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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. The announcement of the CYSN framework was met with confusion and fear by many across the province. 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 Hitacu**, **British Columbia** – one of five communities on the West Coast of Vancouver Island that participated in the engagement.

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.

Inclusive communities are healthier communities. Building inclusive communities 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 surrounding communities
- West Coast of Vancouver Island communities
- Richmond

ENGAGEMENT WITH WEST COAST COMMUNITIES

Between August and November 2023, in-person engagements took place with families, youth, Elders and community service providers in several communities along the West Coast of Vancouver Island in British Columbia. The West Coast communities have a total population of 7,626 people. The median age of people living in the West Coast communities is 39 years compared to 48 years in British Columbia as a whole. Thirty percent of people living in the West Coast communities are Indigenous.

To ensure a culturally safe process of engagement, the Community-Led Collaboration Project partnered with a local facilitator with strong community relationships. The facilitator engaged nearly 200 people in conversations about their experiences, ideas, and hopes for a future where all children with disabilities or support needs can thrive.

Engagements took place with the following communities/community groupings:

- Ahousaht (50 people engaged)
- Hitacu (Five people engaged)
- Opitsaht (33 people engaged)
- Tofino and Ucluelet (47 people engaged)
- Ty-Histanis and Esowista (49 people engaged)



Image Courtesy of Tofino Trails

l. Clayoquot Sound Biosphere Region's Vital Signs® (2025), Clayoquot Biosphere, online: https://clayoquotbiosphere.org/files/file/6541460ea68ct/CBT Vital Signs 2025.pd
2025.pd

^{2.}lbidem. 3.lbidem.

ABOUT HITACU



Image courtesy of Powell River Peak

Hitacu is located on the eastern shore of Ucluelet Inlet across the bay from the District of Ucluelet. It is a modern post-treaty government of the Yuułu?ił?atḥ people.⁴ Hitacu has a population of 321 people.⁵ Children up to the age of 14 make up 26.6 percent of the population of Hitacu. Over three-quarters of the population (81.3 percent) are of single Indigenous ancestry.⁶

To get to Ucluelet, the residents of Hitacu can take a boat across the bay or drive (which is the most common access). The trip takes about 20 minutes, and people do it regularly to purchase groceries for their families. Children in Hitacu attend the local elementary and high schools in Ucluelet. Hitacu has its own health clinic, recreational hall, and daycare. The community also has its own community nurse, and the doctor from Ucluelet comes once a week.

The Strong Start program put on by School District 70 also visits the community every week.

Over three-quarters of the population of Hitacu (81.3 percent) are of single Indigenous ancestry.⁶

^{4.} Yuułu?ił?atḥ Government (2024), online: https://www.ufn.ca

^{5.} Statistics Canada (2021), Itatasoo 1, Indian reserve (IRI) British Columbia [Census subdivision]. online: https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/details/Page.cfm?

Lang=E&SearchText=httacu&DGUIDlist=2021A00055923807&GENDERlist=1,2;3&STATISTIClist=1,4&HEADERlist=0

WHAT WE HEARD IN HITACU

The facilitator was invited to engage in conversations with the local community by a service provider based in Hitacu. Engagement in Hitacu took place in October 2023 with:

- Two family members
- Three community service providers

In response to the question "What is working well in Hitacu?", family members and service providers shared:

- There is a doctor who visits Hitacu weekly to see children and caregivers in the community and to expedite referrals to specialists, as needed.
 - In addition, there is a full-time community health nurse who provides vaccinations, and helps families with referrals, patient travel, equipment and supplies.
 - The Nation has also hired a full-time physiotherapist (PT) to support children and youth with needs.
- Strong Start offers a weekly program in the community and children of all abilities are welcome to attend.
- Daycare goes above and beyond for children with support needs. For example, local daycares hire private speech and language pathologists (SLPs), but only when they have the available funding.

"It would be nice to have a place to meet other parents out here who also have a child with a disability because they are the only ones who really get it."

-Hitacu family member/caregiver

The following table details community members' thoughts on opportunities for improvement and ideas for meaningful change in Hitacu:

Conversation themes

Supporting details

LACK OF SERVICES AND SUPPORT (CHALLENGES ACCESSING SUPPORTS)

"To think you can just see children with support needs and their families over a Zoom session is not ok. The children need real people who sees them in person and the families need to connect with the service provider in person (...) I understand that during the pandemic this was a challenge but there is no excuse anymore (...) The children and families deserve the services that they are entitled to and everything else is not good enough."

