.

Participants who have access to direct funding through the Autism Funding Program also emphasized that the amount of funding available for children between the ages of 6-18 with autism is insufficient with the cost of living and rising service fees. As fees rise, the caps for reimbursement to families remain the same, meaning the portion of services families pay for out of pocket has risen significantly in the last 5 years and continues to do so as service providers and practitioners raise their fees to cover their own rising operational costs.

Some families with a child or youth between the ages of 6-18 who are currently receiving Autism Funding are struggling to afford therapy and other types of supports. These families' financial burdens are exacerbated when they are unable to access school supports.

To ensure individualized funding supports the needs of all families and is equitable, it has been recommended to increase the amount of funding and to expand access to all children and youth with support needs.

“...funding needs to reflect rising costs. One of our service providers charged about \$150/hour when we started; the fee is now \$240. We never received the under-six funding for our children, and there's a sense of urgency to 'make up' for lost time. \$6,000/year doesn't go far enough.”
– *Parent, online feedback form*

“Compensate families for all expenses incurred when travelling outside their communities for therapies.” – Community-Led Collaboration Project, *Invest in Communities: To build better networks of support for B.C. children and youth with disabilities and support needs, and their families (Invest in Communities)*

Concerns were raised about needs-based assessments, particularly regarding how ‘need’ is assessed. For example, some participants discussed how determining the needs of a child, youth and their family may be challenging because needs may fluctuate and change over time. Some participants expressed concerns that this approach would require reassessing needs, forcing families to go through additional administrative steps and to repeatedly share their stories, which they felt could be intrusive.

Participants raised the concern that needs-based assessments may result in children with lower levels of need being excluded from accessing the supports and services they require. Participants shared examples of how limited funding and capacity in the current system, particularly in areas like Direct Funded Respite and one-to-one support in schools, demonstrate that this approach may lead to some children and youth’s needs being overlooked.

“Needs based sounds best on paper - but given the scarcity of funding in the education system and the wait times for things like respite, I am quite confident that moving to a needs based model would only result in more youth who have support needs but aren’t ‘Bad enough’ falling through the cracks.” – Participant, *online discussion*

Additionally, participants were concerned about who assesses the needs of children, youth, and families. Some participants fear that supports and services could be withdrawn if an assessor mistakenly interprets a child’s or youth’s progress as a sign that they no longer require assistance.

“When a child is receiving adequate support and a family is receiving adequate respite and support, the needs decrease, but that doesn’t mean that the support isn’t needed. It means the support is working.” – Parent, *online discussion*

Many participants felt that families are the most knowledgeable about their needs, and their perspectives and decisions should be central in assessments for direct funding, services and supports. Engagement highlighted the importance of clear guidelines and careful consideration of how a needs-based approach would be integrated into assessments to best respond to a family’s circumstances.

“Where there is a needs-based assessment, who is determining the need and what supports will be offered?” – Minister’s Advisory Council

Challenges of individualized funding

Despite calls to expand individualized funding, engagement feedback showed that while individualized funding is valued by many families and seen as a positive alternative to often overextended agencies, a wholly individualized funding approach would not work for all families.

Limited access to local services and supports, particularly in rural and remote communities, can be a challenge where not all families are able to fully utilize the direct funding they receive. Participants raised concern that an individualized funding approach requires families to have the time and capacity to find resources and services on their own. For example, it was shared throughout engagement that the funding payment process is difficult and can be a barrier to accessing services, where not all families are able to utilize their funds. **Some parents and caregivers find value in receiving additional help with navigating supports and managing their direct funding.**

“The individualized funding approach may work very well for some children and families, especially in urban communities where finding services to purchase may be easier. However, many families find that purchasing services is a laborious and very challenging process, and they may not know what specific services their child actually needs or how to integrate complementary services... There are so many families that do not have the time, energy and personal resources to navigate the process to access the funding, find service providers and travel around their community, or to another community, to access them.” – Participant, discussion forum

“...the current model of [individualized] funding in B.C. 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).” – BCACDI, Position Paper: BC’s CYSN Service Delivery Transformation (Position Paper)

To ensure individualized funding is more equitable and assists children and youth with support needs and their families, several solutions were suggested:

- Increase and expand individualized funding to all children and youth with support needs
- Create a flexible funding model that considers a family’s unique needs, strengths and experience
- Expand the range of services eligible for funding, including dietitians, family counselors, and community and recreational programs
- Ensure funding covers the costs and billing that is reflective of direct service time and indirect costs of administration

AGENCY-COORDINATED SERVICES

Engagement underscored the importance and value of agency-coordinated services. In the social service sector, many of these services are provided by non-profit agencies that are led by citizen board members and guided by client feedback. Participants shared how families seek agency-coordinated services to get help with finding information, resources, and services, and completing applications and forms. Non-profit organizations, like child development centres (CDCs) hold important roles in providing services to families with children and youth with physical, neurological, and developmental disabilities, as well as mental health and behavioural challenges.

“[Agency] coordinated services were integral in enabling our family to access resources. We were under an immense amount of stress with a medically complex infant and [the] staff were integral with their wraparound service to ensure our child received the services they needed and our family was supported.” – Parent, discussion forum

Participants expressed how agency-coordinated services provide a centralized point of access to supports and facilitate a family-centred, coordinated approach to care planning through multi-disciplinary teams and cross-collaboration of sector agencies. This approach can be especially helpful when children and youth are going through transition periods and families are requiring wraparound and integrated supports and services. During engagement, participants discussed how accountability, through evidence-based practices and accreditation processes, used by agencies like CDCs, is essential to providing high quality consistent services.

“We speak, meet regularly with the early learning team at the school district and coordinate our efforts in kindergarten transition planning. It’s not just for our kids that have support needs, but for all the children.” – Frontline professional, Health Sciences Association of BC, Building on What Works: Child Development Centres and the Future of CYSN Services (Building on What Works)

“Well [we’re] physically co-located in the same shared space, which is very conducive to planning, collaboration, just checking in with each other about family priorities... [We learn] so much from other disciplines. You know, some of us are generalists, but learning from OTs, speech paths, physios has been where I’ve gotten my best learning. It didn’t come from my schooling. It came from the fact that we’re together in a shared space with the same families, with the same commitment.” – Frontline professional, Health Sciences Association of B.C., Building on What Works

Operational challenges

Concerns were raised about how stagnant funding to agencies, specifically CDCs, has resulted in oversubscribed, understaffed and fragmented agency-coordinated services.

“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 B.C., the existing capacity of the current system, and the investments required for the system to expand to meet the true need.”

