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PROJECT BACKGROUND

In fall 2021, the Ministry of Children and Family Development (MCFD) announced a new framework for service delivery to Children and Youth with Support Needs (CYSN) in British Columbia (BC). The announcement of the CYSN framework was met with confusion and fear by many across BC. It was also met with calls for greater consultation.

Across the province, individuals and organizations demanded that any framework changes be better informed by the experiences and perspectives of families and children and youth with disabilities or support needs.

The Community-Led Collaboration Project defines children and youth with disabilities or support needs as those who are 0-19 years of age, have a disability, diagnosed or undiagnosed, need support, and/or have a possible developmental delay.

Shortly after the announcement, the BC Association of Aboriginal Friendship Centres (BCAAFC), BC Association of Child Development and Intervention (BCACDI), The Federation of Community Social Services and Inclusion BC came together to:

- Identify the potential of the proposed framework;
- Raise concerns that the changes ahead would effectively respond to the needs of children and youth, their families, the organizations that support them and the communities where they live;
- Present a proposal to MCFD to carry out a provincial engagement from a community development perspective to better inform the changes coming to B.C.'s system of services and supports.

In response, MCFD gave the organizations (referred to in this report as The Provincial Working Group) a grant to conduct a provincial engagement that would inform the transformation of CYSN services in B.C. The engagement, known as **The Community-Led Collaboration Project**, launched in Fall 2022.

This report details the challenges, hopes and expectations for services and supports that families and community service providers **expressed in conversations in Port Alberni and surrounding communities** – one of five initial communities engaged in the first year of this project.

THE APPROACH TO ENGAGEMENT

The Community-Led Collaboration Project's Provincial Working Group partnered with B.C. communities to design a thoughtful, inclusive, culturally safe, and accessible approach to engagement. To guide their work, the group established four project principles:

- **Collaboration.** Engagement is co-designed with community members to inform how B.C. communities can create better networks of services and support for children and youth with disabilities or support needs, and their families.
- Community-driven change. The project builds upon the strengths of B.C.'s current system and
 names the changes needed to best support children and youth with disabilities or support needs and
 their families.
- **Reconciliation and Decolonizing.** Reconciliation and decolonization guide the project's approach to community engagement, which is designed to be inclusive, accessible, and culturally safe, with an appropriate approach that makes space for historically excluded voices and perspectives.
- **Transparency and Timeliness.** Timely engagement summaries are circulated to keep participants informed and help ensure the perspectives most important to the community are captured.

We believe inclusive communities are healthier communities, and this is a **shared responsibility**.

The Community-Led Collaboration Project took place over two phases between September 2022 and December 2024. In the first phase, The Provincial Working Group and their community partners worked together to facilitate in-person and hybrid engagements in:

- Campbell River, Gold River, and surrounding communities
- Castlegar and surrounding communities
- Kamloops and surrounding communities
- Port Alberni and the West Coast Vancouver Island communities
- Richmond

SAFE SPACES FOR DIALOGUE

In Port Alberni, The Provincial Working Group built partnerships with local community organizations including Nuu-Chah-Nulth Tribal Council,
Outreach Therapy, Port Alberni Association for Community Living (PAACL) and Port Alberni Friendship Centre. These partnerships informed approaches to engagement that best reflected the needs of the community.

Local families, youth and service providers were invited to facilitated sessions in several ways including:

- Information posters (put up in community centres and coffee shops);
- Dedicated community website and registration page;
- Emails sent directly to families receiving supports and service providers;
- Community service providers sharing event details directly with organizations and families in their networks;
- Local Facebook groups.

Throughout the planning and implementation of engagements in Port Alberni, steps were taken to ensure cultural safety and accessibility.

Participants were offered:



- Childcare honorariums and onsite supported childcare options;
- Support for transportation;
- Quiet space on site and follow-up support for participants;
- Food and gift cards for all participants;
- A variety of session formats and locations to enhance safety and inclusion;
- Hybrid session formats for those who preferred to participate remotely via Zoom.

In each of the five initial communities, the Provincial Working Group and its community partners also conducted a six-step engagement (see Figure 1 below) to:

Understand the strengths, gaps, and the changes needed when it comes to services and supports for children and youth with disabilities or support needs in BC.

Explore what truly collaborative and connected networks of support can achieve for BC children and youth, and their families.

