THE
FAMILY VOICES
PROJECT

HELPING SHAPE THE
FUTURE OF CYSN SERVICES

Report of Community Engagement

Prepared for the BC Ministry of Children and Family Development

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FAMILY SUPPORT
Institute of BC
families supporting families

THE UNIVERSITY OF BRITISH COLUMBIA
Canadian Institute for Inclusion and Citizenship

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INTRODUCTION

The Family Voices Project: Helping Shape the Future of CYSN Services is a partnership between the Family Support Institute of British Columbia (FSI) and the University of British Columbia's Canadian Institute for Inclusion and Citizenship (CIIC).

The project emerged in response to a request to the FSI from the British Columbia (BC) Ministry of Children and Family Development (MCFD) to conduct community outreach and engagement in BC to gather insights from families and individuals with lived experience about the state and future services for children and youth with support needs[1].

To reach the largest number of families and self-advocates across BC, we embarked on two complementary pathways of engagement. The FSI conducted 17 inperson gatherings in 16 different communities across the province while the CIIC conducted qualitative interviews and focus groups online with 46 participants from across BC. The full team, comprised of members from the FSI and the CIIC, met regularly (starting in 2023 to present) to coordinate approaches and to ensure effective communication across all aspects of the project.

Throughout this work, we heard how important it is for families to have a strong supportive relationship with MCFD and to have access to Children and Youth with Support Needs (CYSN) services and supports that meet their family's unique needs. This report offers highlights related to our findings as one way to honour the words and experiences of the participants who generously shared their stories and perspectives.

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[1] For an excellent overview of the history of MCFD's Children and Youth with Support Needs please see the BC's Representative for Children and Youth's 2024 Report, *Don't Look Away*.

METHODS - WHAT WE DID

In this section, we first detail the approaches, processes, and commitments of the FSI provincial engagement activities, followed by the research methods used that guided the CIIC research activities. The overarching research question guiding the Family Voices Project was:

> ***What do family members and individuals with lived experience of disabilities and support needs see as their desired and needed supports for Children and Youth with Supports Needs Service Delivery in BC?***

FSI Community Engagement

The FSI team was led by Tracy Humphreys, the FVP Coordinator. Seventeen Family Voices Events were held across 16 communities with a total of 108 individuals attending. Of these 108 participants, 20% self-identified as Indigenous. These events were intentionally designed to foster connections and gather invaluable insights from families and self-advocates about the state and future of services for children and youth with support needs (CYSN). Each session was structured to create a relaxed, informal setting where participants felt comfortable sharing their experiences and perspectives. A central commitment for each engagement opportunity was to keep listening as our focus and at the forefront of each gathering.

We built these events with community in mind, ensuring that the venues were in locations that would feel comfortable and culturally safe, and that they were accessible and welcoming. We planned the marketing to ensure that families knew there would be refreshments available and support for them to attend (e.g., reimbursement for travel and childcare). We planned the events to be a relatively casual and open community conversation over allergy friendly food. The gatherings lasted between 2-3 hours.

At the start of each event, we welcomed participants as they arrived. We established comfort and broke the ice through having people create name plates with construction paper, markers, and stickers. We offered refreshments and encouraged and engaged in casual conversation to help build rapport. We provided notepads and pens to jot down thoughts throughout the session, as well as information flyers about FSI, and we left fidgets and markers on the table. These initial moments of informal engagement set the tone for an open, participatory atmosphere.

The more structured portion of the engagements began with a traditional welcome, where possible, led by a local Elder. Tracy expressed deep gratitude for their presence and for sharing their knowledge, which grounded our gathering in the cultural context of the land we were meeting on. Where an Elder was not able to open up the meeting in a good way, we shared a personalized land acknowledgement, taking care to thank Elders and Knowledge Keepers past and present.

After the welcome and land acknowledgement, Tracy introduced herself and the Family Voices Project, sharing her background as a woman with disabilities and as a mother of children with disabilities. Tracy's personal experiences informed her role as Project Coordinator and her lived experiences contributed valuable insights about the broader challenges families face across the province in accessing essential supports. Staff who were also present introduced themselves similarly.

At each session, Tracy summarized the key questions and reviewed the confidentiality of the conversations, ensuring that everyone understood how their contributions would be used to inform research and policy recommendations. Participants were reminded of the importance of keeping others' shared stories private and were encouraged to stay for further informal conversations if they wished.

The majority of time was spent in casual conversations, listening with occasional prompts to ensure we were capturing answers to the key questions, while not limiting what they were able to share. The events were structured around the key questions provided by CIIC, that asked participants to reflect on their positive experiences with current services, what they needed from a new system of supports, and how MCFD could improve its responsiveness. We also explored any cautions families had as the Ministry moved forward with changes.

Often, the discussions just started without a need for introductions or prompting because people felt compelled to share their input. Throughout the discussions, large post-its and flip charts were available to capture participants' thoughts, and the staff and Tracy took notes. At some of the larger events, people divided into smaller groups and we went around to connect with each group through the event, but at most events it was one circle sharing together.

At the close of each event, we ensured we had contact information from participants and sent extra food home with them. We also ensured that participants knew they can come to FSI for further support.

Overall, these Family Voices events provided a valuable platform for families and self-advocates to voice their concerns, share successes, and contribute to the future shaping of support services. The information gathered will be instrumental for informing MCFD about the needs and wants of families across the province for CYSN supports.

CIIC Research Methods

Descriptive qualitative methods (QD) (Hyejin et al., 2016; Sandelowski, 2000, 2010) guided the CIIC research. QD is especially relevant for research projects "aiming to gain firsthand knowledge" of individuals with lived experience regarding a particular topic (Hyejin et al., 2016, p. 24): to ascertain the perspectives and experiences of family members and individuals with lived experience regarding CYSN services. Another advantage of QD is its suitability to projects where time is limited (Neergaard et al., 2009); such was the case in this study where timely feedback was required by the Ministry to inform decision making for a new CYSN framework in BC. Ethics approval was granted by the University of British Columbia Behavioural Research Ethics Board [H23-03233].

Sampling and Recruitment

Using convenience and snowball sampling, individuals were recruited through the FSI social media and word of mouth. Inclusion criteria were as follows: a family member of a child/youth with support needs and/or an individual with lived experience of disability and support needs; 18+ years; and consents to participate in a research interview or focus group. One hundred and thirty-five individuals indicated a desire to participate. Not all individuals responded to the invitation to review their potential participation, and some were screened out due to not meeting the inclusion criteria. After reviewing project inclusion criteria, 46 individuals met the inclusion criteria and agreed to participate.

Data Collection

Of the 46 individuals who agreed to participate in the research arm of the Family Voices Project, 24 individuals participated in a semi-structured individual interview, and 22 participated in a focus group. Interviews and focus groups were conducted virtually using a UBC secure Zoom account. With participants' consent, all interviews and focus groups were recorded and downloaded onto a password protected laptop. Subsequently, they were transcribed verbatim using Otter AI. Interviews were created to elicit families' and self-advocates desires and needs for the future CYSN framework. We asked:

#1 When thinking about what you need from a new system of services for children and youth with support needs? What is most important to you or your family?

#2 Are there existing supports and services that work well for your family that you'd like to see maintained? What are they? And how have they helped?

#3 How might MCFD respond better to meet the needs of families with children and youth with support needs?

#4 Do you have any cautions for MCFD as they move forward?

#5 Is there anything I haven't asked you that you would like to add/include?

Data Analysis

Qualitative content analysis, a common strategy for analysis in QD studies (Hyejin et al., 2016) informed the analytic process. In terms of analysis, the aim of QD is "a rich, straight description of an experience or event" (Neergaard et al., 2009, p. 24). Thus, content analysis allowed the researchers "to stay close to the data, with minimal transformation during analysis. Such interpretation is low inference" (p. 24).

NVivo 14, a qualitative data management software, was used to facilitate data analysis. The research team met to establish a plan for data analysis and collectively an initial coding framework was developed. QD analytic strategies were implemented: coding of interview data; sorting through the data to identify similar important features; looking for commonalities and differences among the data for further consideration and analysis; and deciding on categories that hold true for the data (Neergaard et al., 2009).

In line with descriptive studies (Bagwell-Gray, 2018; Pope et al., 2018), presentation of study findings are comprehensive descriptive accounts of the data (Hyejin et al., 2016). As Neergaard et al. (2009) describe, "the final product of QD is a description of informants' experiences in a language similar to the informants' own language" (p. 2). This commitment was central to the research process as we wanted to centre the voices of the participants in the results. The findings presented in this report are supported by verbatim quotes from participants. All identifying information has been changed or removed to protect participants' identities.

RESEARCH FINDINGS

DEMOGRAPHIC RESULTS

Of the forty-six individuals who participated in a research interview or focus group, 37 completed the demographic survey. Of the 37, the majority identified as female; the majority had some post-secondary education; and 11 identified as Indigenous. The geographic representation is very diverse, and many participants identified as belonging to one or more equity deserving groups. The following tables show the results of the demographic survey.

Note: For some categories participants were able to select multiple options, so combined counts may exceed the total number of participants. These categories are marked with an asterisk (*).

AGE	(in years)
Mean	41
Min	18
Max	70

GENDER	
Woman	26
Man	5
Non-Binary	1
No response	5

EDUCATION	
Elementary	0
High school	3
College Diploma	12
Undergraduate Degree	6
Graduate Degree	10
Prefer not to answer	1
No response	5

INDIGENOUS*	
(Any Indigenous identity)	11
Indigenous	7
First Nations	6
Inuit	0
Metis	4

MARGINALIZED IDENTITY*	
Visible minority	4
Belong to an excluded socioeconomic group	6
Visible or invisible disability	11
Gender or sexual minority	1
Experienced systemic exclusion or disadvantage	4

LOCATION	
Lower Mainland	11
Vancouver Island (incl. Gulf Islands)	6
Thompson Okanagan	4
South Eastern BC	3
North Western BC	3
North Central BC	3
North Eastern BC	1
Prefer not to answer	0
Other	1
NA	5
Rural/Remote	13

FVP COHORTS*	
An individual with lived experience (person with a disability) who has received CYSN services or funding	7
A family member with a child or youth with medical complexities	24
A young adult who transitioned from high school	3
A family member of a child or youth with dual diagnoses	21
Other	4

What Families and Individuals with Lived Experience Told Us

> *I think we are owed an apology, and there needs to be some sort of apology or recognition by MCFD that they're not doing this right...Just for them to say, "You know what? We don't know what we're doing. We can't help you. There's nothing we can do. We don't have systems in place. We're really sorry."*

Across all the interviews and focus groups, we heard stories describing the frustration, pain, stress, and trauma that families and individuals with lived experience carry from their experiences with the Ministry and the related systems. Many participants spoke about the lack of acknowledgement from MCFD for the pain and trauma the current system and waiting for change has caused. And, as demonstrated in the opening quote, some explicitly require an apology that acknowledges the harm and trauma done to families due to the lack of service, waitlists, and treatment within the system.

THE RESULTS PRESENTED IN THIS REPORT COVER:

1) The Importance of Family Agency, Advocacy, and Witnessing;
2) The Current State of Affairs; and,
3) What Families and Individuals with Lived Experience Want.

The Importance of Family Agency, Advocacy and Witnessing

At the nexus in the relationship between MCFD and families of children and youth with support needs is the importance of Family Agency.

How families navigate numerous services, including the At Home Program, Autism Funding, respite care, key workers, and specialized therapies, family support, and medical benefits, is key to the overall experience and outcomes of care for their loved ones. The Importance of Family Agency, Advocacy, and Witnessing reverberated across the interviews. This finding underscores the central and important role of families for effective CYSN supports and services. The strength and determination expressed by families to optimize support and services cannot be understated.

The importance of and need for family agency, advocacy, and engagement is a main finding of our research. Many parents expressed the feeling that their voices are marginalized in discussions about their child's/youth's needs. Families shared how the burden of advocating for their child falls heavily on parents and caregivers, and parents described how they must constantly push for services, navigate complex systems, and educate services providers. There is a strong need for the meaningful inclusion and representation of family voices to ensure the unique needs of each family are considered in decision-making processes. In fact. families expressed that without their advocacy, often acting as the *"broker"* or *"middle person,"* their children would not be receiving the appropriate supports and services.