– BCACDI, Position Paper

Participants highlighted how operational constraints contribute to the long waitlists for public services, burnout, and recruitment and retention challenges. This creates barriers to families with mild to moderate needs accessing timely services. Some service providers noted that the demand for individualized funding is partly driven by the increasing waitlist for public services. They suggested that if there was better access to the public system, families might not be as inclined to seek individualized funding.

“Agency-coordinated services have been providing services to children and families for decades. They play a very important role in providing training, education, resources, and services to a very diverse population. Child development centres in particular have provided a great deal of experience and community connections with partners that make it easier for families to coordinate services. This issue is that programs are and have been underfunded. This limit[s] access to programming and services, creates wait times at critical times of development.”

– Participant, discussion forum

Engagement highlighted the crucial role of agencies, particularly CDCs, in supporting families with children or youth with autism, including managing autism funding and organizing intervention plans. However, the current administrative costs for supporting autism funding are unsustainable, leading to the closure of several CDCs' autism services.

It was shared that CDCs are not designed to deliver services via a direct funding model and that this further fragments service delivery. The limited resources and capacity of CDCs lead to inequitable access to early intervention therapies. Families with children and youth with support needs who do not receive direct funding are prioritized for services. In contrast, those with access to direct funding may be denied when requesting to be placed on a waitlist. It was suggested that creating a needs-based behavioural support program through agencies would help to address this service gap. In addition, it would provide a team-based wraparound approach to assist agencies with reaching families with children with complex needs.

Capacity of service providers

Engagement highlighted the many benefits of agency-coordinated services and brought attention to the existing operational challenges and concerns felt by many families. Specifically, participants shared their apprehension with accessing services through agencies and whether those same organizations could provide tailored supports to meet the unique needs of families. It was also noted that agency-coordinated services are often too generalized and families require more specialized expertise. Additionally, participants mention concern with how a strictly agency-coordinated service approach may limit family choice and personal agency.

Engagement also revealed families with direct funding experience confusion about the role of agency-coordinated services. In some cases, families utilizing direct funding to purchase agency-coordinated services results in further strain of wait times for the public services, particularly if the same professional serves both the general population cohort of children with support needs and those with direct funding. Another example of confusion is when families that have been accessing publicly funded agency coordinated services become eligible to utilize direct funding, the child's priority for service shifts, and agencies prioritize children without access to direct funding.

In some cases, agencies like CDCs have established specific service teams that provide autism intervention services. While this approach has benefited families by reducing their own administrative effort in coordinating and accessing services, the invoicing and billing processes create significant financial and administrative challenges for the agency. For example, agencies have to individually invoice the Autism Funding Program after services are rendered for each child/youth that has received autism services.

Some individuals also raised concern about whether agencies have the capacity to facilitate culturally safe practices and meet the needs of rural and remote communities that often face unique barriers to service access. Overall, many individuals expressed their preference for an individualized funding model over agency-coordinated services. These individuals suggested individualized funding provided more flexibility, choice and control for families.

“When families choose [individualized funding] services over agency services, it’s often because they need/want to find service providers who align with their cultural and family values, and this cannot always be accomplished in services provided by an agency in which there is oftentimes an intake professional who then decides which services are accessed or which service providers are accessed.” – Participant, discussion forum

Engagement highlighted that more culturally relevant and safe services and resources are needed for Indigenous children and youth with support needs. Participants suggested increasing access to cultural programs and resources, such as ceremonies, sweat lodges and prayer, through Indigenous organizations. They highlighted the benefits of agencies, such as Friendship Centres, and their ability to offer cultural connection, services, and Indigenous ways of knowing and doing.

“...many families are more comfortable accessing services at [Lii Michif Otipemisiwak Family Service Centre] because of the cultural aspect within the center and that having focus on Indigenous ways of knowing and being increases positive impacts by focusing on a strengths-based approach.”
– Reciprocal Consulting Inc., Community Engagement Report

To improve access to public services and supports through agencies, the following suggestions appeared during engagement:

- Establish adequate and sustained funding that is transparent, data-informed and population-based
- Increase staffing levels and capacity to strengthen the delivery of interprofessional care and support continuity of care
- Lift funding of agencies to expand agency-coordinated services to include behavioural and mental health supports, and create staffing positions that provide family support, respite and crisis supports
- Require more comprehensive cultural safety and trauma-informed practices in agencies

“Without adequate funding, no system can function – regardless of how it is designed and where in government it is situated. This requires a transparent funding formula, co-developed with communities and Indigenous partners and based on current data and/or data-based estimates about the number of [children and youth with disabilities] in B.C.” – BC Disability Collaborative, A Family-Driven Model of Care

HYBRID-SERVICE DELIVERY APPROACH

The benefits of individualized funding and agency-coordinated services were discussed throughout engagement. Whereas individualized funding is preferred by some families, many prefer to access agency-coordinated services.

“65.4% of families would prefer that the ministry directly fund [Down Syndrome Resource Foundation] to provide services at no cost to the family; 34.6% prefer family-directed funding”
– Down Syndrome Resource Foundation, Engagement Project

Throughout engagement it was clear that participants had different perspectives about what is most important to them when building an effective system of services for children and youth with support needs and families. For example, while many participants emphasized the importance of accredited agency-coordinated services, other participants spoke about their preference for individualized funding and the importance of specialized care that may not always be accredited.

“The rigorous accreditation process [CDCs] go through, in addition to their own internal quality improvement processes, provides a standard level of accountability...” – BCACDI, Position Paper

“It was noted that many Indigenous service providers, due to the holistic way that they work, are providing specialized care that is not accredited and many have the skills and support service that are not otherwise available in community (e.g. behavioural consultants and intervention).”
– Reciprocal Consulting, Interior Staff Community Report

Recognizing the value of both individualized funding and agency-coordinated services, and the unique needs of children, youth, and their families, a hybrid-service approach was also proposed throughout engagement. People suggested a hybrid-service approach would provide families the option of individualized funding, agency-coordinated services, or a balance of both. It was suggested that this could:

- Give families flexibility and the option between agency-coordinated services, using individualized funding or a combination of both
- Build upon the existing supports and services that are working for many families and communities
- Provide equitable services and funding which uphold family choice, dignity, and provide families with the supports they need

“A hybrid model of funding delivery based on family preference is the best way to ensure that every family receives the support they require. This includes options for individualized funding for families who have the capacity to manage it, or centre-directed funding for families who prefer to receive all their services through DSRF (Down Syndrome Resource Foundation) through a collaborative model between the family and DSRF’s therapy team.”