Implement engagement that considers the specific circumstances of a community, the young people, and families in need of support, and importantly, the voices of people historically excluded.



Figure 1

In the second phase of the project, the Provincial Working Group:

- Shared outcomes and approaches from the initial community engagements and worked with communities to develop solutions to issues raised.
- Offered up to thirty grants for additional BC communities to conduct their own community engagements.

In each session, participants were asked three questions:

- What services and supports for children and youth with disabilities or support needs are working well in Port Alberni and surrounding areas?
- 2 What gaps in services and support exist?
- What does a better network of services and supports look like in Port Alberni and surrounding areas?

In addition to exploring these questions in hybrid sessions, families and service providers were provided a survey link, phone number and email address to share further ideas.

The survey invited people to answer the three questions listed above.

ABOUT PORT ALBERNI



Image courtesy of Destinationless Travel

Port Alberni is located on the traditional territories of the Hupacasath and Tseshaht First Nations. We acknowledge the Metis, Inuit and Urban Indigenous People who also live throughout this territory. Port Alberni has a population of nearly 33,521 people. Children up to the age of 14 account for 14.8 per cent of the population of Port Alberni. 19.3 per cent of the population are of single Indigenous ancestry, of which 79 per cent are First Nations and 21 per cent are Metis. ²

According to the Early Development Instrument (EDI), a research tool used by the Human Early Learning Project (HELP) at the University of British Columbia (UBC) to help understand healthy child development in British Columbia, childhood vulnerability rates vary significantly across the province, ranging from 21.8% in some BC communities to 72% in others.³

34.4% of kindergarten children are vulnerable in Port Alberni compared to **32.9% of kindergarten children** across B.C. being vulnerable.

In Port Alberni, 34.4% or 177 of 518 children are vulnerable on one or more scales of the EDI upon entry to kindergarten. This compares to 32.9% of all kindergarten children across B.C. being vulnerable on one or more scales. 5

¹ Statistics Canada. 2023. (table). Census Profile. 2021 Census of Population. Statistics Canada Catalogue no. 98-316-X2021001. Ottawa. Released March 29, 2023, online: https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/index.cfm?Lang=E

² Ibidem.

³ Ibidem

⁴ Sourced from the Early Development Instrument (EDI), composed of five scales of vulnerability in children entering kindergarten in British Columbia. The EDI tool has been used by the Human Early Learning Project (HELP) at the University of British Columbia for over two decades to monitor children's development at school entry (https://earlylearning.ubc.ca). The EDI looks at five scales of child development including: physical health and well-being, social competence, emotional maturity, language and cognitive development, and communications skills and general knowledge.

5 https://earlylearning.ubc.ca.

Early Development Instrument research in Port Alberni further indicates that the social and emotional needs of children in kindergarten are higher than their needs in other areas of development, such as physical health, well-being, language, cognition, communication, and general knowledge.⁶

Children are considered vulnerable on the EDI if, without additional support and care, they are more likely to experience challenges in their school years and beyond. Why is this important? Understanding healthy child development – and what is influencing healthy development in your community provides a starting point for conversations and actions that are local, specific to the needs of the children in your community, and led by community champions.⁷

WHAT WE HEARD IN PORT ALBERNI

Engagement in Port Alberni took place in October 2023. Working in partnership with local organizations, Nuu-Chah-Nulth Tribal Council, Outreach Therapy, Port Alberni Association for Community Living and Port Alberni Friendship Centre, the community hosted:

- A session with 14 local families at the Port Alberni Friendship Centre on Tuesday, October 17, 2023.
- A session with 16 local community service providers at the Port Alberni Friendship Centre on Wednesday, October 18, 2023.
- A project table at the annual PAACL Family Fun Fair on Thursday, October 19, 2023, where we gathered input from 29 attendees including families, service providers and community members. Attendees were invited to share their experiences and ideas with the project team while being guided by a graphic facilitator, who captured their thoughts on a large, graphic facilitation that was completed and given to PAACL at the end of the Family Fun Fair.



"There needs to be education for parents on how to find help, so they can build a village."

- Port Alberni parent/caregiver

In all sessions, participants shared what is working well, opportunities for improvement and the ideal vision of what support should look like for families in Port Alberni and surrounding communities. In response to the question "What is working well in Port Alberni and surrounding areas?" participants shared:

- There is a strong network of collaborative, committed, and long-tenured professionals in the community.
- One service provider shared, "We are a resourceful community. Even when there isn't the direct funding, we are finding what we can to make it happen. It's exhausting but we do."

