



MCFD CYSN: Community Engagement Report on the Development of a System of Services for Children and Youth with Support Needs

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1.0 Engagement Background

This section provides an overview of the purpose and methodology for the engagement, including information about the engagement purpose and approach and who we heard from. This section also speaks to some of the engagement limitations.

1.1 Purpose

Reciprocal Consulting Inc (RCI) was contracted by the Ministry of Child and Family Development (MCFD) to support engagement with various communities across British Columbia. The purpose of this engagement was to inform the development of a system of services intended to enable children and youth with support needs and their families to access the services that they need.

This report summarizes findings from engagement that aimed to hear from those who are currently underserved, including children and youth with support needs that have intersecting identities that may impede access to services. Those with lived experience, family of those with lived experience, and service providers were included in the scope of this engagement.

1.2 Engagement Approach

This section outlines RCI's approach to the engagement, including planning, outreach, engagement process, and reporting.

Engagement Planning

Guidance on engagement planning and implementation was provided by a Reference Working Group (RWG), involving service providers and allies to children and youth who have support needs.¹ The RWG supported with the development of engagement tools and approved the approach to this engagement, which included engagement sessions, interviews, and a survey. Through the advising of the RWG, a co-facilitation model was utilized, where engagement sessions were co-facilitated by a local community leader connected to the community being that RCI engaged with.

Engagement sessions were conducted both virtually and in person depending on the needs and preferences of the community. Supports were offered to reduce barriers to participating in engagement sessions including translation services. Honoraria were also offered to those who participated in the engagement.

¹ RWG members included: Adam Wilton [Provincial Resource Centre for the Visually Impaired & Accessible Resource Centre-BC]; Brin Wylie [BC Association of Aboriginal Friendship Centres]; Erika Cedillo [Inclusion BC]; Laranna Scott; Lisa Meneian [Deaf Children's Society of BC].

Please note that there were additional members included in the RWG who are not named here.

In order to increase the reach of the engagement, a survey was also developed and translated into 11 other first languages including American Sign Language, French, Chinese (traditional), Chinese (simplified), Punjabi, Filipino, Korean, Spanish, Vietnamese, Somali, and Tigrigna. Additionally, virtual and in person interviews were offered as an option to participate in the engagement.

Outreach

RCI and co-facilitators supported outreach efforts, which included targeted email outreach to specific organizations who provide services and support to the key communities the engagement intended to engage in order to inform them of the engagement opportunity. Co-facilitators and RWG members supported outreach efforts and sharing the engagement opportunities with families and services providers within their networks.

Engagement Process

The engagement sessions were approximately 2 hours long and took place both virtually and in-person (see Table 1 below). Two to three RCI staff attended each engagement session with a designated note taker and facilitator, along with the co-facilitator who supported with the discussion. The following presents the main components of the engagement:

- ⇒ Introductions
- ⇒ Circle Agreement
- ⇒ Engagement Overview
- ⇒ Discussion
- ⇒ Recap

The discussion included three main questions focused on areas related to (1) available services and resources, (2) needed services and resources, and (3) system shifts and changes required to better support children and youth with support needs. The same questions from the engagement sessions were asked in the survey and interview.

Analysis and Reporting

Data collected across the lines of evidence (engagement sessions, surveys, and interviews) throughout the engagement period was analyzed and triangulated across the lines of evidence to answer the engagement questions.

Prior to reporting, co-facilitators were engaged to support a data validation process, which allowed for findings to be validated by the local community leader to ensure that findings were contextualized and that nuance was captured.

Reporting for this engagement process including a report for MCFD where all data across the lines of evidence is presented, which can be seen in Section 3.0. Specific responses

from each community engaged can be seen in Appendix B. These community reports have also been shared with our co-facilitators.

1.3 Data Collection Methods

This section provides a breakdown of the engagement sessions, interviews, and surveys, including how each community was engaged, where and when the session took place, and how many participants attended as well as a breakdown of survey and interviews completed.

Table 1: Breakdown of Engagement Sessions, Interviews, and Surveys

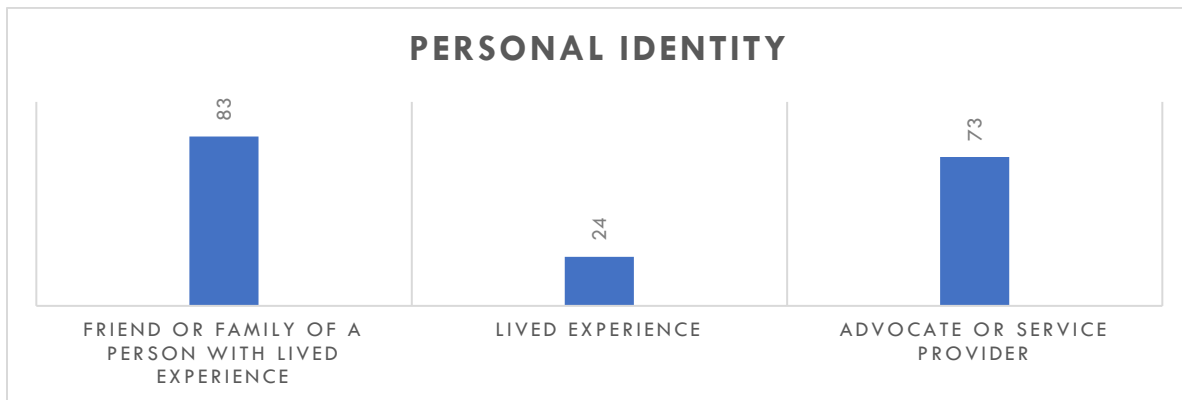
Date	Community	Delivery Method & Location	n
October 26, 2023	BIPOC Session	Virtual	1
November 2, 2023	Families accessing services in the Downtown Eastside	In-person (Vancouver)	15
November 8, 2023	Service Providers delivering services in the Downtown Eastside	Virtual	8
November 15, 2023	Blind and Partially Sighted Community	Virtual	26
November 16, 2023	Deaf and Hard of Hearing Community (family, lived experience, & service providers)	In-person (Vancouver)	3
November 18, 2023		Virtual	13
January 29, 2024		Virtual	15
December 11, 2023	Parents Accessing Services from Settlement Workers in Schools	In-person (New Westminster)	15
January 17 & 18, 2024	Métis Families	In-person & virtual (Kamloops)	14
January 19, 2024	Complex Needs	Virtual	21
January 22, 2024	Family Support Workers	Virtual	7
n/a	Survey	Online	141
n/a	Interviews	Virtual	2
Total			281

1.4 Participant Demographics

While demographic data was not specifically collected in engagement sessions and interviews, survey respondents provided demographic data, which can be seen below. Demographic data related to each session is provided in the community specific reports located in Appendix B.

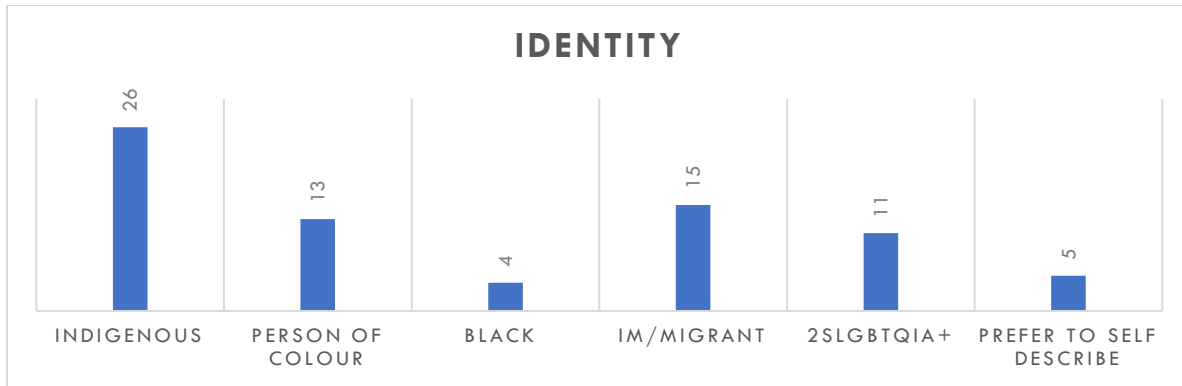
Survey respondents most frequently identified as being **friends or family of a person with lived experience** (n = 83), followed by an **advocate or service provider for children and youth with support needs** (n = 73). Respondents also identified as having **lived experience** (n = 24) (e.g. living with a disability, neurodiverse, neurocognitive). Please note that survey respondents could pick more than one response. See Figure 1 below.

Figure 1: Personal Identity



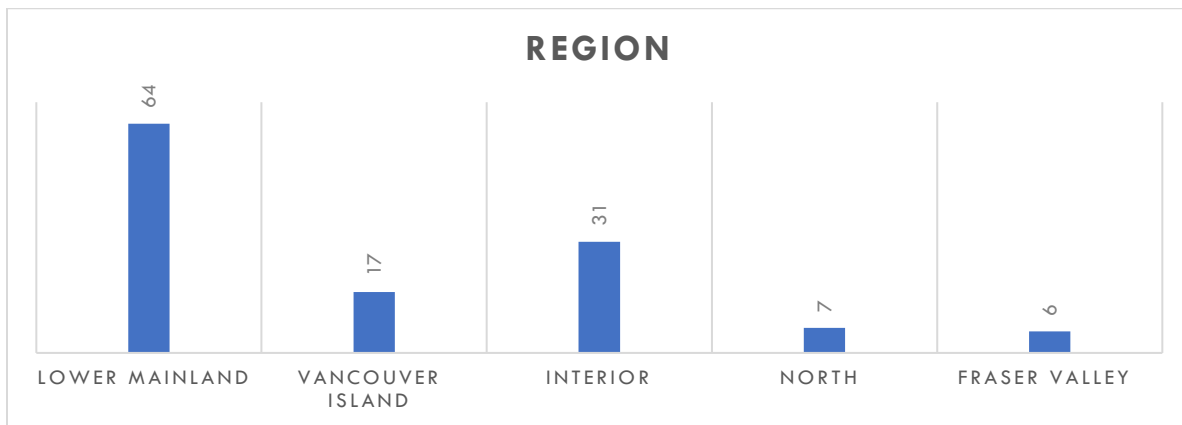
Engagement included participation from individuals who identified as Indigenous, Black, a person of colour, im/migrant, or as part of the 2SLGBTQIA+ community. See Figure 2 for breakdown of number of survey responses by identity. Five respondents preferred to self-describe and noted that they were mixed race, Jewish, and a settler. The remaining respondents did not identify as part of the above-mentioned communities.