– Down Syndrome Resource Foundation, Engagement Project

“Various infrastructures and programs are already working in individual communities (e.g., child development centres, and, for some families, direct/individualized funding). Our goal is to build upon these existing programs across the province, to create a hybrid model rather than replacing them. At the same time, the current community-based model of support is not preferred by and does not work for all families. We envision a hybrid model that combines direct funding and community-based supports” – *BC Disability Collaborative, A Family-Driven Model of Care*

Workforce training and capacity

Workforce challenges were brought up during engagement. Common concerns mentioned by participants included shortages of workers and associated waitlists. Parents and caregivers feel their children are waiting too long for qualified help, especially in the crucial first years of life.

People shared that they saw the biggest gaps in the fields of speech language pathology, occupational therapy, mental health, behavioural intervention and social work. Families also have difficulty accessing family doctors, pediatricians, nurse practitioners, physiotherapists, interpreters, teachers for the visually impaired, early childhood educators, medical specialists and respite caregivers.

The ministry has also heard from various clinical professionals in B.C. who offered strategies to support the sector and address gaps in expertise. Several clinical professionals have acknowledged the benefits of establishing centralized expertise to provide clinical consultation and support to local community-based professionals. This approach would be meant to address the inequities caused by unequal distribution of skilled professionals across the province.

Service-providing organizations expressed difficulty hiring qualified support workers. They stated how many certification programs do not include the needs of all children in their curriculum; learning the skills to assist children and youth with support needs are included in elective courses or as a part of a specialization by the person seeking certification. The shortage of qualified workers was discussed in relation to both child care and school settings, where children are sometimes excluded from their peers and meaningful opportunities to socialize, learn and meet milestones.

Participants noted that even if someone is certified they do not always have the experience, knowledge or skill required to respond to the needs of all children. Some parents shared stories of encounters they described as ableist, with medical approaches being used across different settings highlighting a need for more professional and public education around ableism and inclusion.

Some participants suggested specific initiatives to strengthen the workforce and help address shortages of qualified workers, including a strategy for reaching rural and remote communities. Grants, bursaries, loan forgiveness, paid professional development, travel incentives, help with housing and distance learning options were all suggestions made by participants.

“Investment in education and training of disability specialists and provision of small business incentives for local, independent operators.” – *Parents and Professionals Plan*

Raising and standardizing practitioner wages and creating caseload limits were also mentioned as ways to retain skilled workers.

In engagements related to rural and remote considerations, participants suggested training local community members and hiring more rehabilitation assistants.

BUILDING CAPACITY OF INDIGENOUS ORGANIZATIONS

Participants highlighted the importance of building the capacity of Indigenous organizations because of their integral role in providing culturally relevant and safe supports and services to communities. Recommendations included providing funding to Indigenous organizations in consideration of the additional challenges they may face in addressing the impacts of colonialism and systemic racism in communities. In addition, participants shared the importance of having access to programs which align with their traditional values, language and culture.

“Fund Indigenous organizations to increase their capacity to deliver supports and services within their communities. Funding must respond to the long-term impacts that colonialism and racism have had on families.” – *Community-Led Collaboration Project, Invest in Communities*

Engagement highlighted the importance of addressing workforce capacity issues to improve the delivery of services and supports to children and youth with support needs. Suggestions included:

- Address shortages of professionals that provide specialized services, particularly speech language pathologists, occupational therapists, mental health practitioners, behavioural specialists and social workers
- Encourage training and professional development of service providers and professionals to provide services to children and youth with support needs
- Encourage capacity building in rural and remote communities with workforce incentives
- Address burnout and support the well-being of service providers and professionals by standardizing wages and reducing high case loads
- Build capacity of Indigenous organizations to improve culturally relevant and safe support and service options for Indigenous families

Procurement and contracting

Through engagement, concerns were raised about the procurement process used by the ministry. Participants pointed out that if the approach used for pilot family connection centres is used for the future delivery of services, it may duplicate existing services provided through the child development sector. There was also concern that it may not facilitate the same level of cross-sector collaboration and relationship building as CDCs do.

Many individuals see the move away from consistent and core funding of non-profits to time- and project-based procurement as creating instability and fragmentation of non-profit services that many families and communities rely on. It was shared that contracts need to consider the length of time it takes to develop relationships within communities. Participants emphasized that competitive tendering may also create unfair disadvantages for non-profits. For example, some smaller non-profits, Indigenous organizations, and service providers may have the necessary expertise and culturally appropriate services, but less administrative capacity than larger organizations. This can lead to financial and administrative strains that place these organizations at a disadvantage in the procurement process.

“[We] can ask proponents what is already established to create/ensure cultural safety in their organization. This speaks to the piece about having culturally safe practices embedded and not being a one-off training.” – Indigenous Advisory Circle

Participants are calling for changes to government procurement processes so agencies with the appropriate skill and expertise have the opportunity to fairly participate in competitive tendering. Recommendations included:

- Modify procurement and develop alternative processes to competitive tendering and requests for proposals (RFPs) for health and social services not delivered directly by government or health authorities
- Incorporate a trauma-informed and cultural safety component into RFPs
- Create more stable contracts that support permanent contract work and help establish relationships in communities
- Provide more weight in the procurement process to experienced agencies in communities
- Create opportunities for Indigenous representatives to be included in assessment of RFPs

Rural and remote communities

Those residing in rural and remote areas of B.C. highlighted the geographic disparities in services and supports for children and youth with support needs and their families. This section describes the challenges families experience in accessing services for their children, including workforce challenges, cost of services, and unique challenges such as weather and connectivity. It also underscores the need for more accessible information and resources in these communities to support families. Additionally, this section highlights service providers and practitioners' experiences with providing services in rural and remote communities, as well as the experiences of First Nations and Indigenous communities in rural and remote areas.

WORKFORCE CHALLENGES

Among the topics discussed during engagement, workforce challenges in rural and remote communities was prominent. Participants shared how there is a shortage of physicians and therapists, including those who provide support in schools and child care settings. Local agencies in rural and remote communities also face difficulties with recruitment and retention.

Participants noted there are inconsistencies across regions in accepted qualifications of service providers and the interpretation of eligibility for services, suggesting there is a need to increase the uniformity and standardization of services across the province.

There are a lack of trained practitioners and training opportunities within rural and remote communities. For example, participants raised concern that many training programs operate only in large urban areas. This results in individuals leaving their communities to pursue careers in child development. In addition, these individuals incur the additional costs of extended studies away from home. Participants highlighted the need for more incentives, training and learning opportunities throughout the province to encourage practitioners to stay in and travel to communities.

