



THE
**FAMILY VOICES
PROJECT**

HELPING SHAPE THE
FUTURE OF CYSN SERVICES

Report of Community Engagement

A plain language summary of the full report prepared for the BC Ministry of Children and Family Development (MCFD)

December 12, 2024



FAMILY SUPPORT
Institute of **BC**
families supporting families



THE UNIVERSITY OF BRITISH COLUMBIA
Canadian Institute for Inclusion and Citizenship

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A. What is this report all about?

The Family Voices Project: Helping Shape the Future of CYSN Services is a year-long research project, leading to the original 58-page text-only report documenting stories of real experiences of families in British Columbia (BC). This project is a partnership between the Family Support Institute of BC (FSI) and the UBC Canadian Institute for Inclusion and Citizenship (CIIC). The purpose was to conduct community outreach in diverse parts of BC to hear from families and individuals about the state and future of services for children and youth with support needs (CYSN services).

We did this in two ways:

1. FSI organized 17 in-person gatherings in 16 locations across BC
2. CIIC met virtually with 46 individuals/families across BC

The community outreach and virtual sessions aimed to keep **listening** to families as the focus. The communities we visited were in diverse geographic locations in both urban and rural regions; more than 20% of participants were Indigenous; and there were participants who self-identified across a range of marginalized identities, including visible racial minorities, excluded socioeconomic group, and having a visible or invisible disability.

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.

Ultimately, we are reporting the findings of our outreach back to the Ministry of Children and Family Development (MCFD), upon their request, so they can implement our recommendations.



B. What did our outreach reveal?

Our outreach revealed 3 main things:

The Importance of Family Agency, Advocacy, and Witnessing	The Current State of Affairs of the CYSN System	What Families and Individuals with Lived Experience Want
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The Importance of Family Agency, Advocacy, and Witnessing

The most dominant finding is that **families themselves need to play the central role** in order for CYSN services and supports to be effective; after all, families are the experts on their own child's needs.

Families want to be involved in making decisions about supports and services that are right for their family. Instead, many find that they are marginalized from discussions about their child's needs. When their voices are not heard and represented in decision-making, they then have to go out of their way to push for services, navigate complex systems, and educate service providers. Parents end up doing most of the work advocating for their child, when their input could have been considered in the first place. It is physically, emotionally, and financially exhausting, as well as being intimidating.

"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."
– parent/caregiver

"**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."
– parent/caregiver



Key areas parents and caregivers find themselves advocating in:

<p>- Caregivers need to become knowledgeable about their child’s medical issues and learn the technical language around it in order to intervene effectively.</p>	<p>“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.” – parent/caregiver</p>
<p>- Caregivers need to learn about each of the provincial ministry departments directly or indirectly relevant to their child’s care, including how to navigate them, and what barriers each one has. This includes MCFD as well as the ministries of Education, Health, Social Development and Poverty Reduction, Mental Health and Addictions.</p>	<p>“[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.” – parent/caregiver</p>
<p>- Caregivers need to locate all the funding their child may be eligible for. It is an ongoing struggle to find the relevant specific services and supports, and the funding available for them.</p>	<p>“It’s like the wild West of trying to help your child... You just strap in, try your best. Just be persistent.” – parent/caregiver</p>
<p>- Caregivers find themselves advocating for and on behalf of other families and other demographics as well. Sometimes, they see inequalities in the system such that their own family may benefit from a service, yet other families may face barriers or restrictions.</p>	<p>“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.” – parent/caregiver</p>



The Current State of Affairs of the CYSN System

Right now, there are a few things about MCFD CYSN services that seem to be working. But there are far more things that are not working, and families are desperately calling for systemic change.

The things that are working:

1. Respite	These programs offer families flexibility, choice and control.
2. Individualized Funding	
3. The At Home Program	This program provides some necessary services, products, and medical equipment for children with support needs.

How the system hurts more than helps:

Historical legacy, surveillance, and lack of trust

The historical child protection legacy of MCFD has an extremely negative impact on families. MCFD’s focus on child protection, rather than on supportive and preventative family support for children with support needs, contributes to burnout among parents, particularly in marginalized communities.	“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.” – parent/caregiver
This reality is especially pronounced for Indigenous families due to the current and historical legacy of colonialism, child removals, cultural oppression, and systemic racism.	“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.” – parent/caregiver



Emotional impact of systemic challenges

The multiple and unending barriers to accessing services takes a profound emotional toll on families. They face unmet expectations and broken promises, creating feelings of **frustration and betrayal**. They are continuously misunderstood by service providers, creating feelings of **powerlessness and burnout**.