Figure 2: Cultural, racial, and sexual identity



Survey respondents were also asked to share where they were located and majority of respondents were located in the **Lower Mainland** (n = 64), followed by the **Interior** (n = 31), **Vancouver Island** (n = 17), the **North** (n = 7), and the **Fraser Valley** (n = 6). See Figure 3 below.

Figure 3: Region



1.5 Limitations

Despite attempts to engage organizations and individuals that support or are part of the 2SLGBTQIA+, we were unable to host specific engagement sessions for this community. However, survey responses were collected where individuals identified as 2SLGBTQIA+ their specific survey response are reflected in Appendix B of this report.

What We Heard

This section outlines the finding across all engagements, including engagement sessions, interviews, and surveys. The first section presents services and resources for children and youth with support needs, followed by key barriers and enablers for success. The last section of findings explores participant reflections on aspects of the system that need to change in order to better support children and youth with support needs.

2.0 Resources, Services and Support

Throughout the engagements, available resources and services were a central focus of discussion, including what participants currently have access to in their community for children and youth with support needs and what was still needed. This section presents findings on both what is available and gaps across key support areas. These findings have been organized into characteristics of what and how these services operate or how communities would like to see them operate.

2.1 Accessibility

Creating more accessible services and resources was frequently mentioned as a needed change from participants who noted that services need to feel safe and welcoming so that children, youth, and their families feel comfortable accessing the supports they need (n = 60).

When asked how the community supports youth living in the community with support needs, participants highlighted **creating accessible services** (n = 24). Accessibility was highlighted across a number of resources and service areas. This accessibility extends to how systems are accessed, when they are accessed and where they are accessed from.

Navigating Systems

Navigation aid was a need noted by participants to reduce the burden on parents and guardians to support their children and youth who are deaf or hard of hearing including having case management support from social workers who can support children and youth, particularly in connecting them with deaf and hard of hearing peers and role models. Participants shared the need for options when it comes to supporting deaf and hard of hearing children and youth, including being given the tools and support to navigate the system and make an informed decision on the support they wish to access for their child.

The need for program navigators and liaisons for families was also shared by members of the complex needs community. Participants shared that it would be helpful to have a

person assigned to families who could help families navigate the program, as well as oversee where families are getting funding and mitigate communications with schools and charities when necessary.

- I was flailing after diagnosis, I needed a coordinator to help with appointments, information on resources. There was no support.

As an example of where this support in navigating systems is working well, participants specifically mentioned receiving services at the Lii Michif Otipemisiwak Family Centre (hereby referred to as LMO). Participants shared that LMO had helped them access and navigate services and resources, as well as assist families to acquire diagnoses and provide wrap around support when navigating the system.

Geographical Access

Accessibility based on geographical location was raised across several sessions and communities as a challenge. Participants noted that there is a need to **increase accessibility of services for rural and remote communities** (n =13). This was brought up as families living in remote communities are often not included in engagement sessions; have difficulty finding a doctor; have to apply to multiple agencies in order to access funds; and are isolated trying to navigate services alone. A member of the blind and partially sighted community shared the following about feeling neglect due to their family's location:

- We are ten hours from Vancouver – my son was diagnosed at 5 months old, it took referral to pediatrician to BC hospital just to get a diagnosis; I share in the feeling of neglect in BC just because of our location.

Participants in the deaf and hard of hearing community also noted the need for expanding services and resources geographically. Participants shared that this is important in order to better support children and youth in areas where finding a teacher for the deaf and hard of hearing is difficult. Participants noted that this is not just outside the Lower Mainland, but a need across B.C; there is a drastic need for support in remote areas where students are suffering from language deprivation, with one participant noting:

- Parents have two choices. So one choice is that they mainstream their child with a deficit of resources and exposure to ASL, or they send their child to the dorm. That's their choices. So you know, I mean, parents don't want either.

One family member shared their experience of living in an area outside of the Lower Mainland with limited services and resources and not having access to an interpreter for their child who was in daycare. They described being referred to six different agencies, all unable to support their child until they were two and already language delayed. They further noted that there is only one interpreter supporting five families in their area and their funding only covers one interpreter for both her children.

- If there's no interpreter, that means she cannot understand anything that's happening in the childcare center. 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.

Participants shared there is a lack of specialized services in rural and remote areas, noting it is difficult to access the needed resources. Suggesting the need for more skilled support workers in the north, as youth and children with support needs feel isolated. They also shared about the lack of language assessment in remote areas where no one is qualified to evaluate what children need in order to assess their growth over time so that burden lies with interpreters who are not equipped with the skill set to do language assessments. Additionally, participants noted regional differences where there are inconsistencies in qualification and eligibility across regions and suggested increased uniformity and standardization across the province.

Additional insights shared by participants that can foster accessibility include:

- ⇒ **Direct Outreach** - Outreach services were highlighted by participants when discussing community supports for youth living in the community with support needs. It was noted that they are finding huge success with support teams that go directly to families.
- ⇒ **Centralized Access to resources and information** - Family members talked about the accessibility of resources and services, promoting the need for accessible services for families and youth. One participant suggested having a central place similar to the Family Connection Centres (FCC) to access help and resources to hopefully improve accessibility. Another participant suggested better clarity and communication about the inventory of resources and services available to families and youth.

2.2 Holistic Services

When participants were asked to share about services that they utilize and are helpful for them and their families, it was clear that those services embodied a holistic approach addressing the layered and connected needs of children and youth. Further to this, participants highlighted existing gaps in services and articulated what support for families with might look like if they addressed both the complex needs of children and youth as well as their families and support networks. The following sections discuss the need for increased wrap around supports, support through transition periods, for families, and in fostering community connections.

Wrap Around Service Delivery

The **lack of wrap around supports** within the system was noted by participants who shared the need for holistic support for their children with support needs (n = 22). Service delivery should take a wrap-around approach meaning that services address mental, physical and more areas of an individual's experience.

Participants described the importance of wrap-around support for families. It was mentioned that the LMO Centre in Kamloops British Columbia, specifically provides positive and strengths-based wrap-around services for families, supporting families with all types of needs. Nzen'man Child & Family Development Centre Society, which serves the Nlaka'pamux Nation, was also highlighted as taking this approach to service delivery when staff described that supports that are available through the centre including the following:

- ⇒ Mental health supports
- ⇒ Family supports
- ⇒ Direct support
- ⇒ Therapeutic services: occupational therapy and physiotherapy
- ⇒ Aboriginal Infant Development Program (AIDP)

Participants also described some supportive community-based recreation and sport programs available. Specifically, youth groups for social activities, art-based workshops and programs, sport programs and other recreational programs (i.e. access to the aquatic centre, music classes, cooking classes). Parents and caregivers who mentioned recreational activities, noticed positive improvements in the youth during and after accessing the programs.

A noticeable gap expressed by participants is a lack of therapeutic support and mental health support. Participants mentioned it is challenging to access various therapies without funding or eligibility for specific programs. Participants mentioned a general lack of mental health resources for families and youth, noting that any services available have extreme wait times. It was noted that some counsellors do not have the knowledge or training to work with youth who have support needs. Specifically, noting a lack of counselling support for youth who are hard of hearing. Also, members of the Complex Needs community shared that there is a lack of government-funded therapy resources available through the At Home Program, sharing the need for this especially for school-aged children (AHP). Another participant shared the need for counselling supports for children with psychological problems in different languages, or for interpreters to be available for counselling sessions.

Beyond mental health, participants shared the need for more therapy resources that would contribute to a wrap-around support approach:

- ⇒ Vision therapy is not offered through the Centre for Child Development or IDP

- ⇒ There is limited access to speech therapy, Occupational Therapy, Physical Therapy, Speech and Language Therapy, and mobility therapy and supports
- ⇒ There should be increased access to more types of therapy for youth, including, play therapy, and grief and loss services
- ⇒ There is a shortage of occupational therapists and speech language pathologists who can take on new patients
- ⇒ There is a need for increased funding for Registered Massage Therapy (RMT) through AHP
- ⇒ Speech therapy funding needs to be increased
- ⇒ There is the importance of building continuity and strong relationships with therapists
- ⇒ It is challenging to access therapy services in a remote community, having to travel to access therapy
- ⇒ Mental health supports should be included in AHP including for siblings and parents (which is not currently covered by AHP).

Support through Transitions

Another element of offering holistic support to children and youth is ensuring that **services and resources are available regardless of age or stage** of diagnosis and at times of transition. Participants also shared the need for wrap around support from a person whose role is to support families on their entire journey, mentioning support during wait times for a diagnosis, accessing resources, offering follow ups, navigation of the system, and creating a plan for after a diagnosis is given. Participants shared the need for services that provide support with getting assessment/diagnoses for children and youth. Suggested services included those that provide support with giving advice on getting your child tested, waitlists, and financial support to meet the needs of the costly testing requirements.

Participants also noted the need for improved early intervention for deaf and hard of hearing children and youth. It was shared that if families are unable to advocate and understand the system, they will be restrained from accessing funding. Participants also noted needing accessible specialists for early years as families are consistently told how important ages zero to five are, yet there are minimal supports available during those years due to similar reflections shared around childcare professionals being paid low wages, lack of understanding and training, and little support in remote areas. In addition, participants noted that early intervention needs to be expanded to later years so that children are not aging out of supports during crucial development years.

The need for ongoing and consistent support and resources was noted by participants sharing the frustrations around transiting from early intervention to schools and the lack of support on how to navigate these transition periods. It was shared that often newborns

are identified as deaf or hard of hearing and are given hearing aids and no one follows up with the family until they are school aged and often already language deprived.

Support for Families

The need to shift the system and remove the burden **and take responsibility off of families and provide them with support** was noted by participants so that families can focus on their wellbeing, rather than take on various roles to support their child (n = 40). One participant shared:

- Families are doing too much and have too many roles; families should be able to give input to organizations but not need to carry out all the roles themselves... Families are doing too much and have too many roles and enough is enough, the government and organizations that are supporting us need to step up... As soon as possible create a system where families can be families... Don't have to be therapist, nurse, teacher and all the things we do.

Many participants in the sessions were family members of a young person with support needs, and they most frequently noted that the role of a parent or guardian is crucial in ensuring that children and youth are able to access needed services and resources. The supports that family members provide was articulated across sessions. As well as a call to ensure a level of support and services for families which is key to ensuring a holistic approach.

- “[They] are my passion, so we try and do everything to give him the best quality of life and that involves a lot of different people.”