"Incentives and funding to motivate disability specialists to move to northern and rural regions, reflecting BC's incentive model for family doctors." – Parents and Professional Plan

SERVICE COSTS

Participants shared concern about the increased prices for services which cost significantly less in urban areas. For example, some people shared how families in rural and remote communities often pay a premium for service providers' added operational costs.

TRAVEL

Families face barriers to services when there are limited in-community supports available to children, youth, and families. Often families have to travel to urban centres to access the services they need.

Unsafe weather, road conditions and limited forms of transportation in and out of communities can prevent families from travelling to access the services they need. Some families shared how their ability to show up to a scheduled appointment is hindered by factors out of their control like transit delays due to poor weather. Moreover, added costs are associated with these factors, like extended hotel stays and missed work.

Travelling outside of the community to access services can be a burden on families with limited resources and capacity. For example, not all families have access to a credit card or financial means to stay in hotels and some families have other children at home to care for. Parents and caregivers expressed a need for more flexibility and support in response to these realities.

CONNECTIVITY

Although there are many services and supports available online, not all families have reliable connectivity to access online supports. Additionally, some families prefer and benefit more from in-person services. Through engagement people shared that a combination of in-person services and online services may benefit families. For example, improving access would involve more professionals in communities, travelling to communities, and services delivered virtually when appropriate, if reliable technology is available to families.

ACCESS TO INFORMATION AND RESOURCES

Family members felt that **centralized access to resources and information could help alleviate some of the administrative burden and feelings of isolation when trying to navigate services**. It was suggested that this could help families coping with a new diagnosis or learning how to support their child in their daily life. Streamlined services, online information and service navigation support, as well as self-directed learning and development resources are of particular importance to families in rural and remote communities where services and supports may be more challenging to find.

PRACTITIONERS' PERSPECTIVES

Practitioners and service providers shared their insight into obstacles they face when delivering services in rural and remote communities. They expressed similar challenges that families did regarding the limitations they had in physically connecting with families. For example, we heard that added operational costs of travel and accommodation can make it difficult for practitioners to travel to communities and provide frequent services. Some said that **even if job terms and wages enable recruitment, retention is difficult in rural and remote communities because of housing shortages**. Additionally, practitioners located within communities often have high caseloads due to the limited number of qualified staff available to deliver services in communities.

INDIGENOUS COMMUNITIES

Indigenous families, service providers, community members and members of First Nations communities echoed the challenges that service providers and families spoke about. In addition, it was shared that sometimes seeking support outside of one's community and culture can be disadvantageous. Some participants proposed training community members in order to build capacity at the local level and prevent disconnecting children from their community and support networks. **Many Indigenous participants would like to see a greater investment in Indigenous organizations which are best equipped to meet the needs of Indigenous children and families**.

"To have to choose between living on our territory, learning our culture and language, and receiving services. It's a heartbreaking choice. It doesn't matter what choice I make, we're still going to be going without." – Member of the Indigenous Advisory Circle

Several recommendations were provided to the ministry to create more accessible supports and services to children, youth and their families in rural and remote communities:

- Address recruitment and retention of skilled professionals and high caseloads by creating incentives and funding to increase the number of practitioners and specialists available in rural and remote regions
- Create more training and professional development opportunities in local communities and across British Columbia
- Provide support for travel costs and create online and in-community service options
- Consider a centralized system to provide better access to resources and information
- Invest in Indigenous organizations by supporting them with building capacity to provide services to local Indigenous communities

Streamlined services

A cross-ministry and all-of-government approach was routinely cited as an important step for the Province to take to better support families. This echoes years of feedback the Province has received about how the ministries of Children and Family Development, Health, Education and Child Care and Social Development and Poverty Reduction are not tackling the urgency of this problem together or with the required resolve.

Families and those supporting them would like to see ministries leverage their expertise in supporting children and youth across the life span. Participants mentioned that there needs to be transition supports that are coordinated across ministries to support children and youth through important transition periods in their school years and into adulthood. It was suggested that this would involve a seamless transition from supports and services for children and youth with support needs to adult services and supports. Participants highlighted that transition supports are important, stating that many individuals will require some form of assistance across their lifespan.

“Families need an easily navigable system where they can quickly find and connect to the support they need – not a complicated maze of separate systems, each with its own set of rules and regulations. There could be multiple pathways that lead to a single point of entry, but these should be well-integrated and coordinated to ensure families don’t get lost in bureaucracy.”

– BC Complex Kids Society, Beyond Survival

Participants said a streamlined approach would reduce the time and energy families spend navigating the system, seeking information and coordinating care. The one system approach would see policies align between services offered through Health, Education and Child Care or the ministry, creating fewer roadblocks and barriers to entry for families as they navigate a system between ministries.

It was noted that families of diverse capacities need uncomplicated access to information and navigation support. These supports should be designed to address language barriers and help newcomer families.

“The current system is fragmented and difficult to navigate. Between the siloed Ministries of Education and Child Care, Health, Children and Family Development, and others, there are many gaps, resulting in missed opportunities for collaboration and oversight. A system of siloes is reflective of deeply embedded colonialism and does not serve people well.”

– BC Disability Collaborative, A Family-Driven Model of Care

“I wish that there was a system that if we give consent, the school could be looped in automatically and the physician could be looped in automatically and everyone could be part of a team group of services instead of putting the onus on the family to follow up and make sure that they got what they need” – *Participant, Family Support Institute & Canadian Institute for Inclusion and Citizenship, The Family Voices Project*

Other suggestions, such as a single point of contact, system navigator support, robust online resources, a support portal, and multiple points of entry both online and in-person were cited as ways to streamline services. Families also expressed wanting greater flexibility in how funding and reimbursements are administered. It was emphasized that paying for services, expensive equipment, prescriptions or supplies upfront creates hardship for families who have limited financial resources. In some cases, families shared they simply cannot afford what they need and are going without.

A key component of a streamlined approach also included streamlined diagnosis, where it is understood that those waiting for diagnosis are missing out on early intervention that is crucial to positive outcomes.

“By modifying the BC guidelines and eliminating the current double standard between public and private assessments, the waiting list for assessment would be dramatically reduced. One qualified specialist (a pediatrician, psychiatrist, or psychologist), whether private or public, should be sufficient to make a diagnosis and access treatment.” – *Parents and Professionals Plan*

A recurring solution to fragmented services cited under this theme included moving all CYSN supports such as therapy, access to medical equipment, supplies, respite and home care under the responsibility of a single ministry.