> ***I know what's best for my family and I need to be the one saying yes [or] no.***

Participants were clear that their advocacy is key to their child's/youth's well-being and to the effectiveness of supports and services their family receives. Families stated that they know their child best. As one participant explained,

> *I would add that most parents, if given the resources, are going to be able to pull together higher quality and better care and services for their child than a stranger that lacks adequate education and commitment to that child.*

Families underscored that they are experts about their child's and their family's needs, and they emphasized that they should play a major role in the types of services and supports their family member(s) receives. One participant stated, *"We know what the issues are... we know the challenges... And we know where it's falling apart."*

Families work hard to advocate and continue to be the "squeaky wheel" to ensure that appropriate services are available to fulfil the diverse realities of children and youth with support needs and their families. As one participant notes, *"It's like the wild West of trying to help your child… You just strap in, try your best. Just be persistent."* So, while family advocacy is necessary, many participants described how engaging in this advocacy takes its toll: *"We are struggling so hard as parents, financially, emotionally, socially, economically… What we have to go through on a daily basis compared to Neurotypical families."*

It is not always easy for families to move forward with advocacy. One participant explained, *"It takes a lot for me to ask for help,"* and another shared, *"I just broke down, I cried and I'm like, 'What do you mean if I'm interested? I've been telling you for months that I'm struggling'…"* Furthermore, participants can feel intimidated by different CYSN workers. They expressed concern that their advocacy can and/or has affected their funding and access to supports. One participant shared, *"If you advocate too strongly, there's no funding… Or if you don't advocate, if you don't advocate enough then your child slips through the cracks and they could possibly die."*

In efforts to help mitigate the stress and frustration of constant advocacy, families turn to Facebook and other support groups. Several participants described various agencies that they turn to for help in their advocacy such as the FSI. Some participants described how being able to lean on FSI support workers who have the history with families is imperative with one participant stating, *"The [FSI] has been amazing." Another participant similarly shared, "The Family Support Institute as support has been amazing. For me personally, it's been like a home away from home. My family, my second family, so I love that."*

...the more you educate yourself, the more you empower yourself to be able to actually have an informed opinion and informed position.

Related to advocacy, parents identified specific domains where their advocacy was needed most. One area is the need to educate themselves about the various systems and in the knowledge bases relevant to their child's needs. For example, parents described having to become knowledgeable about medical issues and language to ensure there are appropriate medical interventions and medications being provided. Emphasizing the importance of educating oneself, one participant shared, *"They're not going to take you seriously when you've not done all your research. And the more you educate yourself, the more you empower yourself to be able to actually have an informed opinion and informed position."*

A second domain is learning about the interconnected ministries and how to navigate them. Participants underscored the importance of understanding the inherent barriers in the system itself, including cross-ministerial obstacles. The systems are complex and require a particular technological literacy that may not be present within all families. Again, parents explained, greater connectivity between ministerial support is important to ensure that family advocacy is offered a relevant space and recognized when determining the best supports and services for families.

One specific example that participants spoke about was the interconnectedness between CYSN and the education system. Parents explained that support within the education experience of the children and youth with supports needs is imperative. Having appropriately trained social workers engaged with the educational experience (e.g., such as attending school meetings) can ensure that there is a greater understanding of the family's needs and promotes a collaborative approach between the service providers, the school, and the family. Families understand that there is funding for the schools that pertains to the educational experience of their child; here participants noted that it is critical the role of families who fought for school-based funding is acknowledged. Families also desire greater accountability for how the Ministry of Education ensures funding dedicated to their children and youth is being used appropriately.

A third area requiring advocacy is funding and the struggle to access specific supports and services. Funding is a particular place of tension for families. The *"tedious processes"* of trying to access relevant services is a frustrating experience and often results in the disengagement between families and service. One participant spoke to the relevance of wraparound services and the need to properly fund them, explaining that there is a greater depth to understanding therapeutic needs such as occupational therapy, physiotherapy, vision therapy, dental health, and mental health. Participants spoke to the need for supported childcare throughout the province, and that culturally informed and safe childcare needs to be considered for Indigenous children. Appropriate autism specific supports for children, youth, and adults were underscored many times by many participants. Participants specifically highlighted that the critical gaps that exist related to autism knowledge and funding needs to be addressed.

Finally, a striking thread of families bearing witness to other families' challenges and barriers was present throughout the data, and participants advocated on behalf of these families. For example, one parent shared:

> *But again, because I'm able to speak the language, I'm able to communicate, I'm not scared to ask questions. People are not as comfortable to ask questions because speaking again, as an immigrant, as a person who migrated to Canada, I'm always thinking of people and how do I open doors for them? I'm like, "I struggled. I don't want you to struggle. So, let's communicate and find a way." And even having people that are multilingual and then being on staff and they're like, "Okay, I don't understand this. Would you be able to transfer me to someone?" Or having translation available in multiple languages would make things and the process for people so much easier.*

Families spoke to the more intense, complicated contexts that other families face and provided their thoughts about what these families might need. Parents recognized that specialized services and supports including appropriate funding are required for families with children and youth with complex needs due to their unique circumstances. Other families highlighted particular populations (children/youth with specific diagnoses) whose needs are not being met in the current system. For example, one participant noted that it is important to ensure families are well supported and that there is equitable access to supports for diverse diagnoses such as FASD and Down syndrome. Another participant specifically raised equitable access to appropriate supports and services for children/youth with support needs who are being raised outside their family home: *"[a] child growing up in foster care or a group home is not going to get the same level of one-to-one care and support that the family can provide."* And one parent described the challenges for young parents: *"[it's hard to have to] keep fighting to get the right answer, especially with younger parents that [are] just starting their journey."* Finally, families spoke to the disparities that other families experience due to race and geographic realities (e.g., Indigenous families, rural and remote communities, Northern communities). Empowering parents, caregivers, and our communities through better resources, training and support is crucial to support the well-being of children and youth with support needs and their families.

The Current State of Affairs

This section provides a brief overview of what participants shared regarding their experiences with current MCFD CYSN supports and services. While some families discussed positive elements of MCFD and CYSN support and services, the majority of participants expressed their frustration with the system and advocated for systemic change. In this portion of the report, we share some examples of families' positive experiences and then provide a description of some of the negative impacts on families of the current system as described by the participants themselves.

What's working?

With respect to "what's working", families specifically spoke to three programs: respite, individualized funding, and the At Home Program. For both respite and individualized funding, the participants highlighted the flexibility, and choice and control that these programs offered. For example, one mother shared,

> *I think the respite program is wonderful. It definitely has helped. We definitely benefit from the funds even though they're small, just knowing that we have that little bit of extra money so I can use it. Having that flexibility after Covid, how they changed it where if you don't have a respite person, you can use it for house cleaning or for takeout meals... things that are supposed to make my life as a full-time caregiver easier. I think that's wonderful.*

Another parent stated,

> *Flexibility, I guess maybe would be a better word than choice, but having the individualized funding of the extended therapies, one, getting to choose and really find someone who fits both of them, or I mean the different people, … I cannot even overstate how important that is.*

And, families who were accessing the At-Home Program spoke to the necessity of these services and medical equipment/products for their child/youth with support needs. As one parent described,

> *There is a lot of good. We wouldn't be here. We wouldn't be here. I wouldn't have all the benefits through At Home benefits. I mean, I get unlimited diapers, man, living a good life. I mean, I'm not being sarcastic. I appreciate what they provide. They just have to do better, otherwise they wouldn't be here.*

Finally, families described how having specific community organizations and/or specific workers who provide collaborative types of supports that centred the family's needs in a holistic way were incredibly positive. For example, one parent described how a community living organization provided support with finding caregivers and then funding for these supports rather than having to pay out of pocket:

> *So, I receive respite here through [organization]. And they look after finding*

> *the caregivers. We once upon a time had to find our own and pay and then get reimbursed and all that, but we no longer hold that stick here. So, that's really gone a long way. So, I do appreciate the respite supports that the Ministry provides. I also receive out of home respite, and that was set up through the Ministry as well. And that was super-duper, and I was really grateful for that. But my daughter also is totally eligible for that piece, so that is fantastic. She does spend a couple of weeks every so many months out of home, and that is funded completely by the Ministry. So, I thank all the stars for that. So please continue that.*

And, some families shared positive experiences with their social worker. These experiences highlighted workers who were responsive and consistent in their involvement with the family:

> *Yeah, I think we've been incredibly lucky with our social worker. We've had the same one from the get go. So yeah, five years now we've had the same person and she's very responsive. If I email her or call her if she's out of office, it always says that on her email reply. So, I know right away that she's out of office and won't be back till such and such a date. And if she is available, I hear back from her within 24 hours and sometimes the very same day. So, we are very lucky that way.*

The impact of the current system on families

The challenges families face in the current system caused participants emotional, financial, and logistical strain as they navigate MCFD and related ministries. Participants' stories about their involvement with MCFD conveyed frustration, stress, and isolation. They described an inconsistent and fragmented system of care with systemic gaps and inefficiencies leading to *"the majority of kiddos in the province [not] getting the services that they desperately need."* And they underscored the importance of trust and a caring, responsive relationship with workers.

"the majority of kiddos in the province are not getting the services that they desperately need."

In this section, we discuss participants' skepticism of MCFD's historical legacy as a ministry charged with the responsibility for child protection in the province; present participants' descriptions of some of the emotional impacts of the systemic challenges they confront; and finally, discuss participants' experiences and perceptions of the Family Connection Centres.

Historical legacy, surveillance, lack of trust

> *I feel like there should be a ministry of its own for children and youth and adults and families with support needs. To have that portfolio within MCFD alongside all the other portfolios and responsibilities, it's like [services for disabilities is] the last one that they think about when it's actually, it could have the most impact on some of the other ministries if they invested in that in the early years and in families.*

The historical child protection legacy of MCFD has had and continues to have a negative impact on families. For example, one mother stated,

> *[The lack of effectiveness is] also based on the fact that MCFD was originally a child protection organization and there's absolutely no match or that should be applied to any disabled child in our province to involve them.*

Another parent shared,

> *I also just really wish there was more understanding to the mistrust that people feel and it not be a defensive reaction... It's just the reality of, and I don't think that will ever really change when your organization involves the really horrible and difficult situation of removing children from unsafe situations.*

While not all families explicitly pointed to this historical legacy, it surfaced in nuanced ways. Some families stated that MCFD's focus on child protection, rather than on supportive and preventative family support for children and youth with support needs, contributes to burnout among parents, particularly in marginalized communities. While for other families, this legacy emerged in their descriptions of experiencing surveillance or feeling surveilled. One participant spoke to the vulnerability she experienced because of the fear of being surveilled:

> *It's very, very vulnerable to ask your social worker about these things because you don't know if your family's going to be flagged and investigated and all of that stuff. So, it's very vulnerable. And then when you do ask, and the answer is, "We got nothing." That hurts. That really hurts.*

Another participant shared,

> *And you get asked, "Why is your child behaving that way?" They misbehave themselves. And what does it ultimately lead to? A police car ride. I remember the night that [son's name] did that, tore apart the house. I mean we've been saying this to ourselves as well. We didn't want to go to the ministry. We were scared to death because we didn't know if someone was going to take our child away. Is the police officer going to handcuff a four-and-a-half-year-old kid?*

This fear, and truth, was particularly evident for Indigenous families due to the current and historical legacy of colonialism, child removals, cultural oppression, and systemic racism.

For example, one participant shared,

> *Especially as an Indigenous family, we don't normally go outside our family. We don't like to ask unless we absolutely have to. And sometimes it's a sense of security and safety and especially when you're dealing with MCFD, not just, ... you're always as an Indigenous parent worried that your child's going to be taken away from you or you're going to be labeled. That doesn't matter if you're a foster parent, you're still scared of that inside. You're scared that I'm going to be criticized for doing something wrong.*

Finally, participants described how excessive documentation and monitoring of their children and families cultivates a culture of surveillance that families fear could lead to punitive action towards them. Moreover, the fear of being labeled as neglectful discourages families from seeking the help they need, which then impacts the overall wellness of the child and their family. This leads to burnout and systemic costs.
One participant described,

> *So, I feel like that has to be, they need to sit up and take notice because burnout is a real thing. And I see it happen all the time. And that's my biggest fear. And what they don't realize is if you're burning out parents, that's more kids in the system. That's what ends up happening. You end up with voluntary care agreements, involuntary care agreements, all of those things. And a child in the foster system is going to cost you. I'll tell you right now, because I've done the math and I've looked at the money, and it costs the system three times more than just providing that little bit of extra funding directly to the child's family. And that's where that child should be because you're also doing a disservice when that child is not with the people who love them and care about them and want to support them, but just are burnt out and can't anymore because that child growing up in foster care or a group home is not going to get the same level of one-to-one care and support that the family can provide.*

...they need to sit up and take notice because burnout is a real thing. And I see it happen all the time.

Emotional impact of systemic challenges

Repeatedly, participants expressed and described frustration, distrust, feelings of isolation, and a lack of guidance. Families described a system that is *"broken"* and needing to be *"completely revamped."* Families described a system that lacks transparency where families are constantly having to fight for services and supports.

Families expressed feeling betrayed due to unmet expectations and broken promises. One parent articulated:

> *If you're going to make promises, you better keep them. And if you really want to remove barriers, then get out of your own way. Remove the barriers, make it so that families don't have to go through 67 steps to get something funded.*

While another parent shared,

> *Well, I think they can be more supportive on the whole, because we have encountered multiple social workers who come from a place of, it's not necessarily blaming the parents, but it feels like that where they're like, "This is your responsibility," and we have to justify why we need the supports that we do. And this has been not just one social worker, it's been multiple.*

Families also expressed feeling isolated and lacking guidance and support as they try to navigate complex systems to access services for their children. This has led to feelings of frustration and helplessness: *"Care for the family is really important. It can be very isolating at times and very frustrating as a parent."* Another participant shared,

> *I often feel like I'm reinventing the wheel a lot of times it just because there isn't a place to turn to, or I shouldn't say a person or a place, but there isn't somebody I could call up and just be like, "Oh, this is what I need to do, but I don't know how to do it." Or, "This is what happened, what do I do now?" And it's just kind of trial and error, I think. And that probably makes it even more isolating, and I think even more so when you're in a remote community.*

Isolation was highlighted as particularly prevalent in rural and underserved areas where access to supports and resources is extremely limited.