A need for comprehensive support for parents and guardians who have children or youth who are deaf or hard of hearing was also shared by participants. Participants provided many examples of what their support looks like including:

- ⇒ Bridging the gap between the hearing and deaf world, including writing letters, making phone calls, and supporting with accessing services.
 - ⇒ Supporting with accessing services or navigation included finding therapies
 - ⇒ Connecting with alternative supports for home learning families
 - ⇒ Supporting with maintaining friendships and relationships to have a good social life
 - ⇒ Offering emotional support
 - ⇒ Transportation
 - ⇒ Interpreting
 - ⇒ Education
- “I have the ability to make phone calls to access services. For the deaf community to make an ordinary phone call that a hearing person would not think twice about

becomes an experience in patience and frustration and can be exhausting and time consuming. This is not something I like to do or something I think I need to do, but in our world, where access is limited and it's hard to access, it becomes something that I need to do to make it equitable for [my daughter and granddaughter]. "

Given this crucial role families play, a number of supports were shared that can extend support beyond the individual to the entire family. Participants shared that family supports such as respite, social workers, peer support, and system navigation that exist in their communities. Participants shared that they have access to support workers and childcare professionals.

Respite care was identified as a key support, however when asked if participants have access to the respite that they need, what is working well, and what is not working well with regard to respite, participants most frequently shared that there is not enough access to respite through AHP. Participants who spoke to this commonly shared that the amount of respite given per month only enables families to fund care for a short period of time. Participants explained that the amount they have access to in a month equals approximately 10 hours of respite per month. Participants commonly shared that they are unable to qualify for respite. Parents and caregivers mentioned their struggles with the limited access to respite, mentioning experiencing burnout and not being able to complete tasks needed for caregiving (i.e. going to the grocery store, driving youth to school, sleeping, etc.).

- My first experience here at the home was also kind of respite – even respite the definition is really just giving you a short break from something difficult – we don't need a short break we need huge support on all different levels... I didn't know how to navigate or what I need. I needed sleep I was completely sleep deprived and had dealt with trauma and I had asked for counselling over and over and there wasn't any and now I am paying out of pocket doing specific trauma counselling.

In general, increasing resources and support for family members of children and youth with support needs was highlighted by participants. Participants shared that accessible learning resources for parents and young parents would be beneficial and opportunities to learn in the format of a workshop was noted by participants. It was suggested that a workshop where children and parents can explore different ways children learn would be a helpful tool for the community.

- ...Knowledge is power – if they can have some form of a workshop where kids can come and learn – because that would have helped me when I first came [and] to learn about different ways kids can learn that you as a parent might not know and if I had that... you know that would have helped to be like 'oh maybe that's what my daughter explained that is difficult for me to understand.

One parent noted the challenges with trying to navigate the system of services and resources, including being surprised at how few resources were available for distance learning and how much they had to find themselves, including hard of hearing and vision teachers. They shared the importance of parents and guardians knowing how to access and find resources and organizations.

Participants also highlighted that MCFD has denied support to parents, focused more on separating children from their families. A family member described that MCFD places blame on parents for not being able to properly support the youth, rather than offering supports for the children's needs. For example, a participant shared that because they live in a rural area with minimal services, they are experiencing pressure from MCFD to move closer to resources or fund services themselves. They shared that MCFD communicated to them that if they are not able to provide these supports themselves their child could be put into foster care. This family is now in a position of scrambling to find funds to support their child.

Removing barriers to accessing services was an additional system change that participants requested which would show families more compassion, empathy, and kindness. Reducing the fear and stigma for families was also noted by participants who shared that they need to heal from trauma and that support workers need to give them time to gain trust, rather than be judgmental.

Fostering Connection

In addition to support families through services and resources, many participants mentioned the importance of a **strong support system within the community**, including connecting with other parents and families (n = 16) and others on shared experiences.

- "Finding someone else who has gone through what you've gone through is important, especially in early days of a trauma diagnosis. "

Participants mentioned the benefit of having a strong community support system at LMO family centre, where they feel welcomed and connected with others.

- "Built a new support system [at LMO] I created a family that's not blood related."

One participant highlighted the importance of finding Blind Beginnings:

- "For us we met a lot of other families, an organization can make all the difference because it's an immediate connection to a community of other families that deal with similar things but have more experience than you. I would definitely recommend that kind of organization, that made a whole difference for us."

Additionally, connecting virtually with other parents, through disability groups on Facebook for supports; and another participant sharing the following:

- “Our BC Complex Kids Facebook page started and that brought everyone together virtually to this day, 12 years down the road I am still interacting with new parents or maybe a doctor asks for my name because there is very specific things that are outside of the box... our paths are so unique so trying to help with as much support as possible for me that is...I got that from a lot of parents as well and have been grateful for that – the knowledge sharing just goes on and on and on – it is endless there is a lot to that. “

Participants requested more community building, social and recreation programs. For example, to increase social opportunities for families to gather, suggestions included enjoying dinner together, preparing meals together, and workshops to learn to preserve food. A participant shared feelings of isolation, and the desire to have more connection to other families in the complex needs community.

Participants additionally described their desire for more flexible services, including better collaboration and clear pathways between services, as families are finding resources siloed and separated, making access more challenging. Additionally, participants suggesting they need the ability for self-referral to access services.

2.3 Approach

In addition to sharing what accessible and holistic supports would look like, participants offered many insights for the approach taken to resource and service delivery.

Individualized Services

Across sessions, communities expressed the role that applied supports have, meaning those supports that are very specific and designed for the unique needs of children or youth. Several examples were shared from across communities.

Within the At Home Program (AHP) for children with complex needs, participants highlighted what is working well with the **AHP and other in-home services** (n = 34). Specifically, for the AHP, resources include access to funding for medical supplies, increased funding for school aged extended therapy program, simplified administration processes, and benefits of the order system for medical supplies. Participants mentioned their appreciation of having access to medical supplies through funding with the AHP. Participants specifically shared:

- ⇒ Appreciation of having supplies available to order through product distribution centers.
- ⇒ Appreciation for increase in funding for orthotics.
- ⇒ Appreciation for access to medical supplies early on.
- ⇒ Appreciation for funding assistance with expensive medical supplies, although not all supplies are reimbursed.

In addition to the specific At Home Program, participants mentioned the benefit of having programs and services, including therapy services, available in their homes. Including, respite, vision services, speech and language therapy, occupational therapy, physical therapy, mobility therapy, assessments and more. Another participant noted that they appreciated receiving support with ordering medical equipment from a children's development centre in their area.

With respect to supporting children and youth who are deaf and hard of hearing or blind and partially sighted, participants shared many specific services. Firstly, the importance of language preservation. Participants noted the importance of recognizing that Canada has six sign languages, including two Indigenous sign languages and recognizing that ASL is an official language and findings ways to formalize that more. Further to this, the following applied supports were shared:

- ⇒ Access to assistive devices and resources (noted by families)
- ⇒ One family shared a specific experience using Eye Gaze, which activates the eyes and can support in knowing where pain is coming from.
- ⇒ Using pictures to share what the child/youth would like
- ⇒ Using voice support by pressing a button that records a voice and pressing a button for "yes" or "no."
- ⇒ Receiving information about and access to cochlear implants, including funding for implants and replacements.
- ⇒ Having access to American Sign Language (ASL), for both children and youth and their families in early years and as a way for children and youth to learn their own language and culture through learning ASL.

Beyond these examples, participants identified many areas in which service delivery was not meeting the needs of children and youth.

Participants in the complex needs community shared not being able to purchase necessary equipment through the At Home Program. A participant shared that the program would not fund an AAC (Augmentative and Alternative Communication) device

because it was not considered medically necessary under the program requirements.² Examples of needed medical/accessibility equipment such as a shower bed, suctioning, and wheelchair accessibility were flagged. A participant shared:

- My child is going to high school soon, need to be able to access incontinence supplies they feel comfortable and competent in, and be able to change quickly as needed.

Members of the complex needs community also frequently shared that they find it challenging to access medical supplies. Participants who spoke to this commonly shared the need to get doctors justification for ordering medical supplies as a barrier. Participants shared that they are required to justify to a doctor why they need to order food and medical supplies.

- My son has been in the program for 16 years and I still need to put in a claim every time to justify how supplies pertain to his diagnosis. It's very frustrating to have to have a doctor justify everything you do.
- The approved maximum supply amounts do not match usage/need. There is a product that we use more than the maximum supplied by the AHP, I end up buying that separately from another pharmacy and paying out of pocket. This also creates the burden of additional paperwork.
- Approvals can take months. We applied to get a new seatbelt for his [my son's] wheelchair. By the time we got the approval and got the seatbelt it no longer fit him.

A lack of autonomy for families when ordering medical supplies was mentioned by participants. A participant shared that they would appreciate having an accessible website for families to use with a supply list and a place to submit receipts.

Members of the deaf and hard of hearing community generally shared the need for increased support for children and youth who are deaf and hard of hearing and/or blind and visually impaired. Participants identified a general lack of services for the visually impaired and deaf and hard of hearing, requesting access to vision rehabilitation and more deaf and blind services.

Participants shared a general frustration with being offered two options for their child which includes sign language or oral language and feeling like they have to pick one. They further shared the reliance on parents to investigate and be curious about the options without support from the system. One parent who is also a service provider shared that parents have been told they have to pick oral or sign language and sign a document

² Please note that the AHP does not fund AAC devices. This comment reflects the discrepancy of understanding what is offered by the AHP, exemplifying the need to increase clarity about what medical supplies the program offers.

committing to not signing with their deaf child. One family member mentioned their experience of not being told about ASL when their child was born deaf and further, that there was no visual language being provided in early intervention agencies as they are focused on spoken language.

Further noted was frustration with organizations offering biased and ableist resources and not focusing on sign language, noting the importance of increased information about ASL so that families have more access, with participants noting the need for a department for ASL instruction for all deaf and hard of hearing children, as depriving children and youth from ASL leading to a limited vocabulary is abuse.

An important shift in the system mentioned by participants was better support for children and youth who are deaf or hard of hearing and have additional or complex support needs. Participants shared that one of the benefits of having ASL for all children is that there are many other children and youth with other support needs, such as down syndrome, that would benefit from visual communication, so they shared an importance to consider those with multiple or complex needs. Participants mentioned specifically the lack of fluency with those who work with deaf-blind children and youth. An example shared by a participant included that a deaf child with autism not only needs a behavioral therapist, but one that also knows ASL, further sharing that workers are used to working with “typical” deaf and hard of hearing people but not deaf and disabled people who are more isolated and need more access to support.