“Consider moving the At Home Program from the Ministry of Children & Family Development (the ministry) to the Ministry of Health– with an aim to streamline access to essential health-related supports like therapy, medical equipment, medical supplies, and tailored respite and home care– reducing cross-jurisdictional challenges, enabling clinically informed decisions and supporting trauma-informed care.” – *BC Complex Kids Society, Beyond Survival*

Participants throughout engagement suggested the following recommendations to help streamline service delivery:

- Take an all-of government approach with coordinated services and aligned policies through Health, Education and Child Care, and the Ministry of Children and Family Development
- Move CYSN supports under the responsibility of a single ministry
- Streamline diagnostic services to reduce wait times
- Provide information and resources that are easy to navigate and are supportive across the lifespan
- Create a single point of contact, system navigator support, robust online resources and an online portal, to help families with coordinating their care and finding information and resources
- Increase the points of entry for services

Health services

Feedback through engagement emphasized the need to prioritize health and well-being for children and youth with support needs and their families.

Access to a family doctor who can offer referrals for assessments and support was cited as a crucial need as referrals can be difficult to obtain otherwise. A need for more nursing support was also raised in engagement. Participants stated that the shortage of nurses in schools and child care settings is creating barriers for children with medical complexities to attend school and engage in their communities. Nursing support was said to also provide families with much-needed respite, helping parents and caregivers maintain employment and financial stability.

It was recommended that eligibility for nursing support be broadened to include more children and youth who need assistance with daily living, and that the services be flexible to accommodate the unique needs, preferences and schedules of families.

“We couldn’t get proper nursing support services, we had to do all the work, we’re managing everything, it feels like we’re running a nursing home in our home, we want him to be home and not at residential care, but I don’t know what the solution is.” – Participant, Reciprocal Consulting Inc. Community Engagement Report

“This is a huge gap that would drastically improve the well-being of families with complex needs children. I cannot emphasize this enough as parents are often the most skilled in caring for their children and are unable to return to work because of the complexity of needs.” – Participant, BC Complex Kids Society, Beyond Survival

Families shared the hardships and financial strain they experience caring for a child or youth with medical complexity when there are not adequate supports in place. This can be exacerbated when some parents and caregivers must leave their jobs to take on full-time and unpaid caregiving responsibilities.

Better financial support was cited as an essential component in helping alleviate the financial burdens families face, including those related to ongoing specialized care at BC Children's Hospital for children or youth with multiple and intersecting conditions. For instance, participants mentioned that assistance with travel, accommodation and parking costs would help reduce the financial strain on families needing access to specialized services.

Participants also reported families face significant challenges in accessing medical equipment and supplies. These individuals highlighted that access to medical equipment and supplies should be based on need and not be contingent on a child's eligibility for certain programs and services. This would help children and youth who are not eligible for supports like the At Home Program to access necessary medical equipment and supplies in a timely manner. It would also prevent delays in other supports that may be contingent on a child receiving the appropriate medical equipment and supplies, such as home care or respite.

Participants also indicated that overall, there is a lack of funding and support for certain categories of equipment and related benefits such as home and vehicle accessibility requirements, Alternative and Augmentative Communication (AAC) equipment, adaptive recreational equipment and development tools, and certain mobility and positioning supports. People shared that these categories of equipment and benefits are important for supporting children and youth's participation in their communities.

For children who are supported by programs that do provide medical equipment and supplies such as the At Home Program, feedback showed concerns about the adjudication and decision-making process for equipment requests even when clinicians provide recommendations. Feedback indicated that those involved in the decision-making process for medical equipment and supplies are not equipped with the proper knowledge of health needs of children and youth, calling for medical and health professionals to be more closely involved in decision-making processes. Additionally, participants highlighted the importance of considering a child or youth's sensory needs in program decision-making.

"The At Home Program way to get approval for equipment is slow and cumbersome with poor communication. This is taking too much time [away from] direct therapy from the children. Please trust the therapists' judgement more, the time spent in communication with auditors after writing a justification letter is costing the system a lot of money and again taking away direct therapy time from children." – Professional, online feedback form

"I think that the [hoops] that families have go through is ridiculous. My child's feed pump or suction quits, and it's a game of phone tag to get it replaced. We should be able to call and get a replacement instead of having to fill out emails, call this person, call that person to get it approved. These pieces of equipment are our children's lifeline. We need these replaced as soon as possible. Some children's lives depend on these pieces of equipment."

– Parent, online feedback form

Participants called for health to be better integrated into support services to provide families more equitable and timely access to services, supports, medical equipment and supplies. Further suggestions included:

- Help families access family doctors
- Expand eligibility and increase availability of nursing support services
- Provide financial support to help families with costs of caring for children and youth with medical complexity
- Give training to service providers and adjudicators in the context of medical equipment and supplies for health needs
- Provide support, medical equipment and supplies based on needs rather than diagnosis
- Streamline supports like therapy, medical equipment, supplies, respite and home care by moving CYSN services, like the At Home Program, and responsibility of CDCs to the Ministry of Health

Mental health services and supports

To better support the well-being of children and youth with support needs and their families, participants also called for enhancements and greater access to mental health services and supports.

Engagement highlighted that children and youth with support needs face significant barriers to mental health services and require more timely access to counsellors and mental health supports in schools and communities. Additionally, families shared that they experience high levels of stress and caregiver burnout and require more support.

“Develop mental health resources tailored to different age groups for children and youth with disabilities or support needs and ensure they are available to social service organizations, child care centres, and schools.” – *Community-Led Collaboration Project, Invest in Communities*

Participants emphasized that access to community and recreational activities and programs can support the mental health and well-being of children and youth with support needs by fostering social connections, relationships with peers and skill development. For example, summer camps provide an opportunity for children and youth to engage with their peers and provide families some much needed respite.

Participants noted that, beyond long waitlists, many mental health professionals lack the knowledge and awareness of the support needs of children and youth, resulting in insufficient mental health care. It was emphasized that a multidisciplinary approach is essential to support children and youth with co-occurring mental health conditions to address their unique and intersecting experiences. For example, several participants shared how gaps in services for behavioural intervention and mental health supports leave some children and youth, like those with ADHD, FASD and other diagnoses, without supports.

“The suggestion was made to train mental health consultants to specifically support Child and Youth Specialized Services, as well as to build capacity of service providers who are trained in mental health, emphasizing that such improvements would contribute to the effectiveness of support services.” – *Reflections from the symposium speaker series*

Participants recommended family-centred mental health supports that consider the well-being of parents, caregivers and siblings. Feedback stated that families face significant strain on their health and well-being when caring for a child or youth with support needs and navigating a fragmented system of services. Access to counseling, support groups, and respite were seen as necessary to provide families with social connection, emotional support and time for self-care. These supports are thought to reduce stress, caregiver burnout, assist families during transition periods and help families navigate the early stages of a new diagnosis.