Finally, the emotional toll of navigating the systems to access assessments and diagnosis is profound. Parents and caregivers often feel unheard and misunderstood by service providers, which leads to frustration, and feelings of powerlessness and burnout. Many parents expressed a need for a system that recognizes their efforts and provides emotional support for the family and caregivers to help them cope with the challenges they face while advocating for their child. One particular point of contention was the need families felt to paint the *"worst picture of your child"* to qualify for supports. One parent explained,

> *You have to basically talk about your child in the worst way sometimes to get what you need. You have to talk about your child's absolute worst days to get what you need. And even that brings up such a huge amount of grief, reliving these really terrible times. And I think sometimes as a parent, you want to see some of the good stuff, but when you're constantly reminded to tell them about the awful things that you're going through as a family just to get funding for something, it feels awful.*

Family Connection Centres

When discussing their needs and desires for a future CYSN Framework, some families explicitly commented on the Family Connection Centres (FCCs). While there were some aspects of the FCCs that some families appreciated, overwhelmingly, participants in the research shared their concerns and lack of support for this direction in British Columbia. The three biggest concerns raised by participants was the "one-size-fits all" approach; the lack of flexibility and choice and control; and geographic disparities.

One-Size-Fits All

The "one-size-fits all" critique stems from families' recognition of the diversity of families needing CYSN supports and services and the unique needs of every child and youth and their families. Some families acknowledged that this may work for a particular kind of family, but that for many the "one-size-fits all" would not work as they do not always meet the criteria or misfit with what is being offered. For example, one family member described this mismatching this way:

People react to things, they have different past history, and you just cannot do a "one-size-fits all" program.

> *The more you limit people into "Your problem must look exactly like this, and the solution must look exactly like that," the more likely you are to injure people with whatever it is you're doing, you'll miss out the ones who don't look exactly like what you're looking for. And if you're wrong about what the right solution is or if it just doesn't fit that specific person that you're talking to, because everybody's different. People learn differently. People react to things, they have different past history, and you just cannot do a "one-size-fits all" program.*

Another participant similarly shared:

> *If I look at it from a perspective of a functional family with a kid with lower needs, but they're still on the spectrum and whatnot, I think that that's where MCFD gravitates to with their vision. And so, the reason I say that is because a high needs family needs a lot more support. So, I would urge them to look at that globally or even case by case because when they were going into that hub model or whatever, it seemed promising, but also concerning to those high needs families of would they get more support or would it be the same across the board?*

Lack of Flexibility and Choice and Control

As will be discussed in a subsequent section, flexibility and choice and control were central to what families want throughout the data. This was also loudly communicated with respect to the FCCs. For example, a mother described how important flexibility, and choice and control are to her family and concerns about how the FCCs might limit this:

> *We were diagnosed in January and only now in August, so 11 months later do I feel like we have the right team for him. And through that journey we have tried multiple types of providers, specific providers, one's funded through AFU funding, one's funded privately, as well as the publicly available services. And we have required all of that flexibility in order to find the right team for him. And he has begun to flourish and it's wonderful. When I see characteristics of some of these new models that are being proposed and piloted, I'm worried that flexibility might fade.*

Finally, participants expressed concerns that FCCs will exacerbate geographic disparities in the province. For example, one parent shared,

> *The same system cannot be put in place for Vancouver as it is for Fort St. John. They need to understand that it's not a one-size-fits-all. It has to be designed, redesigned for all these different communities, and it's got to be a lot more interactive.*

Another participant explained, *"I think when I heard about the centralized support locations, I felt a sense of panic because number one, we can't access things if they were actually in a physical location."* Another family member described both the geographic challenges and promoted the principle of choice of services:

> *Everything has to be for their needs, not just what's going to be convenient to have at one center or one location, which I know there's some people who are in favor of only having to go to one place because it's really hard to find things in their area. That is also a huge challenge. I live in the lower mainland, so obviously there's a lot more choice here, but maybe they could do a mix of both. Maybe you could have some hubs for people that want to do that, that don't really have any other options anyway.*

What Families and Individuals Want

The overall findings of this research highlight the significant and multifaceted challenges that families face navigating CYSN services and supports for their children with disabilities. Some of the issues include inequitable access to assessment processes, strict diagnosis criteria that often exclude children with conditions like FASD, and stigma and misinformation that surround disabilities. Families described often experiencing extensive wait times and waitlists, systemic inefficiencies, and a fragmented system of support services. The findings highlight a strong need for consistency and continuity of care to ensure that families have culturally safe, stable, secure, and long-term support services.

Central to these challenges is the need for a more holistic, inclusive, and familycentered approach to service provision that acknowledges the emotional, financial, and logistical strains that are placed on families. Empowering parents and caregivers through advocacy and resources, and through fostering a more flexible, needs-based system are crucial for creating an equitable, responsive system of support. With a focus on addressing the complex needs of both the children and their families, these findings support the need for comprehensive systemic reform in how CYSN services and supports are structured. The results presented here fall under two overarching themes: the importance of investing in families and the need for structural change.

We're not going away. We're only getting angrier and more upset. And when that happens, there can be no open communication anymore.

Invest in families

The was a clear message throughout the data highlighting the need for the Ministry to invest in families. Participants emphasized the need for a family-centred approach that recognizes the diversity of families and their unique contexts and needs; the need to improve choice and control for families; the importance of clear communication; and the need to adequately fund services and supports for families.

Adopt and implement a family-centred approach

> *I think that support needs to focus on family in a much bigger way. Right now, support is focused on the youth or the child and the family can get access to things like respite.*

Repeatedly, participants discussed the importance of a family-centred approach. Parents experience incredible stress as they navigate complex systems, while managing the care of their child(ren) and family. The challenges families face affect not only the child but the entirety of the family unit. There is a strong call for more family-centred care that includes support for parents, caregivers (including extended family such as grandparents), and siblings.

Families described how the realities of caring for their loved ones with support needs has a significant impact on the whole family, including siblings, and it is important that social workers, and other professionals involved with the family, are aware of these needs in a more holistic way. Working with families cannot be about "checking a box." It must be about listening and supporting the family in accessing the services and supports that fit with their family's unique needs. One participant stated, *"Listen to the parents. I know that there's money involved, but you know what? If you actually listen and support the family, then it's way cheaper from the beginning than having the family fall apart."* While another parent shared,

> *They need to learn how to work together and stop looking at the money and start looking at the families, because government isn't a business. It's government, and it's supposed to be there for the people that it serves… Right now, it's not.*

And another parent, who is Indigenous shared,

> *A lot of families are coming to the table with some of these things on their mind and on their heart. I feel like it's important for the social workers to realize they almost need to work extra hard to make sure they're coming across warm, accepting, and nonjudgmental, and making it really clear they are there to help.*

Related to a family-centred approach, participants highlighted the importance of mental health supports for the whole family to avoid burnout. Participants cautioned that extended services should be mindful of caregiver burnout (and the need for self-care) describing that many parents and families are in survival mode. This is especially important as not all families have extended family to support the day-to-day experiences. One participant shared:

> *Where is the mental health support for the parents? Where is the health support? "Hey, join this group to get your steps in because these are the things that get dropped off." We forget to eat, we forget to do our stretching and our health suffers, and then we don't have as much to give to our child that is so dependent on us every minute of every day. And then on top of that, we have to remember who did I talk to on the phone yesterday and what did they tell me I was supposed to do? It's so overwhelming.*

Another participant described:

> *It is a mental health drain. It is a financial drain. And if there are other siblings, they need time with their parents, they need support, they need their own mental health support and those things. The whole mental health piece, the whole child and youth with mental health piece is really, really non-existent. And it's been one of my biggest ongoing frustrations is that my youth gets support. I don't get support, her sibling doesn't get support, my husband does not get support. And because of that we're burnt out.*

Further, a family-centered approach must include policies and practices that recognize the evolving and changing needs of families. For example, one mother shared,

> *That ties in with choice because it's not, when my daughter was 8, she needed to work with a physiotherapist, but she was not ready to work with a counsellor. Whereas now that she's 17, she has different needs, and she needs a diversity of practitioners that she can rely on. She doesn't just need a behaviour consultant now. She needs a counsellor.*

Participants advocated for allowing flexibility in how and when families access and use support. For example, participants described the value and importance of allowing families to pause services as needed and not lose access to these services.

> *[The] social worker said, "Let me know when you need them." And then, there's that comfort. It's almost like a blanket to know that these things are there. You're not going to have to fight for them. You're not going to have to wait a year and a half or an application to be approved. Somebody told you they exist, they're there when you need them and you can say, "It's going to be okay. I have this when I need it..." that security to lift you out of that survival mode. And people flourish when they have security. And when you're a caregiver, there's not a lot of security. There's enough uncertainty.*

Another participant described:

> *And then they're like, "Okay, you've had three strikes. You've missed three appointments. Come back next time when you are ready for services." And then if they've done that twice, then they're cut from their services forever. "You've had two chances. You blew both of them. You've got three strikes."*

Some families described needing a break to do other things or situations where there are changes in the family making it hard for them to access all the services at times. However, families were hesitant to miss or pause accessing services and supports because of concerns that they would be deemed not in need of the services. Families are in the best position to assess this.

**It is a mental health drain.
It is a financial drain.**

A family-centered approach also necessitates acknowledging the diversity of families – e.g., ethnic and cultural diversity, including Indigenous families; linguistic diversity; socioeconomic diversity; gender diversity to name some. For example, there must be greater consideration to the reality that there are parents also living with disability, which may be invisible and adds another layer to the situation. One participant described:

> *And, in my situation, I have an extra thing that plays a part because I also have MS. So, then I have extra health concerns that if I don't attend to that can cause really significant challenges to my support of my son.*

There needs to be a broad representation of services available in multiple languages for all families regardless of ethnic or linguistic backgrounds. One participant noted, *"It is important] to stop putting families into neat little boxes and making assumptions about what they need."*

For Indigenous families, participants underscored the importance of cultural knowledge, acknowledgement of cultural values for supporting their child, and the need to acknowledge their ancestral and Nation-based affiliations. Families were clear that culturally safe opportunities for children, youth, and families and addressing on and off reserve realities are paramount. Participants acknowledged that it is imperative for social workers to have the appropriate training to understand the generational trauma that may be impacting Indigenous families. There were several examples in the data of extended family or community members engaging and caring for the children and youth with support needs as the primary caregiver: these may be aunties or grandparents. The families recognized that equity is important to support efforts of self-determination amongst families.

> *It's that children exist within families and children exist within communities. And if you're not supporting the family, if you're not supporting the community, if you're not supporting the culture that that child is living in, then you're not supporting that child. If you're not supporting the mental health needs of siblings and parents, then you're not supporting the child. If you're not supporting the respite needs by actually providing respite services and not just money, when services can't be found, then you're not supporting the family and you're not supporting the child. If you can't help organizations in the community actually build capacity to provide adequate services and supports, then you're not supporting the child because that's what's going on in my community. The supports and services, while they might exist, the wait lists are so long that many children can't access them.*

MCFD must work with families to ensure that everything is "really family-centred," and these principles should inform the solution of providing diligent care in ways that people want to receive it.

Ensure choice and control for families

One considerable theme woven throughout the participant responses was the overarching desire for choice and control when it comes to the services and supports families receive.