- The therapies in the community are working well for families (when available).
- Non-governmental agencies, such as Jordan's Principle, Bear Essentials, Variety, CKNW and the Special Olympics are providing funding and service opportunities.
- The Nuu-Chah-Nulth Tribal Council (NTC) is working well for supports linked to membership on the reserve.
- Culture and community, with an emphasis on supporting Indigenous culture are important and seen as strengths by community and family members.
- Available daycare spots are a wonderful support to the community (when available).

The following table details participants' thoughts on opportunities for improvement and ideas for meaningful change in Port Alberni and surrounding communities.

Conversation themes

Supporting details

LACK OF SERVICES

'[My child can't go to] preschool because they only receive one hour of support per day." - local family member/caregiver

- Families feel there are insufficient services, such as
 Physiotherapists, Speech and Language Therapists, and
 Occupational Therapists, available to meet the needs of Port Alberni families.
- Several parents shared about having to stop working entirely in order to support their child's needs.
- Several parents talked about their children only being able to attend preschool or kindergarten for an hour a day because the other hours do not have Educational Assistant support for their child.
- Some families have had to move outside of the community to receive support for their children due to a lack of local services.
- Families feel there is a disconnect between the services they are told are available and the reality of waitlists.

NAVIGATING SYSTEM AMBIGUITY

"Hard to find reliable, useful information in the sea of internet searches – how to find it if you don't know what you're looking for?" – local family member/caregiver

- Families want someone to help them navigate the system and the supports available.
- Families want greater coordination of services to ensure their child is getting everything they need.
- One service provider said, "[There needs to be a] case manager/navigator with no more than five families on their caseload to support connection with transportation to multiservice collaboration support."

LOCATION AND TRANSPORTATION BARRIERS

"[We need] transportation supports to get to Vancouver for medical appointments." – local community service provider

- Families expressed frustration that they have to travel (or move altogether) to receive services and supports for their child.
- One parent shared, "Nanaimo was the closest physio I could access for my child, we had an opportunity to go, but then the highway shut down."
- Service providers expressed that geographical barriers (i.e. highway closures) impact other professionals' ability to travel and support the community.
- Families want more funding for travel costs, as many have to travel far distances to access therapy or support. One parent shared, "I spend \$120 every two weeks on services that aren't available in Port Alberni and travel 30 minutes each way."

CULTURAL SAFETY

"Education on early childhood trauma and multi-generational trauma is needed." - local community service provider

- Families want culturally safe respite and more options when it comes to choosing respite supports.
- Indigenous families shared that they experience trauma when trying to advocate for their children or grandchildren.
- Several participants said they want the Government to speak to Indigenous people directly to find out what they want and need.
- One family member shared, "Services and supports are needed for all Indigenous People in all places in and around Port Alberni."
 Another family member added, "Truth and reconciliation is needed for people in Port Alberni."

STAFFING AND RECRUITMENT

"Fund tuition for people training in any human support role and tie it to mandatory services in resourcescarce communities such as nurses, therapists and ECEs" – local service provider

- Service providers and families feel that more staff is needed to meet the demand. One service provider said quite simply, "We have the building. We have the model. We can't get the people."
- There is a lack of qualified professionals at all levels of the system. One service provider said, "(We need to) incentivize therapists to come to Port Alberni with housing, community appeal, etc."
- The high number of caseloads is causing social workers to feel overloaded, which they feel is affecting the quality of their work.

SCHOOL YEARS ARE CHALLENGING

"[The] school system kept making promises that the child would see specialists, but it never happened." – parent

- Families feel there is limited support in schools and some even have to move to receive support.
- School support is only based on a diagnosis, not what is needed.
- Children can't go to school because there is not enough EA support, or they can only go for one hour per day because that is all there is support for.