Additional family supports, educational opportunities, information, and resources to enhance parents' and caregivers' capacity and skills in caring for children and youth with support needs were highlighted as key ways to promote family well-being. Often parents and caregivers shared they felt overwhelmed managing a new diagnosis or supporting children with behavioural needs without family supports or resources.

Throughout engagement, participants shared that the limited access to respite and family supports places a strain on many parents and caregivers. Participants are calling for more direct funding for respite and respite services to support the well-being of family members who often take on full-time and unpaid caregiving responsibilities.

“Related to a family-centred approach, participants highlighted the importance of mental health supports for the whole family to avoid burnout. Participants cautioned that extended services should be mindful of caregiver burnout (and the need for self-care) describing that many parents and families are in survival mode. This is especially important as not all families have extended family to support the day-to-day experiences.” – *Family Support Institute & Canadian Institute for Inclusion and Citizenship, Family Voices Project Report*

“Respondents share that ADHD has contributed to significant mental health challenges for both individuals with ADHD and their families. This included burnout, stress, and mental health issues exacerbated by the lack of support, services, or a network of support.” – *ADHD Advocacy Society of BC, Stakeholder Engagement Report*

To provide children and youth with support needs and their families with equitable access to mental health services, **it was emphasized that mental health needs should be embedded in CYSN services.**

Recommendations included:

- Expanding mental health services via schools and community agencies with better access in homes and through individualized funding to make mental health supports more accessible to all families
- Providing counselling, respite, support groups and networks, and other mental health resources for family members
- Creating or strengthening programs that build life skills, social skills and support social-emotional well-being
- Fostering awareness and training for workers, teachers and parents for how to provide mental health support to children and youth with support needs
- Creating resources specific to children and youth with support needs, available in multiple languages and ASL

Inclusive child care

Throughout engagement, the ministry heard that many families with children who have support needs are facing barriers accessing child care due to long wait lists for early intervention supports and limited capacity at child care centres.

Early childhood intervention programs like Supported Child Development and Aboriginal Supported Child Development support the inclusion of children with support needs in group child care, such as preschools, daycare, and school aged care. These programs offer individualized planning, mentoring for child care staff on inclusive practices and, when necessary, extra staffing. However, participants have expressed that they do not receive enough support through these early intervention programs, highlighting how the programs are significantly underfunded. In the absence of extra staffing through Supported Child Development and Aboriginal Supported Child Development, families of children with support needs face additional barriers to accessing child care.

Participants also noted that many child care centres have limited capacity, due to staff shortages and staff burnout. Parents and caregivers reported that their children with support needs are too often excluded from child care settings. Service providers are permitted to decline children for service if they feel they cannot meet their needs, can send a child home on short notice, or end a child care agreement without adequate time for parents and caregivers to make alternative arrangements. Therefore, the extra staffing and support provided through Supported Child Development and Aboriginal Supported Child Development is important for assisting child care teams with building capacity to create inclusive child care spaces.

Many families are left without the necessary supports to work and/or attend school. This is especially a concern for homes with only a single parent/caregiver or parents/caregivers who do shift work. Some families say they are forfeiting valuable income to care for their children at home when there is no space available for their children to participate in child care settings. Additionally, children with support needs miss out on opportunities to learn and socialize with peers during their early development.

“I cannot work because no one can care for my child. We are slowly slipping into poverty due to the lack of support.” – Reciprocal Consulting Inc., Community Engagement Report

Parents and caregivers of children who are deaf or hard of hearing would like increased access to interpreters to enable meaningful participation and development with their peers in before- and after-school care and day care settings. Additionally, there were suggestions for more AAC programs in child care to support the inclusion of children with communication challenges as there are currently limited areas of support during early development.

“If there’s no interpreter, that means she cannot understand anything that’s happening in the child care centre. My youngest has been moved back and forth based on where their interpreter may be at that time. Typically, children stay with their own age group, but because there’s only one interpreter, she has to go, kind of with her older sister, her older sister has to come and be in a class with her.” – Reciprocal Community Report, Community Engagement Report

Many service providers expressed feeling ill-equipped to respond to the needs of all children equitably. Some shared how they feel they lack specialized education or hands-on experience, while others mentioned their concern with having to take on too much, leading to staff burnout and challenges with long-term retention of child care providers. Parents and caregivers expressed the need for more skilled professionals with knowledge, training and experience working with children with support needs. For example, participants noted the need for more Early Childhood Educators trained in support needs. They suggested mandatory certification and training requirements, or offering incentives such as paid training, to help build the capacity and create more inclusive child care centres.

Participants expressed a need for more summer camps and recreation options for children after school and during the summer months. During engagement participants discussed the importance of inclusive spaces, like play areas for children, and the need for equitable opportunities to make social connections and participate fully in their communities.

To improve children with support needs and their families' access to inclusive child care, participants suggested:

- Dependable and consistent child care supports and options to allow parents and caregivers the flexibility to earn a living
- Interpretation services and access to AAC programs and supports
- Training and professional development opportunities for child care providers and professionals
- Summer camps and recreational programs to promote inclusion of children with support needs in communities
- A more robust workforce of support workers available in child care settings

Education and schools

Parents and caregivers who have children with support needs would like to see their children supported equitably in the school system to participate in a way that enables them to build capacity and be included with their peers.

“The current system forces a lot of kids with support needs out of public school and into online learning because the supports the kids need aren’t available in schools. Again, it is completely unfair to expect parents to be responsible for their child’s entire education because the school is too underfunded to support their kid. And then it’s unfair to the kid to deny them an equitable education because they have a disability.” – Parent, online feedback form

Participants felt there is an increased need for consistent access to support in classrooms for their children to be included fully and benefit from the classroom environment. Clinicians and families shared the barriers in being able to deliver or receive consistent services during school hours. In fact, many commented on how a therapist, who has a long-time relationship with the child, is not able to provide therapy during school hours. Instead, school-based policies require school-based therapists to be utilized, and often school-based therapists are limited to providing consultation rather than direct intervention support.

During engagement participants emphasized that children with additional learning or behavioral needs, such as those with autism, Down syndrome, dyslexia, FASD, and ADHD, who may require more support in the classroom, are not receiving the necessary assistance to effectively learn and achieve their full potential. Children who are deaf or hard of hearing need consistent access to interpreters in their classrooms so they can follow what's being taught and engage with their peers. Similarly, it was shared that more access to AAC is needed for school age children with communication difficulties.

Participants would like to see better coordination between ministries to support children and youth with support needs in the classroom, child care settings, and as they transition throughout their school-aged years. This includes a plan to streamline supports and services and address staffing challenges.