There's a much higher incidence of deaf and hard of hearing children with additional support needs. Roughly 40% of the deaf community have other additional support needs. It is a population that has highly valuable needs and a lot of different intersectionality's and it is really crucial that those children and adults, whoever it may be, get access to support they need and the language that is accessible for them... from birth to death.

A common theme shared by newcomer participants was the need for increased language support services. Participants frequently shared the need for English language support for parents and caregivers. Participants that expressed this need shared a desire to improve their English skills through access to free language classes in community centers and libraries. Participant that expressed this need shared that extra support for children to learn English is necessary, but afterschool classes are expensive, and there are no services offered at the community center.

Participants discussed the importance of understanding youths needs, in order to support youth, we need to understand exactly what they need according to their individual contexts. Another participant shared that technology support is needed for learning (n =

1), they explained that their son needs technology support for distance learning; the participant feels that it is too much to place on parents to also provide technological support; so, technology support would be very valuable for their son's development. Additionally, though the Set BC tech program is a resource, the organization is hard to follow up with.

Another important element of providing services that was noted is, when asked how community supports youth living in the community with support needs, participants highlighted service models based on need rather than diagnosis, with Indigenous ways of knowing and being, families are supported based on need, not on diagnosis.

Ultimately, it was noted that there is a need for MCFD to offer strong access to services outside of the school system, as well as looking critically at the service delivery model to make sure that services are not going through one place, instead ensuring that agencies work collaboratively to coordinate service delivery to address the lack of clear roles, responsibilities, and funding structures that currently exists. Finally, participants generally noted the inequity in access and services, in this participants context, for deaf and hard of hearing children and youth.

Cultural safety

Another common approach to service delivery that was shared by multiple communities is that **services must be culturally safe**. An important system wide shift noted by participants is the need for culturally specific supports to better support Indigenous families, children and youth (n = 13).

One participant detailed that supports are tailored for Indigenous families, a philosophy of working with the families has been adopted. Supporting families as much as possible and bringing services to them, rearranging supports to help them rather than being judgmental and punitive for missing appointments. There is a need for Indigenous services for Indigenous families. Specifically, participants mentioned cultural activities at LMO, such as, drumming, storytelling, prayers with elders, and smudging. Describing that culturally safe resources are based in care and support for holistic family wellbeing.

Métis families also reported feeling safer when accessing services at LMO, due to the lack of fear and stigma generally felt within the system. Métis participants also spoke to the need for more services and programs based on distinct cultural needs. Participants shared that there is access to some cultural support, but the need for more culture-based resources was expressed. Specifically, participants need more access to ceremonies, sweat lodges and prayers. Additionally, mentioning they grew up disconnected from their culture and want to be more grounded in their culture.

Participants shared the following specifics related to cultural supports:

- ⇒ Indigenous programs in Indigenous buildings are needed to create a safe space to support Indigenous families who have to frequently contend with racism and bias when accessing services and supports.
- ⇒ There is a need for Indigenous services for Indigenous peoples, including cultural supports, trauma-informed, non-judgmental, strength-based approaches, and no punitive measures used.
 - Participants shared that Indigenous families have experienced intergenerational trauma and workers should be sensitive to that.
 - Participants shared the need to hire social workers and support workers with cultural awareness and lived experience.
- ⇒ CYSN needs to reroute services through Indigenous agencies so that work can be done in a more compassionate way, as participants have been a positive difference for families and youth when this happens.
- ⇒ Families need support from workers who understand the community, who walk on the land, and know the families.
- ⇒ A holistic Indigenous lens and ways to knowing and being is needed to fill support gaps for families and will increase the positive impacts on families and youth as they are more comfortable accessing services with cultural aspects.
- ⇒ Connection to culture through access to Elders who can be available for families and youth.
- ⇒ Cultural programs are needed for Indigenous youth, including art and beading, and hosting gatherings centered around food.

Indigenous ways of knowing and doing focuses on strengths based, need a more open door policy and a focus on Indigenous knowledges

Participants suggested that developing services and programs be based on distinct cultural needs. Participants within the BIPOC community suggested that this would be helpful as this would allow support to be provided for the unique nature of cultural differences within the community.

- ⇒ Need for more resources for newcomers in first languages. It was noted that computer literacy and access to technology were a frequent barrier to participating in English language learning and when accessing resources. Applications for adult education, appointments and other services are often online, which barres access for newcomer families who do not have access to a computer.
- ⇒ It was noted that there is a need for services designed to reach out to the Black community and the Black West African community so that this community can know there are programs designed specifically for their needs.

- ⇒ It was expressed that it would be useful to develop resources on how neurodivergent kids display within the BIPOC community.
- The BIPOC [community] is very big – in that you have very different cultural characteristics and when you design programs... it misses some unique needs on the cultural nature of [these differences], particularly in the BIPOC [community] itself.

A member of the BIPOC community shared that there are no existing services for children and youth with support needs/disabilities in their community, stating that they have looked for support and were still unsure where to access needed support for their children. Community members shared that they are looking for support and that they were unaware or unsure of where to access needed support for their children. Additionally, it was shared that while there is a lack of services tailored to support the BIPOC community, it was suggested that a helpful step is to engage in community members in activities that support neurodivergent children and youth so that the community can be present for children who have support needs.

For the deaf and hard of hearing community, participants shared important considerations for Indigenous families and for families who are English language learners:

- For Indigenous families there is a missing piece related to culture and the need to teach Indigenous children their culture through accessible language as service providers see many Indigenous deaf and hard of hearing students getting lost in the system.
- For families who are English language learners, it is important to provide interpreters in other languages and allow for families to make informed decision.

Participants shared that services are not designed for immigrants to have support in terms of cultural adjustments, nor do services provide support regarding cultural adjustments for children.

In alignment with support for families and building community, the need for accessible safe places for families and youth was described, to ensure they have an environment where they feel they belong. One participant described the need to have a public community center for BIPOC youth with support needs. Suggesting that youth would benefit from a communal space to access services.

Trauma Informed

In addition to culturally safe, participants want to see services that are delivered in a **trauma-informed** way which is a different approach than mainstream services providers. When asked how community supports youth living in the community with support needs

participants highlighted delivering services through a trauma-informed approach and one participant explained there are a lot of barriers with stigma.

Another participant shared that the qualifications for respite are not trauma informed. They shared that program does not account for families' history with MCFD and the mistrust families may have about how MCFD may use their information. More generally, participants noted that the system requires changes to ensure that services are accessible as they currently fear the risk of child apprehension when visiting resource centers and agencies. Families mentioned they can experience significant stress when accessing resources, for example, going to resource centers, needing to contact the police, and when being asked questions about their children. One participant requested the separation of resources for families and youth from the centers for child apprehension, noting this as a barrier to accessing the services they need.

Children and Youth Centered

Participants noted needing to center **agency for the child** because currently all the options and choice are with the parent or guardian, but they should be talking to the child about what they have a right to, sharing:

- If they don't have good access or spoken language and they're being told to double down [and they] put them in a fully mainstream environment and don't use any sign language, who's standing up for that child? Because right now the professionals in the system we currently have, [have] to follow what the parents want, but the parents are not experts. So, we should be having audiologists [as] part of [the] team of experts, but they are not the only people who should be advising parents.

Another example shared around the importance of agency for the child was questioning whose right is it if a teen wants a cochlear implant, but the parent does not. Further, a participant shared that a lot of hearing parents who have deaf children neglect them, and they are not involved because their parents do not engage in advocacy. This participant shared that parents and the system have the responsibility to show their child all the options available and that it should always be focused on what the child needs.

Staff Supported

Another central tenant of the approach to service delivery was in how participants described service delivery being supported by a range of qualified and compensated support workers.

Participants described appreciating their access to support workers, mentioning that the support workers who work with the children and youth have been helpful. They often have

knowledge and experience in trauma, addictions and in dealing with diverse needs. This participant also shared that there are settlement workers³ that act as navigators in the school system, who help families access/navigate service frameworks. Respondents also mentioned social workers, navigators, family or key workers, and multicultural workers, CYSN social workers.

Participants shared the need for increased access to social workers. A participant shared that there is both a lack of social workers and STADD navigators. They shared that they were not supported by their social worker when in crisis and that their social worker did not have enough education to support the family's needs.

Some participants explained that there are a **lack of practitioners and service providers** (n = 25). Examples of practitioners needed include the following:

- ⇒ Lack of practitioners for early intervention, there is a lack of nurse practitioners to do early intervention referrals for assessment.
- ⇒ Lack of mental health practitioners, only virtual therapy is available, youth do not want to do virtual therapy.
- ⇒ Lack of behavioral consultants: there is a lack of behavior consultants, they are so important.
- ⇒ Lack of specialized doctors, especially in certain regions where travel is needed to access doctor appointments.

An important element noted by participants was that the social workers should have lived experience as those without knowledge of the deaf and hard of hearing community should not be making decisions about what services should be provided for deaf and hard of hearing children and youth. It was noted that this suggestion is the opposite of what is being suggested in the CYSN Service Framework for FCCs. However, one participant shared that often people with lived experience and educational backgrounds are turned away from support worker positions as they do not meet the governments requirements.

It was also shared by participants that when you are in early intervention you pick your agency and get your services but once you transition to schools the parents are relied on to navigate that transition. It was noted that MCFD will provide families with a navigator, and families become comfortable with the services until there is another transition into elementary, high school, or post-secondary when the need for re-learning and accessing services has to take place again, relying heavily on parent support. Social workers can also support the navigation between MCFD and the schools, as participants noted the frustration of this process. Also noted was the need for one point of contact to make sure

³ Settlement workers help newcomers to Canada understand their rights and responsibilities and provide support to clients accessing employment, education, housing, healthcare etc. Source: Settlement.org

that families have all resources that are available to them and that language assessments are done regularly.

Additionally, members of the complex needs community shared experiencing infrequent support when accessing Early Intervention Therapies. Families mentioned they could access the therapies every few weeks, which is not enough consistency to accommodate their needs.

Consistency was also noted by participants as it relates to wrap around support, noting the need for support before families are in crisis or become at risk for child apprehension, therefore needing access to addiction support or a texting support line.

- Having wrap around support so you don't have to re-explain your story with every new support workers. Consistent support improved youths lives.

3.0 Enablers/Barriers for Success

Throughout sessions, participants shared recommendations for what change or actions could take place to address current gaps, shortfalls and/or barriers to access. **Increased funding** was a frequently noted change needed to better support children and youth with support needs and examples shared by participants can be seen below (n = 113).