LACK OF RECREATIONAL ACTIVITIES

"I need a place for my child to physically exercise." - local family member/caregiver

- Families and youth feel there are not enough recreational activities available, both indoors and outdoors.
- Several families talked about having to travel to Nanaimo to get access to services and recreational activities (like swimming) for their children.
- Families want enhancements to local recreational activities making them more inclusive - this includes more accessible and inclusive playgrounds in Port Alberni.
- Parents are needing to champion and fundraise for recreational supports. One parent shared, "In order to get attention and raise funds for an inclusive playground, my friend and I are personally holding a fundraiser." See link to article below detailing the fundraising efforts of two Port Alberni mothers who attended: https://www.albernivalleynews.com/community/port-alberni-parents-lobby-for-new-inclusive-playground-2273269

LACK OF RESPITE, ESPECIALLY CULTURALLY SAFE RESPITE

" [We need] culturally safe respite, and choices in respite support." – local family member/caregiver

- Parents are feeling extremely overwhelmed and unable to take a break for themselves due to the lack of respite support in the community.
- Family members also shared they experience fear and judgement when asking for help. Specifically, the fear of their child being taken away.

DIAGNOSIS AND EARLY INTERVENTION CHALLENGES

"I have worked with a family that has gone through the diagnosis process three times before getting a diagnosis." - local community service provider

- Families feel they are in an "intense competition" with one another to receive an early diagnosis.
- Service providers feel there are gaps in the diagnosis process. One said, "The child is getting older and older. We all learn early intervention is key, but then it's not happening."

ENGAGEMENT FOLLOW-UP

Following initial engagements in Port Alberni, additional virtual engagements will take place:

- Reporting Back to Community Virtual interviews and/or a survey with local community partners and families inviting them to review the Community Report and provide their feedback to ensure we've correctly captured and interpreted the community's feedback, hopes and expectations?
- Solutions Table Meeting A virtual session inviting a broader group of community members, including those providing support to families in healthcare, education, recreation, and local government, to hear the engagement results and develop solutions for the community to consider and implement for meaningful change.

Throughout 2024, the Provincial Working Group will share preliminary results and project updates with MCFD. In January 2025, summary reports of all sessions will be submitted to MCFD. For a full list of community engagements, visit www.inclusionbc.org/campaigns/clcp-grants/.

The expectation from the Provincial Working Group and Local Engagement Teams is that the transformation of the CYSN program will better respond to the needs of BC communities and, most importantly, of the young people who are at the centre of this work.

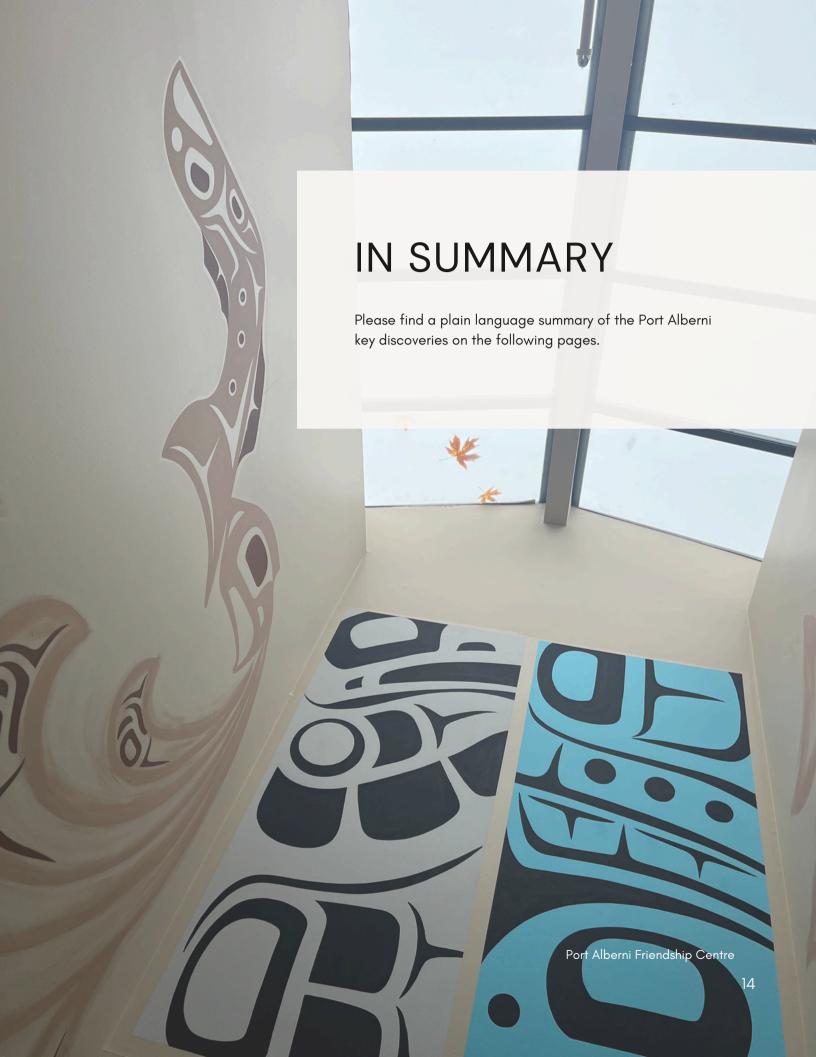
In all cases, the outcomes of The Community-Led Collaboration Project remain with the communities who participated. The hope is that the participants' ideas and experiences will serve as a road map for BC communities as they work to build better networks of services and supports and make changes in their community to best support children and youth with disabilities or support needs and their families.