“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.”
– parent/caregiver

In rural and underserved regions, access to supports is extremely limited, or even non-existent, creating feelings of **overwhelming isolation**.

“I often feel like I’m reinventing the wheel a lot of times it just because **there isn’t a place to turn to**. . . 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.” . . . And that probably makes it even more isolating, and I think even more so when you’re in a remote community.”
– parent/caregiver



Family Connection Centres

<p>One-Size-Fits-All:</p>	<p>The services and supports offered by the FCC are too rigid and narrow to be useful or applicable for a diversity of families.</p>	<p>“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. . . everybody’s different.” – parent/caregiver</p>
<p>Lack of Flexibility and Choice and Control:</p>	<p>Families have doubts that the new FCC pilots will be able to provide opportunities for flexibility and choice that are so important to family-centred supports.</p>	<p>“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. . . 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.” – parent/caregiver</p>
<p>Geographic Disparity:</p>	<p>Different communities across the vast landscapes of BC have different considerations, so implementing a cookie-cutter FCC model does not work in catering to all locations.</p>	<p>“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.” – parent/caregiver</p>



What Families and Individuals with Lived Experience Want

1. Invest in families

a. Adopt and implement a family-centred approach	“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.” – parent/caregiver
b. Ensure choice and control for families	“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.” – parent/caregiver
c. Ensure clear communication	“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... 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.” – parent/caregiver
d. Address funding needs and concerns	“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?” – parent/caregiver



2. Implement systemic and structural changes

<p>a. Invest in the human resources for CYSN – both within the Ministry and the allied professionals</p>	<p>“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.”” – parent/caregiver</p>
<p>b. Address the need for training and education</p>	<p>“The total exclusion of FASD from literally everything. . . 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...causing so much harm to our families.” – parent/caregiver</p>
<p>c. Address problems with assessment and improve early intervention</p>	<p>“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.” – parent/caregiver</p>
<p>d. Improve inter-ministerial collaboration and cohesion of services</p>	<p>“[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.” – parent/caregiver</p>
<p>e. Create a navigator/advocate role to help families</p>	<p>“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. . . What if there was an in-between person who was able to say, this is the way that you go.” – parent/caregiver</p>
<p>f. Improve supports for transitions to adult services</p>	<p>“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?”” – parent/caregiver</p>
<p>g. Address systemic racism and colonialism experienced by families from equity deserving groups</p>	<p>“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.” – parent/caregiver</p>



<p>h. Attend to geographic inequities</p>	<p>“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. . . 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.” – parent/caregiver</p>
<p>i. Implement cultural safety and ensure culturally appropriate services</p>	<p>“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.” – parent/caregiver</p>

C. What are the key findings from this journey?

Workforce Shortages

- Rural, remote and Northern communities lack professionals altogether
- Professionals in larger communities are always overbooked, and families are on waitlists for months or even years

Lack of Cultural Safety and Sensitivity

- Indigenous families find these services feel like an extension of residential schools
- Newcomer families cannot easily navigate the system or overcome language barriers

Inconsistent and Limited Access to Services

- Families face challenges accessing diagnostic services and specialist services
- Behavioural intervention services, mental health supports, and counseling services are not available to many families

Fragmented and Siloed Service System

- Services are fragmented and do not coordinate with each other at all, leaving each family with disjointed supports

Peer and Community-Based Support

- FCCs are not providing useful or practical community-based support

Trust Issues and Fear of Engagement

- Historical systemic problems, negative personal experiences, and constant changes to services create mistrust and hesitation among families



D. What do we think of these findings?

The findings are not surprising at all! In fact, there are plenty of similarities with three other recent reports that highlighted the problems with the current CYSN system and called for systemic change.

1. *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).
2. *Key components of effective service delivery for children and youth with support needs, from the BC Representative for Children and Youth.* (Mirenda, 2023).
3. *A family-driven model of care: Setting the table for disability rights in BC.* (BC Disability Collaborative, 2024).

MCFD requested that we carry out this project to report back what families tell us, but our project did not reveal anything that previous projects already said. Our project confirmed the following points that were also echoed in the previous three reports.

1. There needs to be a system of **family-centred care**
2. The system is drastically underfunded and **needs much more funding**
3. There needs to be more **transparency and better communication** so families are well-informed
4. The system is discriminatory and needs to be **more inclusive**
5. The current system is fragmented and needs more **collaboration across government ministries**
6. Staff and service providers need better **training**
7. The current system is in crisis and **very urgently** needs the abovementioned structural changes

