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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 Opitsaht**, **British Columbia** – one of five communities that participated in the engagement of various West Coast of Vancouver Island Communities.

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

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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.

Engagement 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

^{1.} Clayaquot Sound Biosphere Region's Vital Signs® (2023), Clayoquot Biosphere, online: https://clayaquotbiosphere.org/files/file/6541460ea68cf/CBT Vital Signs 2023.pdf

^{2.}lbidem.3.lbidem.

ABOUT OPITSAHT



Image courtesy of By Sam Beebe, Opitsat, Tla-o-qui-aht First Nation,

Opitsaht is an Indigenous community located on the West Coast of Vancouver Island, just across the harbour from Tofino. It is located on Meares Island on the unceded traditional territory of the Tla-o-qui-aht First Nation of the Nuu-chah-nulth Peoples. Opitsaht has a population of approximately 150.⁴ Children up to the age of 14 make up 35.5 percent of the population of Opitsaht. Twenty-five percent of married couples have children, while 12.5 percent of common-law couples have children.⁵

Opitsaht is only reachable by boat from Tofino - which costs \$7.00 each way. The commute by boat is short but can be challenging when the weather is bad. **Upon arriving in Tofino, the dock and uphill path to the grocery store, health unit, doctor's office, and hospital can be very challenging for families, especially those using a stroller or wheelchair.**

Children in Opitsaht attend school in Tofino and Ucluelet in School District 70. The children/youth take the boat across to Tofino every morning, and they are picked up by buses that either transport them to the elementary school in Tofino or the high school in Ucluelet. In the afternoon, they are brought back to the dock and return home by boat.

Opitsaht has a population of approximately 150 and is only reachable by boat from Tofino.

^{4.} Opitsaht West Coast N.E.S.T, West Coast Nest, online, https://www.westcoastnest.org/communities/opitsaht#"."text=Approximately%20150%20people%20live%20in%20opitsaht.
5. Statistics Canada (2021), Abonjain Population Profile, 2016 Census, Abousaht [First Nation/Indian band or Tribial Council area.] British Columbia, online: <a href="https://www12.statcan.ge.ca/census-recensement/2021/dp.pd/prof/details/page.cm/lang-E&CENDERIIst=1_2.88E/AISTICIIst=1_4&REDERIIst=0.86OUIDlist=2021A00055923813&SearchText=Opitsat%201

WHAT WE HEARD IN OPITSAHT

The facilitator hosted a three-hour event in Opitsaht on October 3, 2023, at Meares Island Culture Centre, as many of the community members didn't have the means to travel by boat to a previously held event in Ty-Histanis. Some community members expressed feeling quite isolated since the ocean divides them from Tofino and the rest of Tla-o-qui-aht. As one person shared, "We are simply forgotten over here. There are so many events and fun things happening in the other communities but never over here. Service providers don't seem to come here (...) it is hard for families always to be the ones who must go to Tofino on a boat".

The following people attended the session in Opitsaht:

- 18 local families
- 14 community service providers
- One Elder

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

- The sense of community connection. Families rely on each other for support as there is little support from outside providers. This includes networking and troubleshooting amongst themselves. The local service providers take on many roles and work together to service the children and youth in the best ways possible. One person shared, "Because services are not available, we usually figure it out ourselves. We have to!"
- The Wickaninnish Elementary School in Tofino is a great place for children with support needs.
- Local support workers take on as many roles as they can and work together to support children and youth best and advocate for their needs.

"We are simply forgotten over here. There are so many events and fun things happening in the other communities, but never over here. Service providers don't seem to come here. It is hard for families always to be the ones who must go to Tofino on a boat."

-Opitsaht community member

The following table details participants' thoughts on opportunities for improvement and ideas for meaningful change in Opitsaht:

Conversation themes

Supporting details

NAVIGATING SYSTEM AMBIGUITY

"Having a child with support needs can be overwhelming and having that one trusted person who helps navigate it all and support the family's journey would be a great support system to have."

-Family member/caregiver

- There is no social worker in the community and on the West Coast of Vancouver Island.
- Families are struggling to fill out paperwork to get funding or support for their children and youth.
- Families aren't aware of available supports because families do not know they qualify for them, and/or the paperwork is too overwhelming.
- Support for children and youth to get on waitlists for assessments is a significant gap in available services.
- A liaison support worker is needed to assist families in navigating the system and connecting with outside services, as well as to help with paperwork.