> *…freedom of choice is really [important]… the ability to choose which practitioners we want to work with [including] not just the field of the practitioner, but also the specific practitioner… [it is critical] it's the right personality skillset fit… As a family, being able to have some freedom of choice I think is really important.*

This theme of choice and control again rests on the diversity of families' needs and desires. Families described how choice and control allowed them to access services that worked for their family's unique needs. For example, one parent shared, *"So, allowing for families to help in the identification of what the goals are, what the services are that would actually be helpful, and then maybe continued allowance of families to have some freedom with how to use funding."* Thus, families spoke about the importance of having a choice of services and therapies, and who provides those services and therapies. For example, one participant explained:

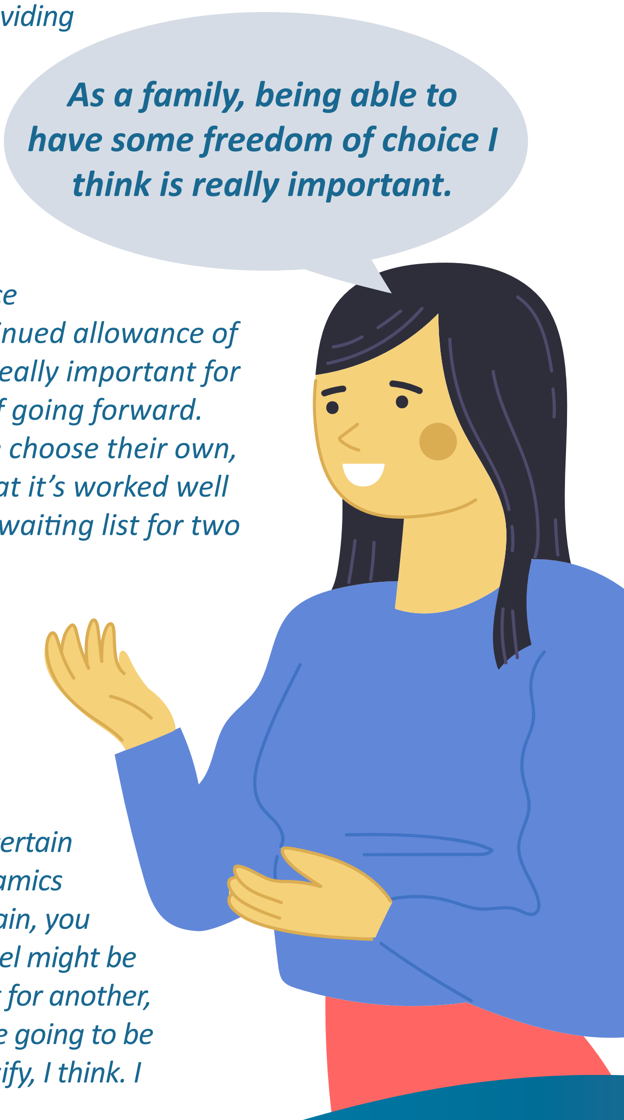
> *You just can't do a one-size-fits-all program. And that's why just providing the money, universal basic income type of thing, autism funding, at home program, the fewer loops you have to go through, the easier it will be to access. And then families will have the ability to use it in the way that benefits their children the most.*

Another participant offered,

> *And so, if I was thinking about what would need to be in a service model that would be accessible to us, I think first of all, the continued allowance of having families pick the service providers that work for them is really important for us... provide flexibility and options more than prescribed ways of going forward. Instead of paying your counsellors to sit in your office, let people choose their own, give recommendations or something. Maybe, "This is a place that it's worked well for people and we'll pay for it." But not go ahead and go on our waiting list for two years for six sessions.*

Families also spoke of choice in regard to individualized funding. They described how individualized funding facilitates choice and control; that said, families also emphasized the importance for families to still have other options if that is what works for them. One participant shared:

> *So, I think you need to look at offerings that meet the needs of the greatest variety of families… And it can't just be one program or a certain format. It just can't, because that's not how families work. The dynamics are different. They have very different needs. And I sort of think, again, you have to have diverse offerings, and sometimes that star bright model might be perfect for a number of families, whereas ARC is going to be perfect for another, and the FCC, the offerings they have and programs and referrals are going to be perfect for other children and families. So, you have to sort of diversify, I think. I don't think that you can kind of put all your eggs in one basket.*



Ensure clear communication

Families and individuals with lived experience expressed the need for and their desire for reciprocal lines of communication and transparency about what kinds of supports and services are available: clear communication from the Ministry as well as mechanisms to ensure their voices are heard and considered.

> *I just think they need to listen. They don't do a lot of listening. They do a lot of talking and that's great... I feel like you're all in your offices and you're listening to us over the phone or via emails or whatever to all our suggestions and, "Yeah, okay, whatever. And we'll take it into consideration." But you're not living it. They're not in the day-to-day grind. So, I feel like they actually really need to listen. They need to take the time to see what a day is like for a parent with a child with special needs and then maybe that might help them clue in a little bit more.*

With respect to clear communication from the Ministry, participants shared many stories of miscommunication that led to the professionals and family members not being on the same page.

> *I was asked when moving my son to a new school, "Does he have a CYSN worker?" And I'm going, "Not that I know of," and she said, "Well, he's supposed to have one." And I'm going, "Oh, well, I don't know about that." Nobody said anything about it. I've been dealing with social services now since he was two and a half years old, and I've adopted him now, but I have friends that are still dealing with them and social services leaves everybody out of the loop when we've got special needs kids, they don't tell us what we can do, what we can access, what we can't, and we're sort of just trying to do it with minimal resources to get these kids help.*

In addition, families want transparency about the data collected about their families in the reporting systems. Families expressed how MCFD has so much information about them, and about what is needed, but they don't see that information shared. One participant asked for *"more openness. I mean, they don't tell you anything."* Another parent shared,

> *Without that communication piece, it's hard for those other needs to be built and to get the resources and the support you need. Very, very rarely would I get an email saying, "Hey, we're just checking in to see how you guys are doing?"*

Some younger families underscored the importance of social workers using plain language to help them navigate the system better. One mother stated,

> *I've heard a lot of acronyms and a lot of different mechanisms for that. Talked about leads by these other folks. I am steeped in it, but ignorantly steeped in it. I don't know what any of them mean or what they are, and I don't think they are yet applicable to me.*

Frequently, families spoke about the challenges of timely communication with their social worker. When explaining the frustration this causes, one participant suggested that a toll-free number for family support for CYSN – "like a 411 number" – would be helpful. Moreover, families described the importance of being able to provide feedback to MCFD about the services and supports they are receiving or not receiving. One parent described,

> *Just like your MLA, I should be able to walk in just like I can to my MLA's office, book an appointment and sit down with my MLA and express my concerns; that should be happening with MCFD. They should not be on a pedestal where people who they're serving, they can't be reached. That's not okay. And your only point of contact is your CYSN social worker. And that's wonderful. They're wonderful people, but they're not in charge of change and they can't make executive decisions on funding. They can't make executive decisions on if a family needs more support, it has to be pushed to the higher ups. But we don't get to plead our case to them. We don't have any access to those people. And that's definitely important. They need to provide that.*

As a result, greater communication with families is desired. One participant noted they have only heard from their social worker once in 10 years. Other participants believe more opportunities for focus groups or surveys with formalized feedback methods will help ensure there is transparency for families, data availability, and being able to voice their concerns without feeling as though some of the efforts offered to families are merely "lip service." Families want to share their experiences, and the opportunities and challenges that their children and youth face, especially the long-term consequences of not addressing the mental health crisis since families feel frustrated when not being heard.

It's almost a full-time job, seriously filling out the forms, contacting the social worker, contacting everybody, organizing appointments, managing the budgets.

> *And I would find it so helpful if the social workers could send out a yearly update as to all the services that are out there. Like I said, I'm a pretty savvy parent. I don't work for money outside of the home because I can't. I have to stay flexible for [child's name] and for the other kids. So that means that I spend a huge amount of time managing all her stuff. It's almost a full-time job, seriously filling out the forms, contacting the social worker, contacting everybody, organizing appointments, managing the budgets.*

Participants had some pragmatic recommendations. They encouraged service providers to ensure there is appropriate medical related literacy supports available to families that need to access services so a *"seed of knowledge"* can be planted for families to know how to best support their children, youth, and families entirely. Others suggested, making a handbook available for families to understand what may be available and how to access the services. This knowledge about what is available and how to access without having to struggle *"jumping through hoops"* is critical.

Finally, as described above, participants strongly articulated a need for improved communication. In addition to the views described above, participants highlighted the need for a formal and structural feedback mechanism. For example, one suggestion was for a working group of family representatives that could inform services:

> *Like I said, if you ever did get a working group going, I would definitely be interested to sit on it. Even as [child's name] is aging out, I think I could be valuable, right? Because I've been through the whole way through and we're starting our next adventure.*

Similarly, another parent described, *"I really, really still think that a working group would be helpful. So, you've got parents, you've got social workers, you've got the directors, whatever, they're listening, right?"*

Address funding needs and concerns

Financial burdens are a consistent concern for many families. Participants described how having to pay out-of-pocket for assessments, therapies, and interventions not covered by insurance or public funding causes financial hardships. The financial strain is compounded by administrative inefficiencies, which further exacerbate the stress on families. The allocation of resources is often seen as inequitable with families struggling to secure support for their child's needs.

Three specific common desires for funding were expressed: wanting the Ministry to continue and increase autism funding while ensuring choice for families with different needs and preferences; improve the flexibility of that funding; and make funding for supports and services, such as the autism funding, more inclusive to families who are not eligible due to a specific diagnosis (e.g., FASD, ADHD).

Families underscored the financial hardships and increased costs associated with supporting their child/youth with support needs, and they want the Ministry to increase the funding available. For example, one parent shared,

> *Funding is just so behind the times. I don't know everything has gone up, right? We're in a recession, people, I mean you can say we're not, but we are in a situation now where our service providers that we do have, or people we do fund, have exponentially, their fees jumped so high and in the whole time that we've had respite funds or autism funding funds or any of that stuff that's from CYMH*

> *and MCFD has not changed. The autism funding has remained at $6,000 since enactment. It has not changed. And so how do they expect us to maintain the level of care and support that our children need with the same amount of money from year to year?*

Repeatedly, participants underscored their desire for the Ministry to maintain and improve the current individualized funding for Autism and to broaden the funding for families whose children have other diagnoses and do not qualify. As one family member stated,

> *When I look at how the adult world goes and how you can get individualized funding, you can get the funding yourself and manage it and hire, and you have a micro board. Those things should be in the children's world so that it's not such a big change when you get to the adult world.*
>
> *They have figured out some good systems and have managed well, certainly in individualized funding. And that could be modeled in the children's world for families, so that you just carry on.*

...so how do they expect us to maintain the level of care and support that our children need with the same amount of money from year to year?

Another family member cautioned,

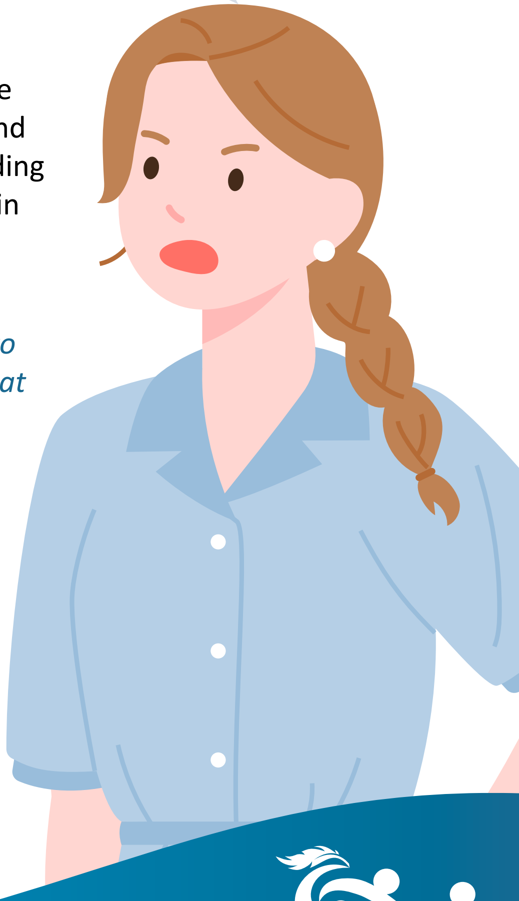
> *Going back to that portion for you with the $6,000, if you've got autism, so yes, I know that not everybody has it and that's not right, but I know they're wanting a new system. I know they're wanting to take it away. And truthfully, that would be detrimental because then it would be, so they say needs-based, but I know what needs-based is like, and whoever is louder gets the support.*

Requests for increased flexibility of individualized funding included increasing the amounts available to families, increase the ability to direct bill for services, expand the types of supports and services that the funding can pay for, and provide funding to families when they need it and need to access it quickly (e.g.., when they are in crisis). For example, one family member expressed,

> *We're a single income family. I'm on disability. So, I just don't have the financial means to be able to afford it. So that's huge. I think they need to really take a look at the funding that they provide families and realize that it is incredibly out of touch with how much services are nowadays.*

While another parent expressed that "flexibility" should include being able to use the individualized funding to attend to the whole family's needs. They stated,

> *Autism is an individual issue, but it's also a family issue. It affects every single person in the household. So yeah, the idea of funding, not necessarily being allocated to one specific child, but to the family, and that should be monitored to some degree so that the family's not taking it and doing all these things and leaving that child behind, but that it's being used to support everyone in the family.*



With respect to increased access to direct billing, families spoke of the burden of having to pay out-of-pocket for assessments, therapies, and interventions not covered by insurance or public funding. Waiting for reimbursement for equipment, services, and other assistance is a burden and discouraging. One mother explained,

> *What do people do if they have no credit to order things ... and to have [the funding] sit there for months on end and just not being able to access those fundings... I usually purchase my own children's stuff and get reimbursed from autism, but I know there's 9 out of 10 people can't do that. And what does that look like? Do they never get to purchase their things unless they find an organization or agency or some sort of support place that will do that and help them to do that upfront, that cost and then get reimbursed or whatever.*

Another parent described, *"It's ridiculous how long it takes to get anything approved, how long it takes to get payment back. It's just so many hoops to jump through. It takes them too long to reimburse people. They're super nitpicky."* And, families commented on the value of increasing the types of services that can be used with individualized funding. For example, one parent described the therapeutic value of supports such as recreation services and social activities (e.g., private swimming lessons, horseback riding, etc.).