- So many of our children and so very capable but need better supports and resources to reach their potential ... {The government} also needs to support training in these areas but some still have barriers.

3.1 Funding

The types of funding and way it moves to families and communities was raised multiple times. Participants were asked to consider if, in the future, they would prefer to have direct, individualized funding for therapies, similar to the SAET accessed through the AHP, or if they would prefer centre-based, agency hosted therapy similar to how Early Intervention Programs and the proposed Family Connections Centre (FCC) model deliver therapy. Both benefits and challenges were shared with either model, resulting in the use of a hybrid model suggested to ensure that all families unique situations are accounted for.

Individualized Funding for Therapies

Participants described they want the flexibility of choosing the right provider for their needs. Participants want the ability to choose providers who can meet the needs of the children and youth, highlighting that a strong relationship with therapy workers is important to them.

- We need to be able to match the needs of our child with the right provider for them. It is a relationship and that is key for the success of the therapy.

Furthermore, suggesting that the individualized direct funding needs to be flexible and without limitations, allowing families to allocate funds across an array of services without limits on the type or cost of therapy. Participants described they need access to therapies not typically covered with funding, or not accessible in rural locations due to a shortage of therapists and the distance required to access services.

Challenges with Centre-based/Agency-hosted therapy

Participants described that it can be challenging to get adequate care with center-based therapy. Suggesting that therapists at centers may not meet the needs of the children and youth, and they prefer being able to find a suitable therapist. One family mentioned they

risk losing access to resources and support depending on where they live, describing wanting to move to a more affordable city, but feared losing access to their supports due to the move. Another challenge mentioned was that specialized therapists are often not available in community centres.

Participants noted some potential in centre-based, agency hosted therapy, but mentioned some key suggestions for improving the model. Participants noted that models such as FCCs can be beneficial, but centres would need to be in every community to be effective. Additionally, that there needs to be adequate housing for employees of the centers. Participants also noted that waitlists to access therapies needs to be reduced in order to support youth and children. Participants shared that there needs to be increased support for therapists at centers including trainings, especially in remote communities. One participant mentioned that the centers need to be in accessible locations.

Hybrid funding model for therapies

Some participants suggested a flexible hybrid model between center based and individualized funding for therapies. Mentioning it could be beneficial to have access to center-based therapies and individualized funding depending on their needs, noting they need more access to specialty services and therapists. Participants emphasized that a single model of accessing therapy is not sufficient to cater to the needs of every family. Suggesting they need flexible options to choose direct funding for private therapy or accessing therapy through a center-based program. Describing that some children and youth may benefit with a community center-based program, while others need access to specialized therapy.

Beyond the broad recommendations from community around funding models, participants also mentioned that the available funding has been helpful for youth and children. Specifically describing the positive benefits from ASD funding, funding for medical equipment (I.e. power wheelchair), and funding for children to attend a specialized school.

Families noted that funding is an essential resource for families with children and youth who are deaf and hard of hearing, particularly for those who need additional financial support.

Participants who commented on elements of the At Home Program that are working well also shared that increased funding of the school aged extended therapy program has been beneficial. Another participant shared that more funding is needed to keep offering the supports, further explaining that their programs have grown and that the centre [Nzen'man Child & Family Development Centre Society] has a lot of capacity and could take on even more services if funding was available.

Additionally, the need for MCFD to change its service provision structure was shared by participants. Participants shared that in order to better support families, CYSN workers need more education on advocacy and discrimination toward neurodivergent individuals, as well as increasing their communication with families:

- CYSN workers need to return phone calls and emails and be willing to work with other people (not families) when the families don't have capacity to engage or advocate.

Participants shared the need for services to be focused on the needs of families, and meet them where they are at, rather than waiting for family to have more capacity. A participant shared the need for MCFD to invest in supporting and educating families and caregivers to allow them to lead their child's care if that is what they would like. A participant shared that the needs of the child and family should be determined by a multi-disciplinary team regardless of if they have a diagnosis:

- Helping communities facilitate the coordination of current services across community providers, allowing the experts to deliver the services needed in their communities with the required funding is what is needed.

3.2 Specialized Support Workers

Across communities, there was a call for more support workers (interpreters, ECEs, social workers) and that they have the skills and training to better support families. This includes taking a critical look at the need for **retention and training of specialized staff** to better support children and youth (n = 36). In addition, participants provided recommendations to see an increase in the available support workers and ensure better service delivery.

Participants were asked to speak to what services and resources are needed for children and youth with support needs in the deaf and hard of hearing community and they most frequently spoke of the need for interpreters. Many participants noted a lack of interpreters for children and youth who are deaf and hard of hearing, noting challenges for children and youth to engage in activities, sports, or participate fully in daycare and school due to a lack of interpretation.

Participants also spoke to challenges related to a lack of interpreters across British Columbia including a lack of intermediate or higher education for interpreters due to the inability to find an instructor to teach it and a lack of incentives or encouragement for people to go into interpreting, including incentives for ASL proficiency and for professionals to move and work in remote communities. For example, it was shared that there is only one ASL course at the University of British Columbia (UBC), and only one teacher that can teach it. Additionally, there is only one program that covers topics related to children and youth who are deaf and hard of hearing with additional needs, showing the lack of capacity and information for the community.

A few other reasons shared as to why there are few interpreters included low wages and a lack of standardized pay rates, which can lead to unqualified candidates in interpreting positions and that those who are deaf and hard of hearing cannot become interpreters themselves, therefore further limiting access to interpreters.

- We need tuition forgiveness for interpreters. There needs to be a massive investment in building that pool of skilled workers. Because you either get someone who has the language knowledge or the specialty knowledge. And people who have both are so few we can count on one hand and sometimes you wait years for an initial consultation.

The need for one full time interpreter per deaf or hard of hearing child was noted as a need to provide equal access and with more deaf and hard of hearing children being born each year and only 250 interpreters in B.C., there needs to be 50 interpreters graduating each year to keep up with the need. Participants also shared that in the school systems, Early Childhood Educators (ECEs) and interpreters needs to have separate and clear roles and that deaf ECEs should be available to provide support to deaf and hard of hearing students. It was noted that Provincial Deaf and Hard of Hearing Services (PDHHS) would be a good fit to provide this service as they already have the resources and knowledge available.

Qualifications for Teachers of the Visually Impaired (TVIs) were also discussed as being too rigorous which provides a challenge to addressing the TVI shortage. For example, the qualifications for TVIs in BC require a teacher training program or separate visual impairment endorsement as a Master's which reduces the number of participants in TVI training programs.

A participant shared that there are specialized positions that should receive higher wages so that students continue studies to become specialized in supporting children and youth. A participant shared that the waitlists for accessing deaf-blind intervenors is very long indicating a need for increased funding.

A participant shared that there is not enough support in early stages of diagnosis for families, sharing that there is a need for support from social workers in the early stages of diagnosis. The participant did not feel supported by their social worker or that they had enough education to support the family's needs and another social worker did not communicate when they were needed, they did not answer the participant's call when in crisis.

Participants from the BIPOC session further explained the importance of hiring more workers to decrease wait times for services and to hire staff with lived experience to provide peer support and improve outcomes for children and youth.

3.3 Childcare & Respite Support

Participants frequently shared the need for **accessible childcare services** (n = 16). Participants requested improved childcare support to address barriers for single parents, low income parents, and parents who work shift work. Participants who mentioned accessible childcares services commonly shared a need for after school care for their children. A participant shared that they have to be at home with their child after school because all the after-school programs offered through the school are fully booked, which is a barrier to finding work.

A service provider provided some context to the apparent deficit of available childcare supports. They explained that there are no free or low barrier childcare programs for children. They shared that although there are some drop-in programs that exist, parents need to attend these with their children. Participants shared that there is no space available in afterschool programs. Also shared that there is a lack of inclusive childcare, explaining that their child needs one-to-one support from MCFD to access daycare during school breaks while parents are working. Similarly, a participant shared:

- Parents and special needs children are being denied inclusion in daycare due to lack of 1:1 support at daycare and no enforcement of guidelines for daycare centres to accept and care for all children as set by the CCFRI.

These challenges were echoed by the deaf and hard of hearing community:

- ⇒ There is a need for deaf and hard of hearing daycares for youth under two and a half years old so that children can have access to language during the work week for working families.
- ⇒ There is a need for more one-on-one support, even when a childcare center or preschool is considered inclusive, this is still missing for deaf and hard of hearing students.

As discussed earlier, respite care is a key support for participants. However, they shared that there are a number of barriers to accessing respite. Participants shared that there are long waitlists for respite. Participants who mentioned this noted:

- The nature of the long waitlists creates uncomfortable competition between families.
- Respite waitlists hinge on children aging out of the system. Therefore, families can be on the waitlist for years.
- Because of the long waitlists, families are encouraged to pick medical [funding] over respite.

Additionally, a participant shared that local respite homes were not a safe space for their child and did not address their child's needs.

Participants shared that the lack of affordable caregivers and childcare services often leads to caregivers burning out. This also includes parents who are primary caregivers for

their children. Participants shared that balancing a full-time job without an alternative full-time caregiver is not possible. Participants shared:

- Parents should not have to be excluded from the work force because of care for their children. Consultation at 12 -2 isn't accessible to employed parents in typical jobs.
- I cannot work because no one can care for my child. We are slowly slipping into poverty due to the lack of support.

3.4 Barriers Limiting Access

Participants shared a diversity of **barriers limiting the accessibility of resources and services** (n = 35). Barriers shared by participants ranged from long waitlists, transportation, timing, documentation and age limitations among others. The following section outlines barriers mentioned by participants in detail.

Waitlists and Wait Times

Participants shared **long waitlists** as a common barrier to accessing services (n = 24). Participants highlighted that waitlists for accessing services are a significant barrier, requesting improvements to reduce waitlists for services. More specifically, noting waitlists are long even if the need for services is high. A participant who spoke to this shared that children who have difficulty hearing, or who have ADHD or Autism have to wait long periods of time to receive a diagnosis. This participant shared that when a child is autistic, the assessment to get formally diagnosed has an eight-month waiting list. Additionally, one participant mentioned wait times for services can exceed the timeframe where services are no longer needed for families. Lastly, participants described that access to services can be dependent on diagnosis, although wait times for receiving assessments and diagnosis can be long.

- I have been on a waitlist for 2 years for Supported Child Development and I am close to having to quit my career to be a full-time caregiver because I can't get extra support for my daughter who is in day care but may be kicked out when she is 3 as she is too "high-need."