“The ministry should work more closely with the Ministry of Education to ensure children with complex needs are better supported and understood in the school environment. Schools are significantly understaffed, both with EA’s and staff to support EA learning and development. Diploma programs for supporting children and youth with complex needs should be reviewed to ensure those entering the field have adequate training. The complexity of a child and family’s needs has increased significantly since 2020. This results in early burnout and exiting the field, with students then losing access to their right to be at school due to lack of support.”

– Participant, online discussion

Participants reported shortages of Education Assistants across the province, with capacity and staffing issues exacerbated in rural and remote communities. This is due to difficulties recruiting new hires in communities where housing and transportation can be an issue.

Throughout engagement it was shared that there continue to be challenges with finding qualified practitioners within schools to assist children and youth with support needs. Participants highlighted that there needs to be trained staff and opportunities for professionals to develop field experience.

It was also noted that participants want to see improvements to the training and education of professionals working within the school system. For example, it was suggested that education assistants and other education professionals be trained in working with children with support needs, complex medical and/or behavioural challenges. This would help to incorporate learning supports into schools that consider the needs of all children and give equal weight in the learning process for roles intended to support their inclusion and development.

“In general, the teachers/professionals in this field need to be better prepared, compensated, and supported to do their jobs, which will help ensure that greater quality of care and attention is given to the children in need to support their development at this critical time.”

– Professional, online feedback form

It was suggested that a paradigm shift is required to help all children achieve their potential and to move away from ableist approaches in care and education. Families have shared that disabilities are often viewed within society as problems that need to be fixed. Families would like to see their children centred in strategies that accept and support children and youth holistically, rather than focus on “fixing” deficits. Suggestions included ensuring individualized planning, enabling continuity of service provision within all the environments in which children function, and utilizing multidisciplinary and relationship-based strategies that foster a positive learning environment. This was seen as an important way to support the well-being and inclusion of children and youth with support needs within schools.

“A majority of intervention services should take place within schools and within a child’s school day, with inclusion and specialized learning built into that child’s curriculum. There is too much spread between home services and school services and they need to be able to work together with ease.”

– Parent and service provider, online feedback form

“All students’ experience is affected by the supports these students receive.”

– Professional, online feedback form

Participants are calling for more equitable supports in the school system to support the inclusion of children and youth with support needs. To improve service delivery, it was suggested to:

- Create additional learning and behavioural supports for children with autism, Down syndrome, dyslexia, FASD, and ADHD
- Provide interpretation supports for children who are deaf, hard of hearing or have communication difficulties
- Expand AAC supports for children with communication difficulties
- Coordinate with cross-ministry partners in the delivery of supports to school age children and youth
- Improve and increase training and professional development of education professionals to build their capacity to work with children and youth with support needs
- Create multi-disciplinary approaches and relational-based strategies to foster positive learning and inclusive environments

Emergent Themes from Engagement with First Nations Rights and Titleholders

As stated in the introduction to this report, in an effort to fulfill the commitment to co-develop legislation, policy, and programming and as part of fostering meaningful reconciliation, the ministry led a distinct engagement process with First Nations Rights and Titleholders that was guided by the Declaration Act. The engagement explored a system of services for children and youth with support needs that better aligns with a First Nations' vision for children, youth, their families and communities.⁹

There was considerable overlap between feedback through broad engagement and engagement specific to First Nations Rights and Titleholders. Themes and findings specific to the First Nations Rights and Titleholder engagement stream are discussed in this section.

Accessibility

Rural and remote considerations were often at the forefront of these conversations. Large portions of First Nations populations are located in rural or remote areas, where access to local services is challenging. Services may not be available locally which requires families to travel for services and can create significant access barriers. Individuals discussed how there are inequities in funding allocated to rural and remote communities. Indigenous agencies have noted that they struggle to provide services in both rural/remote and urban areas.

Ultimately, these challenges affect the ability of children and youth who require CYSN services in rural and remote areas to fully participate in their communities, limiting their access to the opportunities around them.

Racism and biases

The impacts of historical and on-going racism and biases are a key reason for the overinvolvement of the child and family services system with Indigenous families. Individuals explained that the racism and bias that exists within the ministry creates an oppressive system of surveillance.

On top of this, residential schools, the 60s Scoops, among other policies enacted by the federal government and the Province have led to intergenerational traumas which perpetuate and increase the likelihood of interactions with the child and family services system.

Racism and biases make services unsafe for Indigenous families which leads to service avoidance when families are in need of support.

In addition, the child and family services system has historically been developed without the input of the families that are most impacted by it. During the discussions, individuals explained that they do not see their voices or perspectives impacting the system.

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⁹ *Children and Youth with Support Needs – First Nations Engagement - govTogetherBC*

Part of what is needed to move forward is a commitment to train staff in cultural safety and local, community-specific histories to ensure they are practicing in a way that enhances safety within communities. In general, individuals shared that they would like to see the Province engage more with communities to work collaboratively to develop solutions that are community-driven and grounded in local context.

Mental health supports

The trauma experienced by First Nations individuals is complex, wide reaching and often intergenerational. Whole families may be dealing with the impacts of traumas on their lives. As a result, individuals would like to see mental health supports that engage whole families. In addition, Elders and community leaders should be involved in the design of mental health supports for their communities so that those supports reflect their values and needs.

Despite the need, it was expressed that there are few mental health supports for children and youth with support needs available, especially in rural and remote First Nation communities. Access to mental health supports in these areas often requires travel outside of the community. During the discussions, individuals expressed concern for the children and youth experiencing negative outcomes as a result of access barriers.

Cultural appropriateness and safety

During engagement it was expressed that assessments are not culturally safe.

Individuals felt that the cultural appropriateness and safety of assessments for First Nations families, children, and youth could be improved by developing a centralized filing system. This would prevent families from having to retell their stories to different people, which can be frustrating and risks re-traumatizing families. It was shared that safety for children and youth could be enhanced by doing assessments in the cultural context of their community, including undertaking assessments on the land.

Supporting and enhancing children's and youth's cultural connections should be a focus of CYSN service delivery. Conversations during the engagement highlighted how cultural connection is key to putting children and youth on a positive path. However, because of the negative impact colonialism has had, and continues to have on Indigenous cultural continuity, shifting to support this kind of service delivery will require time, effort, and funding.

Co-development and collaboration

First Nations have diverse cultures, languages, histories, customs and practices. It is important that the Province engage with First Nations communities to inform a co-development approach to CYSN system reform. Co-development is essential to this process because each First Nation knows the needs and priorities of their communities best, and knows what approaches offer the best solutions. Individuals stated that the Province must approach co-development with a flexible and distinctions-based mindset that openly considers novel community-developed solutions that centre local contexts.