Finally, participants encouraged the Ministry to include the flexibility to assist families with funding when they are experiencing a crisis. For example, one participant described, *"It feels like there's nobody there to help you when you're in crisis… So [it] was disappointing that there doesn't seem to be anything there when parents actually need a fast turnaround."* Another parent described:

> *Where's the master list that says what people can get access to tightly held secrets. And so finally when we were in crisis about a year and a half ago because my daughter developed sudden and severe mental health problems and had to be hospitalized, you feel like you're asking for the moon because you don't know what you can actually ask for. And if you don't ask, you certainly never get it. But they'll never volunteer what they can do.*

Implement Systemic and Structural Changes

Within the systemic change, participants underscored the need for more/better trained and knowledgeable CYSN workers and allied professionals with realistic caseloads (for example, social workers, speech language and occupational therapists, behaviour interventionists); the need for timely and improved assessment procedures and early intervention; the importance of interministerial cooperation; the need for navigators to support families navigate the system(s); the need to improve the transition to adult services; and the importance to address systemic racism and oppression experienced by families from equity deserving groups, including, the need for culturally safe and appropriate services.

• Invest in the human resources for CYSN – both within the Ministry and the allied professionals

As mentioned previously, participants described experiencing inconsistent and fragmented services and expressed their frustration with a lack of continuity of care. Participants highlighted that one contributing factor to this relates to challenges in human resources. In fact, the need to address shortcomings in human resources for CYSN was a significant topic for participants. Specific concerns were raised about CYSN social workers as well as the need for well-trained allied professionals in all areas of the province.

With respect to CYSN social workers, participants discussed the need for consistent quality relationships with the same worker, the need to reduce caseloads, the need to improve the education and training of social workers, and the need to increase the diversity of the workforce and invest in recruiting and training professionals to meet the needs of rural and remote communities.

Repeatedly, participants described having multiple social workers. This reality of changing workers creates a disruption in care and support and negatively impacts the family's relationship with the workers. Parents clearly emphasized the importance of having consistent relationships with CYSN workers who understand the unique needs of their children with disabilities. For example, one family member shared,

> *Also, consistency in providers instead of it switching. But I think the main thing that our family needs, the new system is just not feeling like we need to beg, scrape, and plead for what we need, that we're believed that we're heard and that we're not excluded due to our son's diagnosis.*

Another parent described,

> *So, when we finally got the autism diagnosis and were accepted by CYSN, we had a fantastic CYSN social worker. She provided, she filled out paperwork with us, told us what to do. She was fantastic. Unfortunately, she's moved on and we have a new social worker who's nice, but he's not proactive. So, I had one social worker in 10 years and then I had 2, 3, 4, 5 different social workers. That's what my current social worker is like. I don't go to him because he's not, I have a social worker in the family service side and I go to her because she's actually proactive. And for CYSN, I go to the supervisor.*

These changes in workers are disruptive to families: *"And every time that we restart, we spend the entire appointment about stuff to educate them, and then the last five minutes, they're like, 'Oh, try this.'"* The same parent stated,

> *And we do have a social worker, we have had five of them in the last five years. Frequently, they'll change and we don't even know the name of the person or they'll send a letter saying, my card's enclosed, it has my contact info. There's no card in the letter. That person is not, they're clearly overwhelmed. They're overburdened with all of the different things.*

Similarly, one parent expressed: *"The parent has to repeat the story 14,000,000 times to 14,000,000 different people. And it's wearing and it's debilitating to the spirit, you know, like, come on, people."*

Participants described how these changes exposed inconsistencies in approaches across offices and workers. For example, one mother shared,

> *I started out with the ministry in [name of city]. So, I was living in [city] at the time with my daughter. So, it was one CYSN social worker there; came with one tool belt of not just bedside manner, but also tools in the kit. When I came to [new city], totally different... I was so floored by this move that I had to start from scratch. "We're not in Kansas anymore." I'm like, "What happened here? Why am I getting such different information?" ... There was a lack of consistency and coherency moving from one town to the next.*

In addition to the high turnover of workers, families spoke about the lack of contact with their workers, which has a negative impact on the families' experiences and their access to supports and services: *"Figure this out. We can't do a squeaky wheel in order to be heard, in order for a social worker who cares to be assigned to your case."* Many participants described lack of contact with their social worker.

> *I'm not going to hear from her until maybe I have a huge issue that I don't know what to do with or until my child is older. So, I don't really feel supported per se. I know that I will have to reach out, and I know I'm not getting any, I haven't received any new information.*

Some families acknowledged the effects that high caseloads have on the social workers' abilities to connect with families:

> *The lack of social worker time. Their caseloads are too big, and they don't return calls one or two times. You have to call them until you've really got any kind of relationship with them... but also smaller caseloads. Someone said they should pay social workers more for what they're worth, and that could be as true as well.*

Another family member described,

> *Your social worker is a key person to help you navigate. When I finally was able to speak with my social worker, it was immensely helpful, but it took her probably a month to respond to me. At the beginning, she was just so overloaded.*

The high caseloads and turnover of social workers is detrimental to families' experiences and the importance of establishing a trusting, collaborative relationship with their social workers. As one family member described:

> *Well, I think we need social workers who actually have time to do their work. I mean, we never hear from our social worker ever. I've met with her once in 10 years, I think maybe twice. So, I'm always the one that emails her and says, "This is what we need. Can you provide it?" And the answer is pretty much usually, "No, we don't do anything like this." But the answer is never, "No, we don't provide this, but how about this? We do provide this." So, they're like the gatekeepers to the whole system, it feels like. But yet I pretty much have no relationship with our social worker at all, which reminds me I'm due to send her another, "Hey, how's it going? Anything out there? This is where we're at." Yeah. So, I think the whole social worker thing is just ridiculous.*

• Address the need for training and education

Across the interviews, participants questioned the qualifications and training of CYSN workers and underscored the importance of social workers and the allied professionals working with their children being educated about disability and traumainformed care. Participants described that this lack of training led to unqualified workers negatively impacting the family-worker relationship and the quality of support families received: *"I had to beg for a different social worker. She was horrible. She was inexperienced, she was young, she needed a lot more support and a lot more guidance of how to be a social worker."* Another parent expressed:

> *Let's stop calling people who aren't social workers, social workers, okay. Because that is, you can't bring a college complaint against an individual and you have a false trust ... and I know that everyone also has a little bit of a different background in social work, but that kind of critical social theory like feminism, all that. But they have lit degrees, English lit degrees, how are they supporting kids and families too? And how are they supporting society in the long term when they know about Beowulf? So, let's get some qualified people and positions. Let's have some checks and some balances.*

Similarly, one parent stated, *"Social worker education is crucial."*

With respect to the kinds of education social workers need, participants stressed that education related to disability and working with families is crucial: *"I think just better informed, qualified people that work with the children and youth with disabilities and more support in this."* Parents can encounter social discomfort and exclusion due to a lack of understanding about disabilities. There is a clear call for better training for service providers across the sectors within healthcare, education, social services to ensure they understand the specific needs of children with disabilities and their families. The absence of understanding and disability knowledge exacerbates the difficulties that families face, which can lead to poor outcomes for children with disabilities:

> *It's the lack of knowledge of what disabilities are, number one. It's that negativity of that deficit-based language. What you don't have, not how amazing you could be. If I just look at me as that example, I often interrupt, no kidding, no shit, Sherlock. But if I rephrase that to say he's really passionate about topic X, Y, Z, and it's not because he's a subject matter expert or something like that. ... But look at it like that because that is how someone may very well look at a disability. So that lack of awareness, that lack of knowledge, and the lack of manpower in people, and I think a lot of the money gets sucked into these really stupid administrative tasks.*

The lack of understanding and training in disability studies results in stigma and misinformation surrounding certain conditions and can prevent families from accessing appropriate services. Some families with children and youth with FASD particularly emphasized the effects of stigma and lack of understanding: *"children that likely do have FASD, are getting diagnosed with something else because again, of the stigma attached to FASD. So yeah, it's just, there has to be a change."* Another participant shared,

> *The total exclusion of FASD from literally everything for the entire age groups into adulthood and nothing. It was just sort of a blip. And it was done because people are so uncomfortable to have that conversation. And there is so much misinformation and stigma out there about it, and that is our barrier to moving forward at all. And it's really harm. It is causing so much harm to our families.*

Finally, participants underscored the need to recruit and train diverse CYSN workers and allied professionals. Participants described how more diversity of workers and professionals can create a positive environment for families. For example, one family member shared:

> *But sometimes it's really helpful to have providers that have more diversity, maybe providers that are neurodivergent or I know somebody who's doing her social worker training and she's autistic. Fantastic. This is what we need. We need more diversity among providers and services that are out there.*

And, some participants suggested strategic initiatives to increase the workforce, which can also help address shortages of qualified professionals in rural and remote areas: *"Can there be incentives for, they're doing that for ECE, they've done that for ECE, so did they do that? I think for some other professions. So, let's think about those educational incentives to help fill those gaps."*

• Address problems with assessment and improve early intervention

Across interviews, participants spoke of problems with assessment and the need to improve early intervention. With respect to assessments, family members described long wait lists, challenges in getting a diagnosis, and inequitable access to CSYN based on strict diagnostic edibility criteria. For example, one parent described:

> *It’s wild. And I tell people, it’s not that I don’t think that children without diagnosis should have support because my son went an incredibly long time without being diagnosed with autism. We knew at 18 months, and we had to fight until he was nine and things had to get extremely bad before he was diagnosed. I mean, he had to be hospitalized in psychiatric services at a very young age, multiple times for anyone to take notice. So, we missed out on a lot of early intervention funding. When we got this funding, we thought, “Okay, finally we’re going to be able to do some catch up.” But we’re like, “This isn’t enough for us.” And they’re like, “Oh, well the school district gets a bunch. They can help you.” Then when I found out about the system, I was like, “Okay, that’s great,” but I fought so hard to get him that funding.*

Similarly, another parent expressed, *“I watched my kid go without an awful lot of services and supports because she wasn’t considered critical enough or disruptive enough, and now she’s aging into a service that I know for a fact is substandard.”*

Related to challenges in getting a recognized diagnosis, participants spoke of the need for more equitable access to services, highlighting the challenges of a system that relies on diagnoses for eligibility of services. Families reported being denied support or funding because their child’s condition(s) was not recognized or prioritized the same way as ASD:

...unless she gets an autism diagnosis, I don’t get a social worker to help me even though [we have] a full hand of diagnoses right now.

> *...around equity. My other daughter has Down syndrome and I know she’s going to have significant needs not just in childhood but beyond. And somehow my son is better resourced for his needs because of his specific diagnosis, and she doesn’t have the same opportunities as far as the public system is concerned. So, I think the model of AFU funding is a good one, but it does need to be expanded to include others.*

Similarly, another family member shared

> *And I think that’s been a hard one for my family is my daughter has multiple disabilities, and we’re told I don’t have access to a social worker. None of her diagnoses qualify for that. So, unless she gets an autism diagnosis, I don’t get a social worker to help me even though [we have] a full hand of diagnoses right now.*

Interestingly, families who were eligible for CYSN and receiving support also recognized this inequity. For example,

> *It’s really difficult. It’s really difficult because I know somebody who’s got a kid with Down Syndrome, and then I feel like crap because we get access to autism funding, and they don’t. So, I don’t know what to say. We just have a ridiculously high number of kids that need support, and I don’t know what the best way of doing that*

> *is. I just know that nothing works without parents and there should be nothing out there. I'm stumbling on the expression. Nothing for us without us.*

Families described wanting a more flexible, needs-based approach to CYSN that does not exclude families based on diagnostic labels. One participant described,

> *I think that a needs-based approach is really what we'd be looking for. Our kiddo is complex and doesn't necessarily fit in all of the boxes that an assessment might show us. And without some sort of label, we don't get access to services that professionals are recommending to us.*

While another family member added, *"I would concur quite strongly with that, that I think that sticking with a medical model and trying to fit everyone in that box is not meeting the needs of everyone."*

Finally, these challenges with assessment underscore the importance of early intervention and participants clearly made these connections as they shared their experiences. For example, on parent shared, *"So, he has acquired secondary diagnosis due to the fact that he was unable to receive the consistent interventions he needed from a young age going forward."* While two other parents shared,

> *And as we know, the brain develops the most in the first seven years of a child's life. So, get them the supports they need as early as possible as well as the family because [it's] a huge shift in your life and potentially your expectations of what parenthood would be like when you're gifted with a child that has extra support needs.*
>
> *I can't make my child wait three years. Three years. And my child would've been close to tween age by that time. And it's like by that time, we've missed three years of anything we could have possibly, possibly have done to help her. And so, we were like, "No, we're just going to pay out of pocket." So, then we just waited maybe five months, four months, something like that.*

And, finally a family member commented,

> *Despite the diagnosis, whether it's ADH or not, ADHD, complex behavior, down syndrome, FASD, really any child that is presenting with additional support needs could benefit from those early intervention dollars in addition to the other professionals involved in their life.*

• Improve inter-ministerial collaboration and cohesion of services

> *Everything is so compartmentalized. But if they were able to leave the systems together so that at least they talked to each other, then potentially we could get better supports in place all around for children it would be so much better.*

Participants highlighted the complex and interconnected systems that they navigate, and they strongly advised of the need for interministerial collaboration and a cohesion of services across ministries. Families want MCFD to work with other ministries (Education, Health, Social Development and Poverty Reduction, Mental Health and Addictions) to ease the transition between services that they require to meet their family's needs and to support their family member's well-being.