Participants shared the need to adjust the funding model for services to address wait times by investigating how to get immediate support for families. They suggested having a two-tiered funding process to get funding for a diagnosis and then additional funding after receiving a diagnosis.

Additional Barriers

Transportation - Participants commonly noted that transportation can be a barrier, and there is a need for safe and accessible transportation to services and resources.

- Transportation to services, transportation is such a huge barrier, families often do not have transport and some families are 100 km away from anything.

Lack of newcomer-specific supports - Participants in the MOSAIC community shared the need for newcomer-specific supports to address the barriers that newcomers face when accessing services, including lack of proper documentation or identification, lack of permanent residency, fear of deportation, financial instability, age limitations, challenges accessing education and language barriers. BIPOC community participants shared that services to assist those who have immigrated would be a useful step to address these barriers.

Timing - participants shared the need to expand service hour availability to include evenings and weekends to accommodate working parents and children who are in school.

Housing - Three participants noted that there is a need for the system to change to include supportive housing for youth and families. Participants described that they would appreciate more low-income supportive housing and more housing centers staffed with specialized workers to support the youth and families with their support needs. Housing centers need to be inclusive of all aged youth, low-income families, youth with mental health issues, and be adequately resourced. Participant further noted the need for housing with built in supports that is affordable.

Aging out - Participants also shared the need for improved resources for adults/youth who have aged out of care, including mentorship opportunities, safe and affordable housing, affordable food and nutrition and general services to reduce isolation. **Stigma and judgement barriers** - Participants shared the need for more trauma-informed approach's to service delivery. Participants who spoke to this shared:

- Stigma and judgement barriers, there is a barrier of stigma and judgement to get access to funding through MCFD and families do not want to connect with CYSN because of the fear of stigma, they would rather go without services.
- Fear of child apprehension, families know that children and family supports and MCFD apprehend children, families do not want to access supports for fear of apprehension.

4.0 Systemic Change and Collaboration

Across sessions, a desire for systemic change was raised by communities. Participants called on multiple actors (schools/education, health care system and government more broadly) to lead and implement changes at the systemic level to ensure accessible, holistic, and effective resources, services and supports for children and youth and their families.

4.1 School System

In sessions, families described the current strengths of the school system that can be expanded to foster more support. It was noted by participants that they currently have access to teachers for both deaf and hard of hearing and visually impaired children and youth (n = 12). Families noted having weekly access to the teacher, who shares community opportunities within the school for their child. It was also noted that it would be devastating to not have access to deaf and hard of hearing teachers as they are an access point for learning and access to the deaf and hard of hearing community.

When newcomer parents/caregivers were asked what services and resources exist in their community that are helpful for children and youth with support needs, parents shared about school lunch programs and therapies. Parents shared that high school students who identify that they are unable to pay for lunch receive an 80% subsidized lunch. For elementary and middle school there is an online program where parents can input the amount they can afford for lunches.

Additionally, mentioning that having Certified Education Assistants and specialized teachers available is beneficial and has made a significant impact on youth's school experience and participants mentioned that therapy services are available in schools.

Changes in Schools and Education Sector

Systemic changes related to **support and resources in school and education** was noted by participants highlighting the challenges that children and youth with support needs can have in mainstream schooling (n = 15). A need for more or improved supports for youth and children in schools was shared as challenges come from teachers already being busy in classrooms. Suggestions from participants included more training for teachers and education support workers and more investment into school districts. Participants also described that hiring more Education Assistance that have additional training is needed for those working with all youth with neurodiversity, which will only benefit all youth in the classroom. Additionally, one participant suggested having more options for alternative or flexible education and school options for youth who are unable to go to school (i.e home schooling options, specialized alternative schools). Part of the support

and resources in school and educational settings include making it more accessible for youth through the following:

- ⇒ Transportation to and from school
- ⇒ Incentives to motivate youth to attend school
- ⇒ Culturally safe and relevant schooling
- ⇒ Outdoor and traditional land based education
- ⇒ Counselling services within the school
- ⇒ Supports for youth with complex needs

One participant advocated for the need for institutions to provide interpreter services for children's extracurricular activities. Participants also shared a need for more language support at schools. A participant shared their frustration with the lack of English language support for their child:

- My [child] has been going to school for four months [and they are] not able to make a sentence. [They are] not learning. [They access language supports from Mosaic], but even that one is not enough. [They are] a bright student, good report cards, [they were] an 'A' student but because the language support at school is only 15 minutes a week, per student [and] because the number of participants is so much in the class or outside the class. That's why the child comes back home and is not speaking the second language.

Participants identified a need for specialized supports in schools. Participants suggested more schools for young children that uses ASL and English. Participants notes noted that school funding is lacking in terms of access to specialized supports, highlighting that more education assistants would be helpful for youth with support needs.

Further needs for support from schools was shared by the deaf and hard of hearing community, including the following:

- ⇒ ASL should be part of the school curriculum, as well as techniques specific to students who are deaf and hard of hearing.
- ⇒ Participants shared needing to integrate deaf and hard of hearing techniques used by educators would support all children with learning disabilities.
- ⇒ Schools need interventions for older high school students who are losing their vision and providing them with information about services.
- ⇒ The schools need to find qualified interpreters to support students who are deaf and hard of hearing who are paid adequately and ideally are native language users or are engrained in deaf culture.
- ⇒ Schools need to be able to support families in finding an interpreter for their child so that the burden does not fall on the family.

- ⇒ Speech Language Pathologists (SLPs) who are Alternative and Augmentative Communication (AAC) specialists are rare and therefore are only receiving support and training once or twice a year to try and make changes to their device as their language grows, which slows down the child's language development.
- ⇒ The schools need specialized support workers to support students with complex needs so that students can have access to SLPs multiple times a week so that families do not have to pay out of pocket for extra supports for their child.
 - This was shared by a participant who noted that they are looking to transition their child into the school system but there is no extra SLP support for their child.
- ⇒ Schools need access to equipment for students who are deaf-blind as when students go to school the equipment is taken over Special Education Technology British Columbia (SET-BC) which is a long and unsupportive process.

One participant highlighted that newcomer and immigrant parents need extra support in schools. Additionally, participants shared that parents need support when their children face prejudice in the school system. It was shared that Black children are labeled as unruly or unreasonable rather than seeing that they need support. It was noted that, when this occurs, parents need support and need to know where to get help when facing prejudice in the school system.

4.2 Health Care System

Throughout sessions, inaccessibility to the health care system was raised by numerous participants as causing an impact. Participants noted that:

- ⇒ They are unable to access family doctors.
- ⇒ Northern Health authority is chronically short staffed and is not able to meet the needs of residents.
- ⇒ There is a lack of doctors available, and there are long wait times to see a doctor in the newcomer community.
- ⇒ Nursing support services are not adequate.
- ⇒ Because they are in Canada on a work visa they do not have access to subsidized medical care for their family, and do not have a family doctor.
- ⇒ It is important to have a family doctor for their children's school activities; some school activities require a doctor's note for participation.
- ⇒ There are long waitlists and newcomers occasionally miss appointment due to their unpredictable lives making doctors less willing to work with them.

Suggestions to address this included:

- ⇒ Implementing low barrier clinics directed toward newcomers. Additionally mentioning families have limited access to families doctors.

A participant shared that there are many families that need nursing support services, and if they do not have access, they should be receiving qualified care aids and other support workers to help them full time.

We couldn't get proper nursing support services, we had to do all the work, were managing everything, it feels like were 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... When MCFD finally got respite for us, but we had to find someone who was qualified because the one through MCFD was not qualified enough, wasn't a nurse.

4.3 Government

Through their participation, communities shared a number of systemic changes they would like to see and the role they saw both Federal and Provincial governments playing in that change.

Accountability

A shift in the system that participants noted wanting to see to better support deaf and hard of hearing children included having more **government accountability** rather than organizations and ministries blaming each other (n = 7). Participants noted that there needs to be accountability as institutions are constantly pushing responsibility onto other agencies to provide support which feels like discrimination leading some parents feeling like they have to give up because they have no options which results in serious consequences. They further reflected:

- There's a lot of blaming of the parents. And you know what I think we need to start with the government and their accountability to their system, that they're supposed to provide equal human rights to every individual don't blame the parents for something that the government has failed to do.

Another participant shared that there is a lack of ownership from the federal and provincial government who have bilateral agreements to provide supports and service for children and youth as part of the Early Years Care Agreement. However, the participant shared that the authority needed through this agreement to give BC Deaf and Hard of Hearing Services and Canadian Deaf Blind Association is not given the authority to oversee this. Lastly, it was noted that part of the system changing to include government accountability means that the government and ministries are responsible for coordinating amongst themselves including better collaboration and communication between the

Ministry of Education, Health, and Children and Family Development and among the various programs offered by various organizations. This collaboration also needs to take place across the different levels of government, as shared by participants.

Accountability is also related to trust which was noted by participants as they reflected on the lack of trust from families engaging with MCFD.

Rights and Policy Frameworks

Consideration for Human Rights of Children and Youth with Support Needs

Participants mentioned the Declaration on the Rights of Disabled Persons, which initially left out those who are part of the deaf and hard of hearing community, however, they have now specifically addressed the **human rights** of deaf and hard of hearing children, which participant share is an important systemic change for MCFD to consider, sharing:

- This was a huge win, and I think it's going to have an incredible impact, and I believe that MCFD really needs to take this into account and consider this.

They further shared that there are accessibility laws in Canada that say that deaf and hard of hearing people should have access to an interpreter, but there is no penalty or advocacy office for those who do not comply, which is an additional system change that is related to the human right of being able to communicate as shared below:

- It's their foundation. It's [their] human right to communicate.

At this time, participants shared that the only steps for families to take when they are not provided with an interpreter is to access the Accessible BC Act or research and file an individual human rights claim, however, this process has a 3-year waitlist which is not a viable option when discussing the rights of a child. Participants further shared the need for systems change when there are countless organizations that have accessibility committees, plans, and mechanism for feedback, but there is no penalty for not following through with these plans.

Further noted was that despite the Ministry of Social Development and Poverty Reduction accessibility directorate overseeing accessibility, they do not have a strong understanding of the deaf and hard of hearing community. Lastly, despite all of this, even if the complaint is addressed, there are not enough interpreters to meet the need of deaf and hard of hearing children in BC.

Recognition of ASL as an Official Language

A change in the system that would better support deaf and hard of hearing children is to formally recognize sign language as an official language by offering it as a language requirement in schools and put this into practice throughout BC. One participant noted the need to reframe our bilingual understanding to emphasize ASL as a natural language.