-Community Service Provider

- According to local families, outside agencies such as
 Outreach Therapy are supposed to provide occupational
 therapists (OTs) and PTs, Island Health is supposed to
 provide SLPs, but the community has received minimal
 support through these agencies.
- There is no paediatrician who comes to Hitacu, and families need to travel to Port Alberni (20-minute ferry ride, plus a two hour drive) for this service.
- Families have a difficult time finding a family doctor.
- There are no support services for children, youth and families living with Fetal Alcohol Spectrum Disorder (FASD), and one family shared it's been extremely difficult to get a diagnosis and there is a lot of shame in seeking diagnosis.
- Families talked about the challenges of travelling to receive supports and that barriers to travel mean their children receive supports inconsistently. Barriers to travel include financial barriers to get to the appointment but also environmental barriers like road closures, challenging road conditions, illness, and other life events.
- With a single income, families find it hard to pay rent and then afford to take their child to appointments out of town.
- Families with children with disabilities expressed being in desperate need of respite.

EARLY INTERVENTION SERVICES

"The infant development program is really missed in the community. We live in a remote community and there is no real support for new mothers (...)"

-Local Community Member

 There is no early intervention team in Hitacu. One family shared there are no baby groups, no parenting groups, no Aboriginal Infant Development Program (AIDP)/Infant Development Program (IDP)/ and no Aboriginal Supported Child Development (ASCD)/ Supported Child Development Program (SCDP). One parent/caregiver shared, "First, we have to deliver our babies out of our community and are often gone for a month. Then we come home and there is no one who really checks in on us and our babies and their development (...) How are you supposed to know if your child is delayed in development?"

MENTAL HEALTH

"I would like to access the mental health worker that comes into our community but simply choose not to because I cannot make an appointment. I do not feel like sitting and waiting among other community members to be seen. It is none of their business that I want support."

-Family member/caregiver

- There is a mental health worker coming to the community, but it's drop-in only. Families see this as a barrier as many do not want others to know they are seeking mental health services, especially for youth, and fear running into people they know while seeking mental health support.
- Families shared that it's very stressful, exhausting and anxietyprovoking to have a child with a disability and not enough support. Constant advocacy for services, lack of support, driving to appointments, and completing extensive paperwork takes an enormous toll on families.

RIGID FUNDING

"I also know of a SLP in the area that I would hire but I am not allowed to use the autism funding for that as they are not on the list. It doesn't make any sense. Furthermore, to know that the autism funding drops down to \$6,000/year instead of the \$23,000 we get now doesn't make any sense (...). If anything, I think their needs might be higher and will be more expensive."

-Family member/caregiver

- The rigidity of the funding model makes it difficult for families to get the supports they need in their own community from a local service provider and/or therapist.
- One parent/caregiver shared, "We must get a service provider, to help our child, from the Registry of Autism Service Providers (RASP) list. None of the service providers on that list are out here on the Coast. That means we will have to travel as a family to see a service provider on the other side of the island, even though there are people out here I can hire privately like the physiotherapy."

OTHER THEMES: AFFORDABLE HOUSING, STAFFING AND CONNECTION

"It was hard for me to relate, and it still is hard to relate to other moms whose child does not have a disability. There is a great amount of grief involved in my journey and I have no one to share that with. Other parents just don't get it. It would be nice to have a place to meet other parents out here who also have a child with a disability because they are the only ones who really get it."

-Family member/caregiver

- There are no support groups for families and parents of children and youth with a disability or support needs in Hitacu.
- There are not enough workers to work as Early Childhood Educators (ECEs) because of the pay which is not enough to cover the cost of living on the West Coast. One person said, "A fair number of people on the West Coast have their ECE but choose not to stay in the field as the wages are too low and do not cover the cost of living."
- There is no access to affordable housing and the cost of living on the West Coast is higher compared to Port Alberni, for example.
- Opportunities for connections between families with children and youth with support needs is needed. Families often feel isolated and alone.

A VISION FOR SUPPORT IN HITACU

As part of the conversations in Hitacu, parents, caregivers, and community service providers were invited to envision an improved network of services and supports for children and youth with disabilities and support needs.

In response, people shared their visions for the future of the community including:

Consistent services and supports. Permanent, dedicated and consistent supports from OTs, PTs, SLPs and a FASD key worker that delivers services, in person, in the community. This also includes a paediatrician who comes to the community monthly.

Accessible and culturally safe mental health services delivered by a diversity of counsellors who offer addiction, grief and loss supports.

OTs, PTs and SLPs in the elementary and high schools in Ucluelet (where students from Hitacu attend school) and the needs of students are addressed effectively.

Opportunities for connection between families, children and youth with supports needs.

This could include potlucks, information sessions or simply a place to meet and share stories and get emotional support.