Families described a lack of cohesion and lack of communication between ministries. For example, one parent emphasized,

> *[there needs to be a] cohesion of services… it feels like everything's very disjointed… I wish that there was a system that if we give consent, the school could be looped in automatically and the physician could be looped in automatically and everyone could be part of a team group of services instead of putting the onus on the family to follow up and make sure that they got what they need.*

While another parent underscored the lack of communication between ministries and the resulting burden on parents to ensure this communication happens. She shared:

> *My daughter was hospitalized twice about a year and a half ago because she developed bipolar disorder. And it was like there was no flag that was sent to her social worker about this. I'm not sure she even knew about it until I informed her that this was going on, but I never really got the impression that she knew what was going on. So, I don't know if there's any formal system in place for keeping social workers informed other than parents reporting. I'm not sure, but I kind of would've hoped for some kind of a welcome to bipolar package or something.*

...if they were able to leave the systems together so that at least they talked to each other, then potentially we could get better supports in place...

With respect to interministerial cooperation, many family members communicated the challenges of the transition time from MCFD to the Ministry of Education and the shift in focus on services and supports:

> *And one of the biggest challenges that we faced was when my child went into school and hit the age of six, the funding paradigm shifted and the focus of therapy shifted to in school. And the school districts aren't supported in the same way because it's a different ministry. It's no longer MCFD, it's the Ministry of Education. And because of that, it became a lot more difficult to provide consistency and therapeutic approach, and we lost a lot of ground because of that. So, I think what I would like to see is that continuity of not even just funding, although it would be nice, but allowing families to stay with the therapists that they're working with and not have to worry about funding it independently to be able to ensure that kind of consistency of improvement and of support.*

The siloed reality of Ministry responsibilities was a clear point of contention for families.

> *[I] would really like to see better integration of service between the ministries, between the Ministry of Health and the Ministry of Children and Families between those ministries and the Ministry of Education because a child goes through all of those ministries to get appropriate service, and those ministries don't communicate with each other.*

Another family member described their frustration as follows:

> *That's one of my biggest frustrations is the buck passing between the ministries. Ministry of Health will take things this far and then it's like, "Oh, well, you've walked out the door. It's your problem now." And then the Ministry of Education will take things this far, "Oh, well, it's only between nine to three." And then MCFD is like, "Oh, well, the Ministry of Education is supposed to pay for their school age support." I'm like, "Really? Because that doesn't happen!" It doesn't happen. So why are you still saying that? And it really, they need to learn how to work together.*

Finally, some families also highlighted the challenges navigating the provincial and federal disability supports and suggested a more streamlined process to ease the burden on families. One parent shared:

> *Make it easy, make it automatic. If you're doing your tax forms and you have, I don't know, obviously you probably need a diagnosis at some point, but if you can say on your tax form, "Hey, I have a kid with a diagnosis," and they automatically give you support, that would be fantastic. And none of this going back over and over for one more diagnosis and one more set of forms and oh, you're already diagnosed, but now you have to fill out a different set of forms to get money to support your family. And the whole cross section of disability and poverty is really intense.*

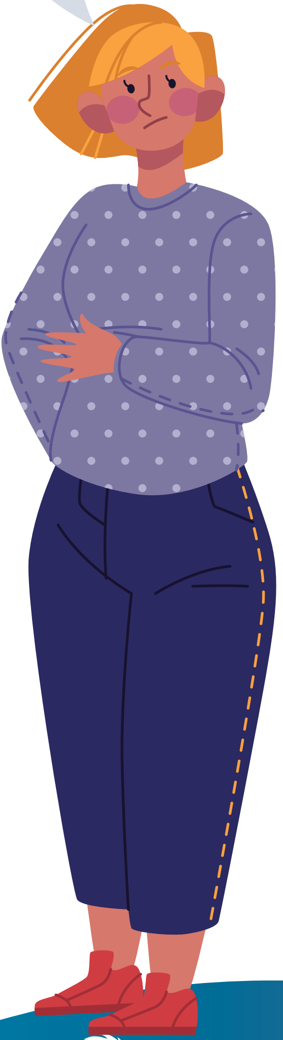
- Create a navigator/advocate role to help families

> *There to be some way to realize that when families get to those really hard points, and I think it's not just us that gets to those hard points, especially if there's dual diagnosis or there's support needs. Things get challenging sometimes for them to realize that there needs to be an advocate or there needs to be someone that can step in and say, "Okay, here's what we can access or here push, or let's remind this referral that you've been on for three years, or let's do some things to keep things moving. How can we make sure your family is safe and that the needs of your child for ultimately safety right now are being met.*

Participants discussed the need for some kind of navigator role or a family advocate to support families who are accessing CYSN and the complex interministerial landscape discussed above. As one parent shared, *"It would be nice if we were spoiled to have a coordinator who's assigned to us to say, 'Hey, these are the resources that you're allocated or possibly can access. These are the pots of funding ...' somebody who knows shit."* Another participant dreamed,

...asking the parent to remember this contact for this service, this contact, and so on and on, it is so overwhelming and things get missed and services get missed.

> *But what if we can dream? What if there was somebody to help you through what to do and where to go and say if there is funding or if there is not funding, what your child, who you can actually go to, because right now what's happening is you're under six. You get $18,000. You get the diagnosis. You're overwhelmed. You go to, I forget where we went for OT, but anyways, and they say, great, they sign you up ... So, what if there was an in-between person who was able to say, this is the way that you go. These are some good resources.*



And another family member shared,

Where I am now with my son being 22, the biggest gap that kind of screams at me is who is the person who brings it all together? So, asking the parent to remember this contact for this service, this contact, and so on and on, it is so overwhelming and things get missed and services get missed. There almost needs to be a broker or just this middle person who can bring all these things together, all the paperwork, all the contacts, all the names, all the systems, and present it to the parent and say, "This is what we have. I will help you contact and communicate with this multidisciplinary team because they all need a multidisciplinary team." While one parent expressed:

> *So, I wish that was a little bit more accessible to people, even if it's not like, oh, this is my social worker, just somebody who you can talk to and figure out if you're using the correct services or if there's options for more services. Figuring out how to navigate that. A system navigator, it doesn't even necessarily have to be a social worker, but even stuff, I mean FSI does a lot of peer support, things like that where you can unlock somebody's brain and just try to understand what's going on.*

A navigator role was clearly seen as a need for participants as they frequently commented on not knowing what services and support or funding were available to them. Families described not knowing where to turn for information and spending a lot of time researching and trying to learn for themselves, on their own. One participant described:

> *I don't even know how much time I spent researching through the ministry website and all that, but I found it confusing. I had to reach out to private associations and say, "This seems really confusing to me. Do you have experience with that? Can you tell me what this means? Can you tell me what that means?" Right? It's not abundantly clear sometimes what all the information means and certainly not clear on the steps that are required to get your child diagnosed. I was a fish out of water. No one told me what I needed to do. I had no clue.*

Another participant shared,

> *It's like we need [an independent advocate] that's not paid by a certain organization, so they're not confined by that organization's policies and rules and regulations and restrictions. They are open to all services and all supports that could be of a help to your family. I can't tell you how many times I would call somebody and they'd say, "We don't do that. That's not our department." "Okay, so do you know who could?" "Not really, but I'm sure if you Google it..." I could have done that, but then there's wasted time and it's over and over and over with that wasted time.*

Participants also described a lack of transparency around what services and supports are available to them:

> *Also never, it was never presented to me, these are the resources we have that you could access. I felt like I always had to go through the fine print, look everything up online, "Hey, are respite funds available. Hey, is this available? Is that available? Is funding for this supplement or that thing available?" It was never offered. I always had to seek them out and ask for that. So, if there was a way for them to offer services in a way that was easier for families to access as opposed to tired parents that are already burnt out, caregivers having to dig through the piles of hypothetical paperwork online to find the information and then request it... And I'm at the point where I need a system navigator because I'm too burnt out to even try and look for services anymore.*

• Improve supports for transitions to adult services

> *It's always me lately, the last couple of years, looking on the internet to see what's available for him because he's about to age out and I have no idea... He doesn't age out until August. And so, I'm trying to prepare for September, "What the heck am I going to be doing?" I'm working full time. I think the whole process is chaotic. It is just so chaotic. You got to wait till that 11th hour to try and figure out what you're going to do with your family member.*

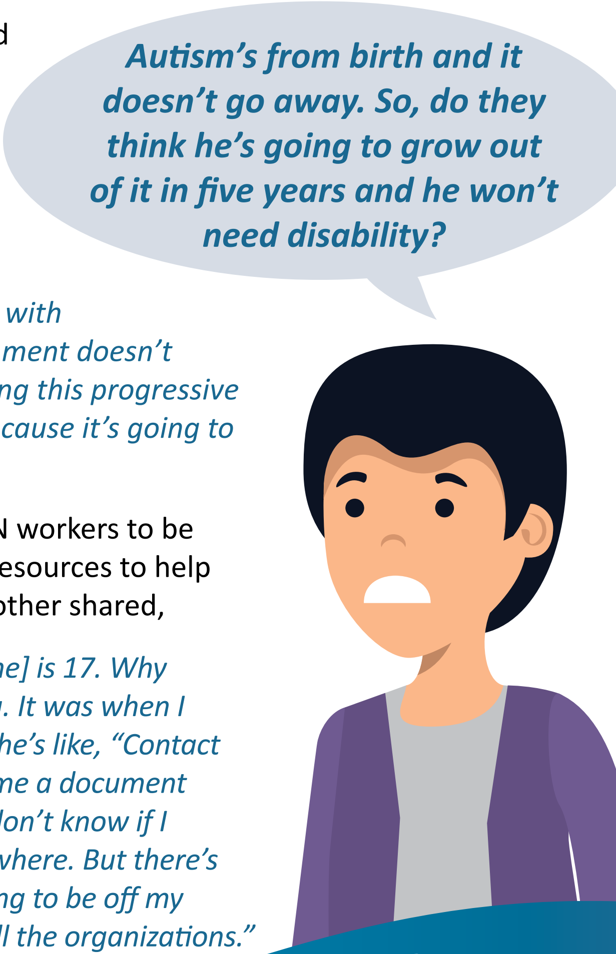
Transitions are stressful times for all families, particularly for families with transitioning youth with support needs. Not surprisingly, families spoke to the challenges they experience during these times and emphasized the need for more support navigating the transition to adult services and the need for continuity of care. Some families highlighted the challenges with the abrupt end of MCFD CYSN services and supports. As one family member described:

> *It's almost like with the disability tax credit, when they give you a chunk of time that you're approved for. When they approved my son for five years, I was like, "That's interesting. Autism's from birth and it doesn't go away." So, do they think he's going to grow out of it in five years and he won't need disability? How do the government officials make those choices? I'd love to know. And MCFD just says, "Oh, they don't need autism funding anymore. No, that's fine. They're 19 now. Figure it out. Go apply for provincial disability. You're not our issue anymore." What?*

While another parent expressed:

> *I'm not naive to think that he may benefit from any systemic [change] in his lifetime because he's going to be 13. And unfortunately, that's a whole other bag of worms with them aging out of the system and the supports, right? That's another thing that they need to respond better to is adults with disabilities. Because if we think there's very limited supports and money for children, let me tell you what happens when these children become adults.*

Some families connected the lack of interministerial cohesion to the need for continuity of care. For example, one family member advanced: "And also, I find it a bit frustrating, and I think there's a huge big gap between MCFD, SDPR, and CLBC. I think it's ridiculous that CLBC is a crown agency. [CLBC] should be part of both ministries."