Expanded and Focused Funding

Participants noted the need for MCFD to consider funding programs that families trust, not fear, and support could be available to those organizations when families do not want to access services through MCFD. Participants also noted the importance of funding for Indigenous specific programs and the need for those services to be housed by Indigenous centers. One participant noted that families are opting for private assessments and services due to a lack of trust or past trauma related to accessing services.

- After being denied so many things – reached out to MCFD in tears and I said I just need something, and they told me to surrender child to foster care; they said once in system they could get weekend respite – and I said have you lost your minds; it's such a defeating feeling.

To address the shortage of specialized support workers, participants noted the role that the government should play in ensuring adequate funding for free tuition or tuition forgiveness for interpreters, as well as appropriate wages. To demonstrate the impact of not having interpreters in the schools and the impact that this has on a deaf or hard of hearing students is shared by one participant:

- My [grandchild] has a passion for volleyball. She can't access volleyball because they can't afford [it] and they can't fund interpreters to be there for her to join the community clubs. So, she's got this amazing talent, but no way to access clubs. And we go into different areas, we've gone to BC sports [and] they say they don't have enough money or interpreters to find interpreters for that. So equal access does not happen without interpreters.

A Centralized Organization

A suggested shift in the system in order to better support children and youth with support needs included the development of **centralized organizations** that specialize in particular support needs (n = 14). Suggestions for what these organizations would like this included the following:

- ⇒ A provincial body not represented by the medical model, religion, or worldviews to provide a model that will work for all families.
 - This will remove the competitive model that is currently in place, related to political power such as cabinet shuffling and funding shifts

- ⇒ This organization would oversee standardization of services, programming, and funding.
 - This would include overseeing school curriculum, advertise programming and services, meet the needs of employees with lived experience and explore alternative options for families
 - Funding oversight would be done by this central organization to ensure that funding is allocated appropriately, including the ongoing costs associated with supporting communities
- ⇒ This organization would handle central coordination through a coordinator or clerk that would consolidate all resources and services
 - Requests for support would be completed through this organization to ensure that supports are available when needed including support when medical equipment breaks
- ⇒ All policies and laws would need to be vetted by this organization to ensure that those with expertise are constantly involved and advising on any matters related to the community.

On a larger scale, creating a centralized system for all children and families with support needs to eliminate the burden of having to navigate diverse and complex service frameworks.

Creating Space for Advocacy

Deaf representation was a shift that participants would like to see in the system as they reflected on the **voice and needs** of the deaf and hard of hearing community being missed in important conversations (n = 9). Participants shared that they were very few deaf and hard of hearing people in positions and power in B.C, particularly in government, including the CYSN Minister's Advisory Council. A participant shared the benefit of this:

- We are starting to see deaf professionals moving into higher positions and the payoffs and the amount of improvement in such a short time has just been astounding.

Participants shared that in some of the key deaf and hard of hearing organizations there are no culturally deaf people in leadership positions, noting that there are ideologically deaf people who use spoken language approach, which is fantastic, but there also needs to be culturally deaf people using a fully accessible language, noting the need for deaf-led advocate services for hearing and deaf and hard of hearing parents and their children.

Five participants shared the importance of the system having input and advocacy from families to ensure that families have control over what the service model looks like as communities have unique needs.

- I want to say thank you. My voice has gone unheard in MCFD CYSN and the brief time we did have a CYSN worker until he didn't qualify... I have been waiting for this day to see changes in the system... It took me a long time to find my advocacy voice... I am emotional here – because there are a lot of people who don't have a voice and don't have that strength – it's valuable like all these other parents here to speak up for people who don't or can't.

5.0 Considerations

The following section outlines areas for consideration in the development of a revised Children and Youth with Support Needs system of services based on feedback and reflections shared by participants.

1. Create a system navigator role that can support families and youth starting at birth and through diagnosis and the transitions into different areas of care.
 - a. Participants articulated a need for more support for families including in the areas of case management, transition support, navigating the system, and advocating on their behalf.
 - b. System navigators can support with creating and disseminating information about CYSN supports and services, including clearly articulating eligibility criteria.
 - c. System navigators can offer suggestions for supports and services that children and youth with special needs and their families can access in the event that they do not qualify for support.
 - d. Participants shared that they are often having to fill the role of system navigators ensuring that children and youth are accessing needed services and resources that work for them.

2. Create a better system of support for parents and guardians of children and youth with support needs, including respite, access to daycare, and mental health support that does not require personal funds to access.
 - a. Respite:
 - i. Respite and childcare were identified as one of the biggest needs that families of children with support needs have as well as one of the biggest costs.
 - ii. Many families had difficulty accessing appropriate and affordable childcare and respite services. For example, participants reported that there are a lack of individuals who provide respite or childcare services for children with support needs and that many services that are available are not able to care for children with medical complexity.
 - iii. Participants reported that many families experience burn out because they lack support to help care for their child.
 - iv. Consider increasing funding allocation toward respite and childcare services and revising eligibility criteria to be lower barrier.
 - v. Consider providing access to training and professional development with regard to caring for children and youth with special needs.
 - b. Mental Health & Counselling Supports
 - i. The need for mental health related supports for families was shared by participants who reflected on a lack of support for families,

- particularly as it relates to mental health supports right after diagnosis.
- ii. Families shared that there is not enough mental health supports offered, and the support that is offered has long waitlists and unqualified mental health workers.
 - iii. There is also a lack of mental health support specific to youth. There is a need for more counsellors trained in supporting children and youth with support needs.
 - iv. Mental health supports was also shared as crucial from families with their own lived experience and trauma.
3. Consider how a safe space can be created for families and children with support needs.
 - a. Families noted that they are often faced with the fear and even threat of apprehension and as a result will avoid accessing needed services and supports.
 - b. It is important that families and children and youth with support needs have a safe space to access services.
 4. Work with partners and agencies to create a recruitment and retention strategy for special needs service providers. The recruitment and retention strategy can consider wages, position hours, benefits, and supported professional development as methods of retaining staff.
 - a. Participants frequently cited long waitlists, overlarge caseloads, and a lack of staff to meet the current need. Participants also frequently suggested that CYSN supports and services could be improved if there were more resources for staff.
 - a. A lack of staff in general was found to impede accessibility of CYSN services and supports. It was reported that many staff who work in special needs programming experience burn out and are not adequately supported to remain in the job.
 - b. Consider the feasibility of offering subsidies or tuition forgiveness for individuals seeking education in key service provider fields.
 5. Work to develop and support the implementation of a CYSN framework that fosters and enables equitable access to CYSN services and supports. Within the framework, consider how eligibility criteria and culturally safety impact access to supports and services .
 - a. Participants frequently spoke to the need for a more culturally appropriate and family/child-centered approach to service provision that considers not only the diagnosis, but the child's overall needs as well as the needs of the family.

- b. The need for culturally appropriate services was identified by several communities including those who identified as Indigenous, newcomers/immigrants to Canada, and the deaf and hard of hearing community.
 - c. Consider how children, youth and their families can be given more voice and decision making in the supports and services that work for them. Participants generally expressed a need for more autonomy, but the need for more choice was particularly acute for those who were part of the children with medical complexity community.
 - d. Consider the rights of those who are in the deaf and hard of hearing community and deaf blind community to access language.
6. Consider conducting a study on how to most effectively support transportation to CYSN services and supports. Transportation was frequently identified as a barrier to accessing CYSN services and supports as well as a main cost to both families as well as agencies.
 - a. Transportation challenges impacted families in urban communities as well as families in rural and/or remote communities.
 - b. Barriers to transportation for families included a lack of vehicle, the cost of traveling (i.e. gas, food, accommodations), and public transportation not being a feasible option (i.e. not available in community, not feasible for some children with sensory needs).
 - c. Transportation costs to agencies included staff time driving to see clients or driving clients to services and appointments, and support for families to travel to services (i.e. bus tickets, gas cards).
7. Consider how the CYSN framework can support streamlined, yet individualized services and how this framework can help to bridge to services and supports in the education and health system.
 - a. Participants expressed frustration with the patchwork of services and supports and the siloed agencies. The current landscape results in gaps in services and families having to make difficult choices about what services and supports they can access. It also results in an exhaustive amount of time to remain up to date on what services and supports are available and where.
 - b. Consider a mechanism for streamlining and centralizing information about services and supports. The purpose of a centralized system would not be to mandate a one size fits all approach, but rather streamline and map out what is available, support system navigation, promote quality control, and include the voices of those with lived experience.

- c. Consider how the framework can support CYSN to better communicate and collaborate with services and supports offered through the education and health system.
8. Collaborate with the Ministry of Education to assess the effectiveness of the special needs services and supports school age children.
 - a. Participants reported that they had less autonomy regarding special needs services and supports for their child once they reached school age, that services and supports were less accessible, and that the services and supports they did receive were of lower quality.
 - b. Participants expressed a need specifically for more education assistant and more interpreters in schools. Participants also reported a need for 1:1 support in schools.
 - c. Participants also commented on the quality of services and supports available in schools. There is a need for quality control to ensure that school supports are equipped to support children and youth with diverse support needs.
 - d. Consider developing a strategic path forward with the education system on how to enable access to adequate language and communication for children and youth who are deaf or hard of hearing that does not solely rely on those in the deaf and hard of hearing community to learn how to speak English.
9. Collaborate with other divisions within MCFD (i.e. child protection) and other Ministries to ensure that families are supported before children end up in MCFD care.
 - a. Participants reported that many families are in crisis by the time they are accessing CYSN services and supports and that supports are geared towards supporting an individual child and not towards supporting a family to support their child.
 - b. Participants stated that CYSN services and supports were easier to access for children in care of MCFD than for biological families and that it is even recommended that families put their children in the care system so that they are eligible to access more supports.
 - c. Find a means of collaborating with other MCFD divisions on identifying and supporting families who have children with special needs and are at-risk of having their children apprehended or placed in voluntary care.
 - d. Separate out child apprehension from services and supports. Many families are afraid to access needed services and supports due to fears of child apprehension.
10. Continue to contract services with Indigenous agencies that provide culturally safe services and supports such as Lii Michif Otipemisiwak Family Services and Nzen'man Child & Family Development Centre.

- a. These organizations are examples of a service delivery model that takes a holistic family and child centered approach to service delivery where supports are provided based on need rather than meeting criteria.
 - b. Indigenous participants shared that they are receiving culturally safe services through LMO, where they have access to Elders and holistic support including traditional teachings and cultural activities.