The importance of establishing government-to-government relationships between First Nations and the Province was discussed. Individuals stressed that services and regulations should not be defined through a top-down approach from the Province to communities. It was shared that enhancing collaboration between First Nations and the Province would involve Indigenous-led initiatives, the resumption of jurisdiction, the development of Coordination Agreements and stable funding.

INDIGENOUS-LED SERVICES

During engagement, individuals shared that an important part of improving CYSN services involves placing services in the hands of First Nations communities. Conversations during the engagement sessions indicated that it is important to have First Nations involved in not only the administration and delivery of services, but also in the design and control of services to support the needs of their individual communities.

Some suggested that for some First Nations communities this will look like the resumption of jurisdiction in the child and family welfare space, while others will be seeking to form a new relationship with the ministry to co-develop solutions for services that work for them, something that is currently taking place on a pilot scale.

Indigenous-led services are especially important to ensure that the services being provided in any given area are culturally relevant. This enhances the safety of the families accessing those services in addition to supporting the cultural development of children and youth in their communities' ways of being.

Trust and relationships

CYSN service improvement cannot be successful without a commitment from B.C. to earn the trust of Indigenous families, and communities. Individuals reported how stigma and fear impede the willingness of families to engage with the system. This can be especially acute in smaller communities.

Individuals shared how they view the development of a trusting relationship with B.C. as growing out of a willingness for the Province to be highly transparent, and to make space for communities to make decisions about their children and youth in ways that align with their values.

During engagement it was noted that many families fear accessing CYSN services due to the risk that child protection services may become involved. Some families reported stressful and traumatic experiences dealing with child protection services. First Nations families and those with other intersecting identities are reluctant to access support services due to the current and historical legacy of colonialism and policies and practices of assimilation that have caused trauma and harm to families and communities. Many people mistrust the ministry and want to see a clear distinction between child protection services and services for children and youth with support needs and their families.

To respond to the unique needs of Indigenous children, youth and families in B.C., it was suggested to:

- Improve access for those living in rural and remote areas of the province
- Fund Indigenous organizations to provide culturally relevant supports that centre local contexts
- Improve access to culturally safe and relevant mental health supports
- Address systemic racism and biases
- Develop culturally appropriate assessments and staff training in cultural safety
- Separate services and supports for First Nations children and youth with support needs from child protection services
- Engage with Indigenous communities to inform a co-development approach to CYSN system reform
- Establish government-to-government relationships to respect and uphold First Nations' inherent rights of self-determination and control over services and supports in their communities

Considerations and Next Steps

The past two years of research, feedback from over 5,000 people across B.C., as well as findings from the evaluation of piloted changes to CYSN services have provided inputs to help guide the path forward.

The Province has heard the urgency for action as well as many recommendations on how to improve and deliver an all-of-government approach to supporting children and youth with support needs and their families. The Province is also working within the context of growing fiscal and economic pressures requiring careful consideration in balancing what matters most to families. This includes reviewing programs and services to ensure they continue to support their needs.

Based on the findings of this engagement, it is clear the Province will need to deliver and co-design a model that:

- Includes the provision of individualized funding in a way that addresses expectations, equity, sustainability and flexibility
- Ensures that public service models are strengthened while private service models are functioning in the best interests of the service recipients
- Leverages centralized, specialized expertise to assist the workforce and build capacity across B.C.
- Addresses systemic barriers that limit access to valuable interventions in all environments to support children/youth (e.g., therapies during school hours at school)
- Facilitates much-needed mental health interventions for neurodiverse populations;
- Can help services expand to better align with the evolving therapeutic needs of children, youth and families
- Leverages community-based services to better support transitions across the lifespan and promote holistic family wellbeing.

To achieve a realistic pathway forward, the Province will work swiftly to make incremental changes over the next months and years to improve the services. In 2025, the Province began convening a panel of experts, Indigenous organizations and communities, advocates and individuals with lived experience to develop a solution for these key considerations and codesign a service model that is aligned within the health care continuum.

The Province is grateful for this long period of engagement with the public and acknowledges and appreciates the time each person invested in sharing their lived experiences, ideas and perspectives. Through this process, the Province gained valuable insights about the impacts of services; what programs and services are helping and can be expanded upon; the persistent gaps; and where improvements can be made to ensure children and youth with support needs and their families thrive in B.C.

Appendix: Key Terms

Ableism: prejudice, bias or discrimination towards individuals who have disabilities.

At Home Program: A program designed to support children and youth with severe disabilities and complex healthcare needs by providing a range of medical equipment and services for eligible children.

Children and youth with support needs: Children and youth who are experiencing, or have an increased likelihood of experiencing, developmental delay or disability and who require support to optimize their development, functional abilities and quality of life.

Children and youth with support needs services (CYSN services): The suite of MCFD's CYSN services for children and youth with support needs and their families.

Cultural safety: A theory and practice that considers power imbalances, institutional discrimination, colonization, and colonial relationships as they apply to social policy and practice. Cultural safety involves actively exploring and challenging complex power relationships including the way that bias, stereotyping, discrimination and racism impacts how services are delivered and received.

Disability: An ever-evolving concept that is used as an umbrella term to recognize any physical and/or cognitive condition that may create social limitations for a child or youth.

Equity/equitable: A quality or ideal that recognizes individuals and groups have different circumstances which may require different treatment. An equitable system strives to ensure barriers are overcome so that everyone may access the resources, opportunities, power, and responsibility to lead full and healthy lives.

Family: A term that is inclusive of diverse family structures including single parents, adoptive parents, same-sex couples, step-families, married or common-law couples, foster families, intergenerational families and more.

Family-centred: A set of values and approach that recognizes each family as being unique and holding the expertise regarding their child/children and their family needs. The strengths and needs of all family members are considered.

Inclusive child care: Children of all abilities, including children with support needs, have equitable access to quality child care, allowing them to participate meaningfully in all aspects of the child care program along with their peers.

Indigenous: First Nations, Inuit and Métis peoples.

Jurisdiction: The official power to make legal decisions and judgements. This includes upholding the right of Indigenous peoples to self-determination, including the inherent right of self-government and power in relation to child and family services.

Respite: Temporary care for a child or youth with a disability to assist families and caregivers in caring for their children in their homes and communities.

Trauma-informed: Approaches that avoid re-traumatizing individuals and support safety, choice and connection for people accessing and delivering services. Trauma-informed approaches seek to consider the impact of trauma on children, youth and their families.

Children and Youth with Support Needs

ENGAGEMENT REPORT



Ministry of
Children and Family
Development