Another parent stated,

> *There should be a better laddering system for children and youth with special needs into adult services like CLBC... And what the government doesn't seem to understand is that the money that they will save by having this progressive [action]... The thing is, it's going to save them so much money because it's going to produce in so many other areas.*

With the stress around transition, families spoke about the need for CYSN workers to be more proactive in their support of families and for some kind of map or resources to help families navigate the transition from MCFD to CLBC. For example, one mother shared,

> *And she never emails me and says, "Oh, hey, I see that [child's name] is 17. Why don't we meet to talk about transition?" No, none of that. Nothing. It was when I said, "Well, what do I need to do to transition to adult services?" She's like, "Contact CLBC," and that's it. And I'm like, "Okay, but can you at least send me a document that tells me the steps I'm supposed to take?" I mean, I found it. I don't know if I found it through Family Support Institute maybe or through somewhere. But there's no package for, "Here's, I see your child has reached 17, you're going to be off my caseload. So, here's a hundred-page document of all the steps in all the organizations."*

Finally, numerous families emphasized the stress that losing autism funding/individualized funding added to the transition experience. They described losing what they could count on to a different system where there were many unknowns if they would receive anything. One Indigenous parent described:

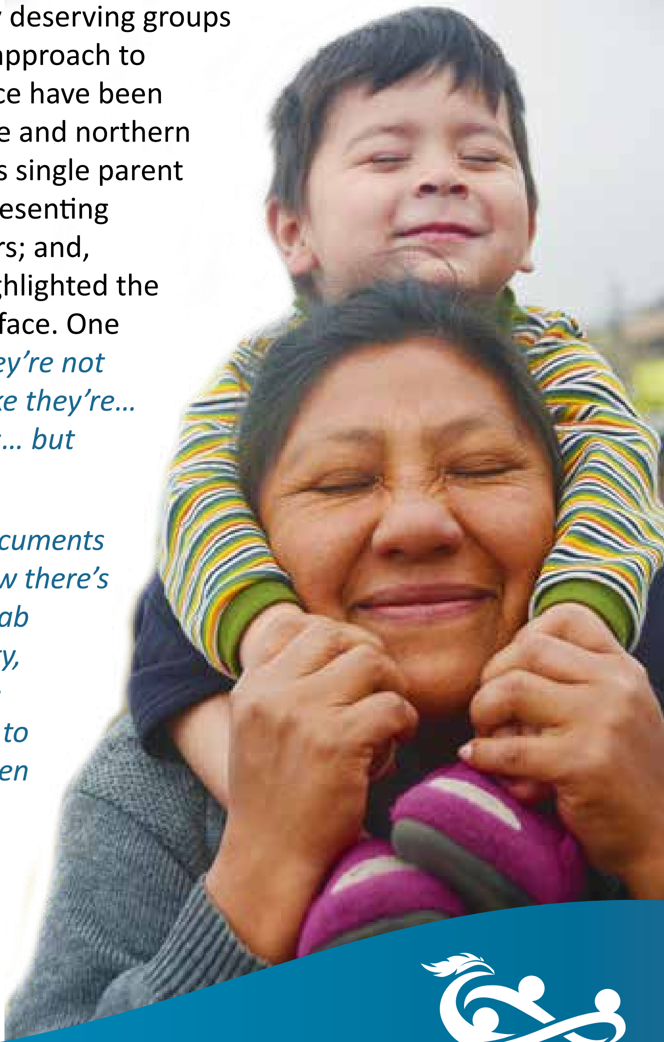
> *I can't do it anymore. And now she's transitioning because she's 18. So, now I'm transitioning to a new kind of service where I have zero guarantees, not even the autism funding. There's nothing. And it's heartbreaking and soul crushing because I have to start all over again from zero. And there's supposed to be transition support.*

- Address systemic racism and colonialism experienced by families from equity deserving groups

> *I guess another thing that I would say is there needs to be more focused support for different, I'm not sure what the right word is, different categories of youth as well. My daughter is also LGBTQIA plus, and when I reached out to our social worker saying she's having a lot of issues right now because of body dysphoria, or she's very angry because her voice doesn't match her gender and things like that, you get nothing in response. Like, "Nope, we don't have anything for that might be helpful."*

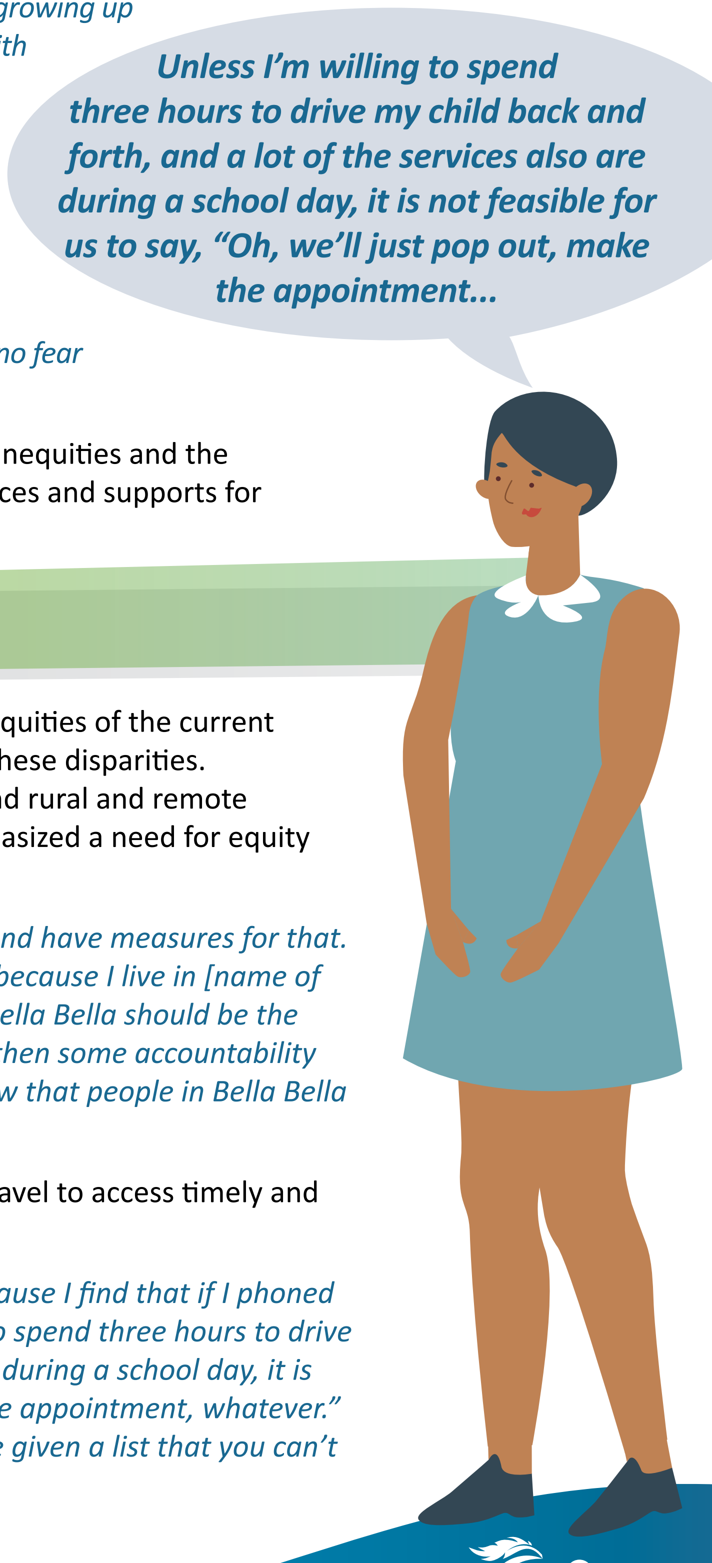
Across the data, a strong theme emerged underscoring the need to address the systemic oppression and barriers experienced by families from equity deserving groups and highlighting the importance of implementing and intersectional approach to future policies and practices. Some of the challenges these groups face have been discussed previously. These include: families living in rural and remote and northern communities; families experiencing socioeconomic challenges such as single parent families and/or families with caregivers with disabilities; families representing ethnically and linguistically diverse communities, including newcomers; and, Indigenous families and communities. Some previous results have highlighted the unique and/or intensified barriers and challenges that these families face. One participant noted how *"The systems are not easy to interact with. They're not intuitive, they're not easy to understand, and I don't want to sound like they're… biased against people or other cultures and people of other traditions… but they're very biased."* Another participant shared,

> *And actually, going back to diversity, it would be amazing if documents from the ministry were translated to multiple languages. I know there's a few that are available in… the majority familiar English, Punjab might be available, maybe Mandarin, but maybe having variety, especially speaking for Arabic or African languages and people that are just new to navigating the system. And it's really hard to come and migrate to a country not knowing the system and then having that language barrier. It's three times harder.*



Another participant's sharing underscores the challenge that intersectional positionalities can create:

> *I have the disability tax credit myself. So, I have some mental health disabilities that I struggle with myself. I would consider myself fairly high functioning obviously and fairly articulate, but I still struggle. I can get my thoughts out for the most part, but I still have a lot of struggles around my disabilities. And then just growing up lower income, and then also the stigma I feel as a mother with a child with a disability like this, I am already coming to the interaction feeling a little less than maybe. And then when a social worker, and to me that's a person of authority... So, that feels like to me there's a power dynamic there that isn't always the greatest sort of feeling. That's different than if you're talking to say a community, someone from community resource, then it's never far from my mind that they can take your kids too. I hate to mention that, but no fear unlocked, that's a reality.*



Two areas additional areas highlighted below are the geographic inequities and the importance of committing to culturally safe and appropriate services and supports for Indigenous families.

• Attend to geographic inequities

Across the data, participants repeatedly noted the geographic inequities of the current system and advocated for new services and supports to address these disparities. This sentiment was supported by participants from both urban and rural and remote communities. Family members and caregivers resoundingly emphasized a need for equity across the province:

> *Services should be equitable across the province as well and have measures for that. So, say, like I said, I sometimes forget about these things because I live in [name of city]... the service that you receive in Prince George and Bella Bella should be the same as the service that you receive in Surrey or so. And then some accountability or that equitable distribution of resources so that we know that people in Bella Bella are receiving the same services.*

Other participants described the geographic distance one must travel to access timely and appropriate services. For example:

> *I guess the first part is how localized the services are, because I find that if I phoned the 1-800 number or I'm given a list... Unless I'm willing to spend three hours to drive my child back and forth, and a lot of the services also are during a school day, it is not feasible for us to say, "Oh, we'll just pop out, make the appointment, whatever." Then it's worse when they're not even close to you, you're given a list that you can't do anything with.*

Similarly, another parent shared,

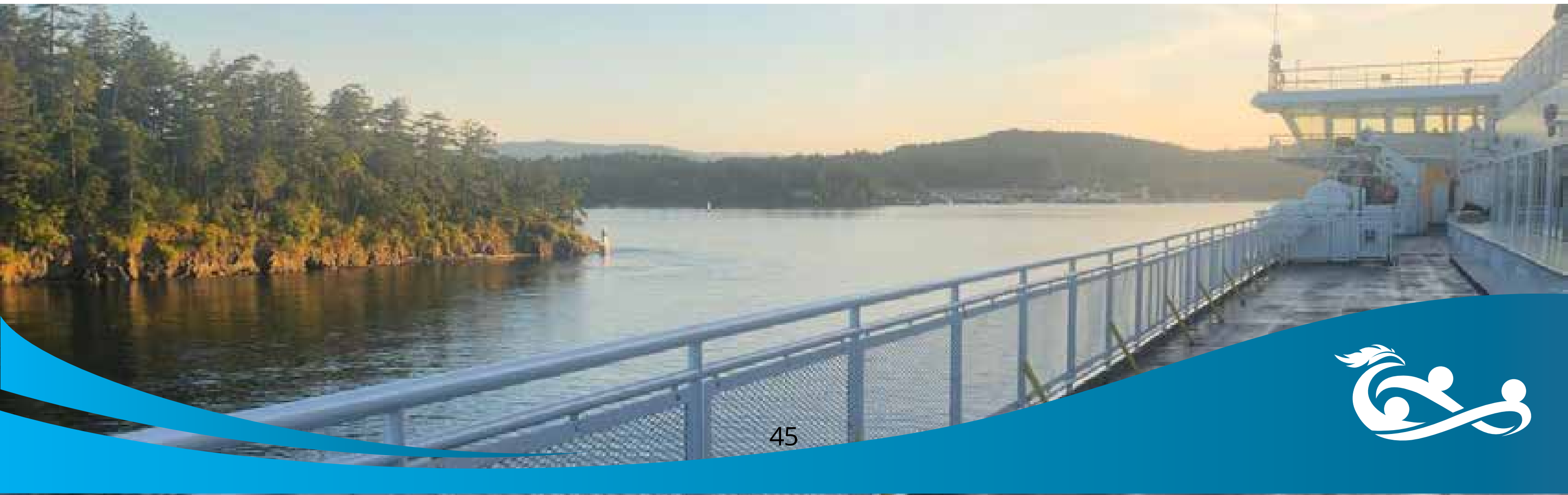
> *We live up north, and so there's like minimal resources. The government was proposing was like the hubs and like we have windy winter roads in the winter, so there's, like, there's even the next biggest town. There's no way I would be driving to [city] in the winter time. Like, like, like a few people die every year driving that highway in the winter. Kids on that road, you know, like, so I don't think a hub would be helpful.*

Relatedly, other family members highlighted the geographic challenges with respect to the lack of choice of workers and therapies to choose from and its implications for costs for services. For example, one participant described,

> *Another thing that's probably also more of a rural issue is if there's a very limited pool of who you can get support from. It creates a monopoly for pricing for services and things like that because you have to, this is what you have to pay. There's no other options. So, then you are spending your funding that much faster, whereas somebody say in the lower mainland who can shop around and go to 40 different people, they're able to do that. So, what am I paying 30 or more an hour for my sons to go to this pediatric speech and development? So, it's ideally supposed to help work a little bit on speech and a little bit on behavior. But yeah, I ran out of funding before my year was up because it's such a high rate, and if you don't have competition or all these other people you can access, then you're stuck paying that by rate or getting no services at all ... So, the type of program you want, you don't have a choice. You got to pay that rate.*

Finally, geographic considerations present distinct challenges to northern and remote Indigenous communities. Not only are the geographical considerations a challenge but many families may not have the adequate transportation or support to attend appointments for their children. The inequities of what is provided locally creates unique tensions for families who value the importance of their children and youth to be raised culturally on their territories and in their communities. For example, one family member described,

> *I had a coworker once who was like, "Well, why don't you just move to Prince George?" And I'm like, well, this was just shortly after I moved here and I was like, "Well, why should I have to? I moved here so my kids could grow up around in their home territory around the support of our community and I wanted them to learn their language and our traditions and culture and that's why I moved here." I was like, "I don't think that's fair that I have to choose one or the other." So yeah, I think I almost started crying when she asked me that actually. And it was definitely something I didn't like to hear.*



- Implement cultural safety and ensure culturally appropriate services

> *I'm thinking what they represent to me is different maybe than what they might represent to someone else. Those are still the people that hurt my ancestors a lot in my culture. So, I guess what I'm trying to say is there's a lot of systemic trauma and generational misgivings that I'm carrying to an interaction with a social worker. And so, when they're coming across cold, it's really hard to get past that.*

The findings presented here consistently highlight the need to acknowledge the distinct history of MCFD, colonization, and Indigenous people. The current and historical trauma experienced by Indigenous families due to colonization, residential schools, and systemic racism continues to shape their relationship with MCFD. There is a necessity for more culturally sensitive and safe practices that honour Indigenous knowledge, and ways of knowing and being.