Outreach worker/s for the daycare in Hitacu to help families advocate to help families with children's daycare needs, access resources and funding opportunities and help them with paperwork.

Flexible and accessible funding. For example, autism funding that allows families to hire a local, registered therapist that serves their region, so they don't have to travel to get support for their child.

Better wages for ECE and support workers in daycare and recreational programs.

More options for respite care for children and youth with support needs and their families.

More affordable housing on the West Coast so communities become more accessible and attractive places for service providers to live and work.

FINAL STEPS OF ENGAGEMENT

Throughout 2024, the Provincial Working Group shared preliminary results and project updates with the Ministry of Children and Family Development (MCFD). In January 2025, the summary reports from the 23 community engagements, including those from community engagement grants and the six initial community engagements, will be submitted to the Ministry of Children and Family Development (MCFD). Community contributions have been instrumental in shaping these reports.

In all cases, the outcomes of the Community-Led Collaboration Project belong to the communities. The hope is that participants' ideas and experiences will serve as a tool for B.C. communities as they work to build and advocate for 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.

Please share this report widely – it is not just a reflection of your community, but a catalyst for the change needed in your community. We believe it holds the potential to inspire a future where every person can thrive and to contribute to a transformation of the Children and Youth with Support Needs (CYSN) program and other programs and services that better responds to the needs of B.C. communities and, most importantly, of the young people at the centre of this work.

For more ideas and tools to share this report, please visit <u>www.inclusionbc.org/what-we-do/community-partnerships-engagement/community-led-collaboration-project/</u>.



WHAT WE HEARD IN

Hitacu

Hitacu is a modern post-treaty government of the Yuulu?il?ath people.

Hitacu is located on the eastern shore of Ucluelet Inlet across the bay from the District of Ucluelet. Hitacu has a population of 321 people. Children, up to the age of 14 years, make up over a quarter of the population (26.6 percent). In October 2023, a facilitator was invited to have conversations with two family members and three community service providers.

What's working well in Hitacu

There are several available community supports that work well for families in Hitacu including:

- a doctor who visits the community weekly to see children and caregivers
- a full-time physiotherapist hired by the Nation supports children and youth with support needs
- a weekly Strong Start program that welcomes all children in the community
- a local daycare that hires a speech and language pathologist (SLP), but only when funds are available.

Opportunities for change

Lack of local supports and services

Families don't have enough support from outside agencies or access to a paediatrician.

Most families need to travel to Port Alberni, a 20-minute ferry ride (plus 2 hour drive) to access services. The need for travel means many children in Hitacu don't receive consistent supports.

Funding challenges

Funding rules make it challenging for families to get supports from local service providers or therapists.

One parent said, "We must get a service provider to help our child from the Registry of Autism Service Providers (RASP) list

None of the service providers on that list are out here on the Coast. That means we will have to travel as a family to see a service provider on the other side of the Island..."

"To think you can just see children with support needs and their families over a Zoom session is not okay."

Community Service Provider

Mental health privacy

Families are struggling to access mental health supports in ways that respect patient privacy.

A mental health worker comes into Hitacu for drop-in appointments. Many families are concerned about their privacy as they, often, run into other community members, while waiting for their appointment. One community member said, "I would like to access the mental health worker that comes into our community but simply choose not to...I do not feel like sitting and waiting among other community members to be seen."

Early intervention needed

There is no early intervention team in Hitacu.

One family shared there are no baby groups, no parenting groups, no Aboriginal Infant
Development Program (AIDP)/Infant Development
Program (IDP)/ and no Aboriginal Supported
Child Development (ASCD)/ Supported Child
Development Program (SCDP) in Hitacu.

"The infant development program is really missed in the community. We live in a remote community and there is no real support for new mothers."

- Family member/caregiver

Visions and Solutions

During the conversations in Hitacu, parents/caregivers and community service providers were asked what a better network of services and supports for children and youth with disabilities and support needs could look like in their community. They shared many ideas and solutions.

More services and supports

Families want occupational therapists (OTs), physiotherapists (PTs), and speech-language pathologists (SLPs).

They also want accessible, culturally safe mental health services, more recreational activities, respite and flexible funding.

Better working conditions for service providers.

Community service providers want better wages for roles such as, Early Childhood Educators (ECEs) and support workers in daycare and recreational programs.

More affordable housing options attract service providers to live and work in their community.

An outreach worker at Hitacu daycare

Families want an outreach worker who can help them advocate for their children.

Families, specifically, want help from an outreach worker to advocate for children's daycare needs, access resources and funding opportunities, and help them with paperwork.

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 Hitacu looks to best support children and youth with disabilities or support needs so they can thrive now and into the future.