11. Continue to support steering committees that include diverse individuals with lived experience.
 - a. Participants highlighted the need to have those with lived experience involved in decision making regarding programming to ensure that it is relevant and meets the needs of the community.
 - b. Participants reported that there is currently a lack of lived experience in advisory and decision making positions. Consider the diversity of support needs and identities that are represented on the steering committees.

Appendix A. Data Collection Tools

All data gathering tools are included in Appendix A including the focus group tool, the interview tool, and the survey tool.

A.1 Survey Questions

Survey Questions
<p>1. Please select how you identify (select all that apply)</p> <ul style="list-style-type: none"> <input type="radio"/> Person with lived experience (e.g. living with a disability, neurodiverse, neurocognitive) <input type="radio"/> Friends or family of person with lived experience <input type="radio"/> Advocate or service provider for children and youth with special needs
<p>2. Where are you located?</p> <ul style="list-style-type: none"> <input type="radio"/> _____ <input type="radio"/> Prefer Not to Say
<p>3. Do you identify with any of the following communities? (select all that apply)</p> <ul style="list-style-type: none"> <input type="radio"/> Indigenous (First Nations, Métis, Inuit) <input type="radio"/> Black <input type="radio"/> Person of colour <input type="radio"/> Im/migrant <input type="radio"/> Newcomer <input type="radio"/> 2SLGBTQQIA+ <input type="radio"/> None of these apply <input type="radio"/> Prefer to self-describe:
<p>4. What services and resources are helpful for children and youth with support needs/disabilities in your community? (e.g. speech and language therapy, occupational therapy, physical therapy, behavioural interventions, assessments, counseling, respite, family support, at home program)</p>
<p>5. What services and resources are not available or accessible for children and youth with support needs/disabilities in your community? Please explain.</p>
<p>6. How do we change the current services and resources so that they work better for more children, youth and families in your community?</p>
<p>7. Is there anything else that you would like to add?</p>

A.2 Engagement/Interview Questions⁴

Interview Questions	
1.	Imagine that a young person with support needs lives in your community, how would you or community support them?
2.	What services and resources exist in your community right now that are helpful for children and youth with support needs? (e.g. speech and language therapy, occupational therapy, physical therapy, behavioral interventions, assessments, counseling, respite, family support, at home program)
3.	Are there services and resources that are not available or accessible for children and youth with support needs in your community? (e.g. because of waitlists, transportation, language barriers, eligibility, cultural safety, aging out)
4.	What do you think this family needs so that services and resources work better for more children, youth and families in your community?

⁴ Please note that depending on the community engaged, these questions may have been slightly adapted.

Appendix B. Supplementary Reports

B.1 Responses from Specific Community Groups

Due to the inability for an engagement session to take place with the 2SLGBTQIA+ and Newcomer and Immigrant Communities, specific responses from these communities are detailed below.

Helpful Services and Resources identified by the 2SLGBTQIA+ Community

Survey respondents who identified as being part of the 2SLGBTQIA+ shared their reflections on the services and resources that are helpful to children and youth with support needs in their community and shared the following:

- ⇒ Counseling (n = 5)
- ⇒ Family support (n = 4)
- ⇒ Speech and language therapy (n = 4)
- ⇒ Occupational therapy (n = 4)
- ⇒ Physical therapy (n = 4)
- ⇒ Assessments (n = 3)
 - At home programs (n = 3)
- ⇒ Behavioral interventions (n = 2)
- ⇒ Respite (n = 2)
- ⇒ Therapeutical support such as music therapy (n = 2)

Two respondents identified **specific programs for deaf and hard of hearing individuals**, such as the Canadian National Institute for the Blind (CNIB), Vision Loss Rehabilitation Canada (VLRC), Deafblind Community Services (DBCS), Blind Beginnings, BC Blind Sports, and Provincial Resource Centre for the Visually Impaired (PRCVI). They also mentioned a Child Development Center on Vancouver Island.

Needed Services and Resources identified by the 2SLGBTQIA+ Community

Respondents noted the following lack of services and resources for children and youth with support needs, including:

- ⇒ **Lack of therapeutic services** including counselling and social supports, such as community gatherings and peer support, as well as disability and neuro-affirming services (n = 4)

Many of the youth I support have expressed an interest in having more social gatherings within their communities that focus less on teaching particular skills and more on building community relationships.

- ⇒ Lack of funding for **respite services** and a need for **individualized funding** for disabilities, other than Autism, to better support families (n = 2)
- ⇒ Lack of funding for the cost of interpreters at schools, performances, recreational classes, and sports programs
- ⇒ Lack of local programming and child development support

Supported child development is VERY limited in all communities and creates isolation and again less ability for caregivers to work even if child can attend school.

For those with intersecting identities (2SLGBTQIA+ and newcomer/immigrant/Indigenous), it was shared that **more support for families** is needed, including daycare and financial supports (n = 3).

System Shifts and Changes identified by the 2SLGBTQIA+ Community

When it came to suggestions on how to shift the current services and resources, respondents shared the need to ensure **proper training and service delivery** for children and youth with support needs (n = 3). Participants noted the need for trauma informed, culturally safe, and disability and neuro-affirming services, as well as increased interpreters with adequate training. One participant further described the need to shift how service providers practice to better respond to the needs of children and youth who are neurodivergent, sharing:

- Take a stand against ABA and other behaviourist and conversion / compliance-based practices, groups, and approaches, and provide Actually Neurodivergent led and Neurodivergent Affirmative service providers committed to challenging ableism, stigma, and outdated/harmful approaches based on stereotypes and pathologizing.

Further, respondents shared the need to **expand and add to existing programs**, such as making programming more available to families and children through increased funding and offering more social components in programming such as allowing participants to arrive early, stay late, and build connections with other participants (n = 3). This was echoed by a respondent who had intersecting identities, and shared that services need to include life skills training, employment prep services, and the opportunity for children with similar disabilities to connect. They also noted the need for counselling services to support families.

Another respondent with intersecting identities (2SLGBTQIA+ and newcomer/immigrant/Indigenous), shared the need for a more standardized process post diagnosis as this would provide better supports to families.

Helpful Services and Resources identified by Newcomer and Immigrant Communities

For those that identified as a newcomer to Canada or an immigrant, they identified the following services and resources that are helpful to children and youth with support needs in their community:

- ⇒ **Speech and language therapy** (n = 4)
 - Including interpreters
- ⇒ **Occupational therapy** (n = 3)
- ⇒ **Physical therapy** (n = 2)
- ⇒ **Family support** (n = 2)
- ⇒ Assessments
- ⇒ Counseling
- ⇒ Vision therapy
- ⇒ Child development center on Vancouver Island

Needed Services and Resources identified by Newcomer and Immigrant Communities

Newcomer and immigrant respondents shared that they have identified a **lack of therapeutic support** for children and youth in their community, such as the local development center not offering vision therapy and no counselling or family support offered (n = 2).

Also noted by a respondent was the need to hire and educate more service providers, sharing that children with support needs are being denied inclusive care in daycare due to a lack of one-on-one support and no guidelines to enforce acceptance and care of all children, as set by the Child Care Fee Reduction Initiative (CCFRI).

Additionally, a newcomer/immigrant respondent shared that there is disconnect between the medical community and the therapy and support community, sharing:

- After the emergent medical needs are handled, there is a several months gap where parents/families are left alone to sort out their new family life until therapists are assigned. No respite or mental health support is given to caregivers or parents.

System Shifts and Changes identified by Newcomer and Immigrant Communities

From a systemic perspective, a newcomer and immigrant family members shared in the survey the need for more increased support for parents and families, noting wanting access to all the support available and making daycare accept all children, sharing:

- Families should be treated and given all the support versus made to feel like they need to wait and be patient for care.

Respondents also shared the need for more services outside of the cities, noting:

- I was referred to Blind Beginnings and found out it's a wonderful organization with people who cared about my son, too bad they don't have more programs in my community.

Lastly, a newcomer/immigrant service provider who completed the survey noted wanting to see more diversity in services, such as speech and play therapy.

B.2 Regional Responses

This section outlines the regional differences between responses from participants. The majority of participants in the engagement are from the lower mainland of BC, and for that reason there is limited regional differences. Although, participants from rural or remote areas most often noted challenges with accessibility or availability of services. Specifically, participants in the north mentioned there is limited resources, specifically therapists or access to respite. Sharing that finding support workers, respite workers or therapists is challenging. They noted that there is a shortage of therapists in the north, resulting in long wait times to access needed therapy. Some participants lived rurally on Vancouver Island or on smaller islands in BC, noting they need to travel to access services. Participants living remotely on Vancouver Island specifically noted there is a shortage of therapists and doctors in their area due to shortage of housing, which is limiting their access to services. One parent mentioned the local respite homes/care homes in the north were not adequate to support their child. One parent mentioned limited access to respite due to high demand in their city, mentioning they would need to move to another location to access respite.

While many participants across all regions mentioned long waitlists, those from the north specifically mentioned long wait times, due to limited resources in the north. Participants from the interior of BC or areas outside of the lower mainland frequently mentioned that they need to travel to the Lower Mainland/Vancouver to access specialized services or resources. Noting it can be a challenge to travel to the Lower Mainland, especially if costs are high and not covered by funding. Participants in the north and interior noted the high cost of medical related travel, especially for youth with complex needs who may not be able to access local services.

- We live in the north and need to travel to Vancouver for medical reasons. There's been a lot of unexpected trips that are only partially covered. It is costing about 1000\$ out of pocket per trip. There are limits on what is covered for hotels, transport, etc.

Participants noted regional differences in terms of funding, noting differences in funding available depending on their region. Participants discuss there is inconsistencies across the province in terms of qualifying for services or funding, saying that not all children and youth receive the same equity of care, additionally mentioning regional challenges with access to Family Connection Centers, noting barriers in accessing services depending on the location of FCCs. Specifically, participants noted less access to therapy or services when their area transitioned to FCC hubs.

When specifically discussing the At Home Program, participants mentioned challenges with accessing therapy in rural and remote areas. Participants in the north or who live rurally mentioned they have limited access to Child Development Centers, noting that

agency hosted, center-based therapy can be challenging if they need to travel. Conversely, participants mentioning as therapy in the At Home Program is individually funded, rural and remote families have limited access to therapists in their regions due to shortage of workers or services. Noting that flexibility is important for families, a reminder that youth and children and families have different, unique needs.

When discussing accessibility of services, participants outside of city centers frequently mentioned transportation can be a barrier to accessing resources. Noting improving transportation options for youth and children with support needs, or ensuring resources are in central locations.