As discussed previously, Indigenous participants described the longstanding history and current practice of the removal of children from families' homes and communities, and emphasized the importance of a culturally safe system of care: *'It needs to be culturally sensitive because otherwise you're going to turn away families that could benefit from intervention support and from behavior support because you've offended them."* This included the importance of support and services being provided within community, by community. For example, one mother shared:

> *So, for [child's name] to continue on with his cultural teaching, there's nobody out there. So, unless his band embraces him and we're trying to do that slow, gentle request without being pushy, then what does he do? I find that part heartbreaking because [child's name] wants to learn about his culture, but it's not been forthcoming.*

Another caregiver said,

> *Making training more accessible to remote communities. Because I was just talking with somebody the other day and I'm like, the last thing people in our community want is somebody from another community coming and telling us what our kids need because they don't understand the dynamics of life here. So having somebody come from Prince George even, I mean, I think it would have to depend on who that person is and understand a lot of our kids are outdoors kids. They don't do a lot of learning inside. And so, building those supports and services with that in mind.*

...there's a lot of systemic trauma and generational misgivings that I'm carrying to an interaction with a social worker.

Some Indigenous participants went on to underscore how recognizing the diversity across First Nations is crucial as is respecting and supporting the value of learning that children with disabilities receive from the land:

> *First Nations engagement, that each community or each region is different, that we all have different needs and we all have different values. And then I think as well, they need to understand that therapies or aren't necessarily, there's more than just OT and PT and speech and language and behavior intervention therapy. [on the land he learns more…] I mean, right now, MCFD wouldn't consider that a therapy, but for him it's done more than therapy's ever done.*

Finally, the positive directions the First Nations Health Authority was provided by one participant, who shared: *"There are new Indigenous health centers being launched through the First Nations Health Authority. Wouldn't those be wonderful starting points [for Indigenous families]."* This same participant explained the challenge that

> *Because people can take cultural safety training and we have mainstream who is like, "Oh, we've done a day of cultural safety training, we're good." And it's like, "Really? Can we put you into every situation and have you walk out and be just as supportive and just as friendly and accommodating and innovative as we are?"*

FSI COMMUNITY ENGAGEMENT SUMMARY

It was very clear that every system is connected.

The Ministry of Children and Family Development's (MCFD) recent service model changes, including the loss of individualized autism funding, were common points of discussion. We explained that the FSI, through the Family Voices project, was working in collaboration with the Canadian Institute for Inclusion and Citizenship (CIIC) who were doing online and phone engagements and would be writing the final research report.

Family Voices Journey – Key Findings Summary

Tracy Humphreys, Family Voices Project Coordinator

Going to so many different communities around the province, I learned that while there are differences in the experiences of families depending on their geographic location, there are a few common aspects that individual communities may not see.

Common Ground Across Communities

While each community's context is unique, core challenges emerged consistently across the province, highlighting both shared and systemic issues.

Top Concern: Workforce Shortages

The shortage of qualified professionals, knowledgeable about supporting children and youth with disabilities and their families, is the most pressing issue in all regions, though it presents differently in smaller and larger communities:

- Smaller and more remote, especially Northern communities: These areas lack available professionals almost entirely, resulting in critical service gaps and limited access to essential support.
- Larger communities: While more professionals are available, they are so overbooked that waitlists extend to months or even years. Families experience serious delays to the point where they age out of the opportunity for support and miss early intervention opportunities.

Lack of Cultural Safety and Sensitivity

A significant concern across communities was the lack of cultural safety and sensitivity in services, particularly for Indigenous families but also for newcomers who may have limited knowledge of English and no understanding of how supports and services work and how to access help. Many families from different First Nations communities around the province had a common concern that MCFD, and often their contracted service providers, do not adequately consider or respect Indigenous ways of knowing, family structures, and values. They also noted pretty much everywhere we went the aspect of child protection and its connection with the Ministry, not only in structure but also often physically in the same office. Families shared that this feels very unsafe and was noted by one family as "basically just an extension of residential schools." This lack of cultural responsiveness erodes trust and has meant that many families would prefer to have no services than to access ones that are not culturally safe.

Inconsistent and Limited Access to Services

There is a widespread issue with accessing services, with families in both rural and urban areas facing long wait times, limited support options, and insufficient resources:

- Diagnosis and Specialist Wait Times: Families across regions reported difficulty accessing diagnostic and specialist services, with waitlists extending for months or years, often exacerbating the challenges they face in supporting their children, and meaning they miss out on critical early intervention services.
- Behavioral and Mental Health Supports: Families repeatedly voiced the need for behavioral interventions, mental health support, and counseling services that are accessible and consistent. Gaps in these services are particularly problematic for children with ADHD, FASD, and other diagnoses that do not receive as much attention as autism.

Fragmented and Siloed Service System

Many families expressed frustration with a fragmented system, where services operate in silos and lack coordination. Parents highlighted the need for integrated case management and a more cohesive support structure, where service providers communicate effectively with each other and with families. The disjointed nature of services often forces families to navigate complex bureaucratic processes on their own, leaving them feeling overwhelmed and unsupported.

Peer and Community-Based Support

Across communities, families voiced a strong desire for more local, communitybased support networks and peer support groups. Connecting with other families experiencing similar challenges would provide essential emotional and practical support. FCCs were seen as potential facilitators of these networks, yet many families felt that this role is not being fully realized.

Trust Issues and Fear of Engagement

Due to negative experiences, particularly with the FCC rollout, there is a profound lack of trust in the system that was already present and was made worse by the way things rolled out initially. Many families are wary of new government initiatives, fearing additional disruptions or inadequate support. This mistrust has made families more hesitant to engage with services, further limiting their access to the support they need.

#1 WORKFORCE SHORTAGES
#2 LACK OF CULTURAL SAFETY AND SENSITIVITY
#3 INCONSISTENT AND LIMITED ACCESS TO SERVICES
#4 FRAGMENTED AND SILOED SERVICE SYSTEM
#5 PEER AND COMMUNITY-BASED SUPPORT
#6 TRUST ISSUES AND FEAR OF ENGAGEMENT

DISCUSSION

Across the two streams of engagement – the FSI in-person gatherings and the CIIC research – we heard strikingly similar things from families and individuals with lived experience.

Participants shared painful stories and described the negative impacts of the current fragmented CYSN system on families: the emotional, financial, and logistical strain they've experienced as they've tried to navigate complex systems, deal with extensive waitlists, advocate for services and supports, all while managing the care of their child(ren) and their family. Indigenous families highlighted the lack of culturally safe and appropriate supports and services, and pointed to the impacts of historical and ongoing colonial practices, particularly the ongoing legacy of child protection in Indigenous communities. Relatedly, participants described the lack of culturally appropriate supports and services from other equity deserving groups such as families from linguistical and culturally diverse backgrounds (including the unique needs of newcomers); families with family members with disabilities (including parents/caregivers with disabilities); families with diverse compositions such as single parent families; families with low socioeconomic means to name some.

We heard a strong call for the Ministry to invest in families by implementing a family-centred approach that includes supports for parents, caregivers (including extended family such as grandparents), and siblings. Moreover, in order to create a system that genuinely supports children and families, our findings direct that MCFD must build trust, improve communication, and create a system that adapts to the evolving needs of diverse families and their children. The findings also underscore the need for more choice and control; improved communication; and increased funding, and improved access to funding and supports for all families with children and youth with support needs.

We heard participants described the need for systemic and structural change. Challenges with human resources both with CYSN and allied professionals are in need of vital attention and investment. A workforce that has knowledge of disabilities and how to best support families with children and youth with disabilities is needed. The recruitment and training of qualified professionals across the province is needed to address shortages of professionals in rural and remote and Northern communities as well as to address the long waitlists in urban centres.

Systemic change needs to entail a cohesive system and coordinated approach that provides continuity of care for families. This includes addressing a broken approach to assessment that perpetuates inequities for families and investment in early intervention. Supports for transitioning youth to adult services is needed, and collaboration and coordination across and between Ministries and CLBC is paramount. Families shared that a navigator or family advocate role will help mitigate the stress of navigating complex systems when having to balance centring and prioritizing their family's well-being at the same time.

Finally, systemic change is required to address racist and colonial structures and practices that disproportionately impact families from equity deserving groups. Importantly, this includes leaving behind the colonial and punitive practices and shifting to a more collaborative, culturally safe, trauma-informed, empathetic, and family-centered approach.

This narrative has not changed over the years. Three recent reports underscore the negative impacts of the current system for families with children and youth with support needs and provide a clarion call for systemic change to CYSN services and supports in BC:

- *The BC Family Survey – Children and youth with special needs report*. (BCEDAccess, BC Parents of Complex Kids, Family Support Institute of BC, and Inclusion BC, April 30, 2020).
- *Key components of effective service delivery for children and youth with support needs, from the BC Representative for Children and Youth.* (Mirenda, 2023).
- *A family-driven model of care: Setting the table for disability rights in BC.* (BC Disability Collaborative, 2024).

All three support and parallel the findings of The Family Voices Project reported here in this report.

The *BC Family Survey (2020)* of 1055 families with children and youth with support needs include five key recommendations: implement a family-centred approach that promotes flexibility, and choice and control; invest in families financially; ensure clear communication; increase inclusivity of supports and services to address the inequities families experience who do not meet strict eligibility criteria for CYSN; and improve interministerial collaboration to achieve a more cohesive system of supports for families.

Similarly, the Representative's for Children and Youth (RCY) report – *Key components of effective service delivery for children and youth with support needs* (Mirenda, 2023) – supports and mirrors the findings of the current research and engagement. In this review of 50 peer reviewed research studies, six key components for effective CYSN service delivery were identified:

1. Provision of family-centred care;
2. Cross-sector collaboration and connections to community networks and resources;
3. Coordination of services across therapies;
4. Sufficient, accountable, equitable funding allocation, and sufficient resources;
5. Services customized to meet individual needs (intensity and quality); and
6. Staff training related to the service delivery model.

In this review, Mirenda (2023) provides evidence that expands on these six key components drawing on the researchers' findings to provide a strong rationale for the consideration and implementation of these components in BC's CYSN supports and services. The current research presented in our report documenting families' desires for CYSN supports and services underscores and supports Mirenda's findings of the reviewed research.

Recently, the recent report of the BC Disability Collaborative (2024) presents the findings from a recent BC Disability Summit held in June 2024 (with 77 participants from 43 provincial organizations that represent children and youth with disabilities). The BC Disability Collaborative is a collective voice of member organizations working together to advocate for services and supports for families. In line with the previous work cited here and this Family Voices Project Report, at the fore, participants of the summit agreed that *"we need a **new family-driven care model** – one that truly puts disabled children, youth, and their families at the centre"* (p. 3). With regard to the current system, the report describes similar findings of the *Family Voice Project Report*. The current system is "grossly underfunded, discriminatory, trauma-inducing, inequitable, fragmented and difficult to navigate, and leaves many kids out (p. 3). The report calls for adequate and sustainable funding; quality care, including capacity building (e.g., an increased workforce and a qualified workforce), equitable access, and accountability. Again, these calls echo the voices of the families who participated and shared their stories in the *Family Voice Project.*

Finally, across these recent reports on CYSN in B.C., there is a singular position highlighting a sense of crisis and urgency to address the systemic and structural barriers that families face (BCEdAccess, BC Parents of Complex Kids, Family Support Institute of BC, and Inclusion BC, 2020; British Columbia's Representative for Children and Youth, 2023; Mirenda, 2023). The families who participated in the *Family Voice Project* also call for urgent systemic changes that align with the six key, evidence-based components to effective CYSN service delivery as outlined by Mirenda (2023).

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