WITH THANKS

The Community-Led Collaboration Project would like to deeply thank everyone who shared their time, ideas, experiences, concerns and hopes with us.

Their words have made all the difference as Port Alberni and surrounding areas look to best support children and youth with disabilities or support needs so they can thrive now and into the future.





WHAT WE HEARD IN

PORT ALBERNI

Located on the traditional territories of the Hupacasath and Tseshaht First Nations.

Over three days in October 2023, 59 Port Alberni families, service providers, and community members shared their experiences and input with the Community-Led Collaboration Project. Together, we talked about the struggles, hopes, and expectations for services and supports for kids ages 0-19 with disabilities or support needs.

What's working well in Port Alberni

- There's a strong network of collaborative, committed professionals in the community.
- Service providers are resourceful, and said they find creative ways to work with what they
- Therapies are working well for families, when they are available.
- There are some good non-governmental agencies that provide funding and services.
- The Nuu-Chah-Nulth Tribal Council has good supports linked to membership on the reserve.
- Culture, community, and supporting Indigenous culture are important community strengths.
- Daycare spots are a wonderful community support, when they are available.

Opportunities for change

Lack of local supports and services

Families feel there aren't enough specialists to meet the community's needs. They said they need more professionals like physiotherapists, speech and language pathologists, and occupational therapists.

Some parents have had to quit work, or move outside the community to get the supports and services their child needs. Families said they're told services are available, but then find out

how long the waitlists are.

Trouble figuring out how to use the system

Families said it's hard to find reliable information. They asked, "how do I find something I don't know I'm looking for?"

Families said they want a case manager to help them find their way around the local and provincial systems. They suggested case managers should have a maximum "[My child can't go to] of 5 families on their caseload at a time. They said they want these systems to be more

coordinated and connected.

preschool because they only receive one hour of support per day."

- local family member/caregiver

Not enough respite

Families said they were struggling to find culturally safe respite.

Parents/caregivers said they felt overwhelmed and can't take the breaks for themselves that they truly need. Some shared they sometimes felt judged when they asked for help. For some, this judgement made them feel scared their child might taken away from them.

More cultural safety

Indigenous families shared that they experience trauma when they try to advocate for their children or grandchildren.

Several families said they want the government to speak to Indigenous people directly to find out what they need.

Better transportation

Families said they want more funding for travel expenses, since they can't access the services they need in their own community.

Highway closures are huge barriers for families, who have to travel 30 minutes or more outside of Port Alberni for services, or rely on specialists to travel into Port Alberni.

"I have worked
with a family that has
gone through the
diagnosis process three
times before getting a
diagnosis."

 local community service provider

Early diagnosis challenges

Families said they feel "intense competition" with each other to get an early diagnosis.

Service providers said they feel there are gaps in the diagnosis process, saying "we all know early intervention is key, but then it's not happening."

More therapists needed

People said there just aren't enough professionals to keep up with demand.

Service providers are feeling overwhelmed by high caseloads. They suggested finding incentives, like housing, to bring more therapists to Port Alberni.

School years are hard

Families said they feel the schools make promises about services that never happen.

Some families said they had to move to get supports. Some children can't attend all-day school because there aren't enough education assistants.

Not enough recreational activities

Families said they have to travel to Nanaimo for basic activities like swimming lessons. The playgrounds in Port Alberni aren't very accessible or inclusive.

Families said they have to push for more inclusive recreational spaces. They've even started their own fundraisers for money to build these spaces.