LACK OF SERVICES

"We tried the Zoom session once, and it was a complete waste of time. I won't be doing that again and I cannot get to Port Alberni to see the SLP. My child is not getting any speech services even though they are delayed (...) the system is failing us, and my child is going into a school that doesn't have a SLP either (...) I am furious but also tired of constantly trying to set something up. The SLP is not reliable and only comes to Tofino once every three months or so. I have other kids I take care of too."

-Family member/caregiver

- Repeatedly, families talked about the need to travel to Tofino to get supports and services for their children.
- There are no physiotherapists (PTs), speech and language pathologists (SLPs), doctors, or community nurses that come to the community.
- "Having a doctor coming to our community would save a
 lot of trips across. (...) it is not easy for me to walk to the
 boat with my four children, get them across and then walk
 up that steep hill (...) it is way easier for a doctor coming
 here than for all the families to go there."
- Medical travel funds are available, but the process is cumbersome, and the request does not get processed in a timely manner.
- "I once had to turn down an appointment for my child that opened the very next day, as we couldn't afford to go. We had to stick with the original appointment that was six months down the line (...); that was very frustrating when my child could have gotten help sooner (...). You pretty much cannot put yourself on a cancellation list because once the appointments do open, there is no way of getting there in time."

CONNECTION AND COMMUNICATION

"It seems like it is just by luck we know about what service providers are here in Opitsaht, which makes it hard to refer families to them. There is no real system or communication put in place and it is all over the map (...) it is also extremely frustrating when it is always different people coming and going with no follow up or when they do not introduce themselves."

-Local Community Member

- There is a lack of coordination and communication between available services and the local First Nations which makes it difficult to know who is doing what, who comes to the community, etc.
- The community expressed a desire for additional familyoriented groups, including pre- and postnatal groups, baby groups, toddler groups, family support groups, parenting groups, and youth groups. These groups offer valuable opportunities for connection and communication among families in Opitsaht.

MENTAL HEALTH SERVICES

"Our youth are so vulnerable and they need someone they trust to open up to about their problems and what support they are looking for (...) we have no youth workers or youth counsellors coming to our community and there is a huge need (...) we need someone who is willing to come and build those relationships and not just some random person that shows up once in a while (...) that won't help anything (..) our youth are struggling and need support."

-Local Community Member

- Counsellors and youth workers do not come to the community.
- There are no mental health services for younger children, such as play or play-based therapy.
- People expressed the need for regular and consistent mental health services operating out of a culturally safe place.
- They also want counsellors who use trauma-informed practices and are willing to learn about the Nuu-chahnulth culture and beliefs.

EARLY INTERVENTION

- There is no early intervention team that regularly visits the community.
- There are no groups for families to bring their babies and toddlers or any pre- or post-natal support groups available.

LOCATION/ TRANSPORTATION

"I have tried waiting for the boat in Tofino with my three children in the pouring rain, in the middle of winter. We waited for hours, and we all ended up sick (...) you kind of take a risk when you leave Opitsaht because you never know when you will be able to take a boat back."

-Family member/caregiver

- Families want a service hub for the West Coast with service providers coming to Opitsaht to support families, so they don't have to travel.
- Transportation to get the services for children and youth with support needs is a huge barrier for families.
- Tofino is the closest community to getting services for the people of Opitsaht but often they will need to travel much further as there are not enough services for their children and youth with disabilities or support needs in Tofino.
- One community member shared, "(I envision) a system in place where you could book a van, with a driver to take you to your appointment within 24 hours. Since the bus service got taken away from us, I see so many people hitchhiking to get to their appointments."

OTHER THEMES: RESPITE, STAFFING, AFFORDABLE HOUSING AND ACCESSIBLE RECREATION AND SPACES

- There is a lack of Education Assistants (EAs) at the elementary school due to low wages and the issue of housing and affordability on the West Coast.
- There are no respite workers in the community, and only one Child and Youth with Support Needs (CYSN) family support worker on the entire coast.
- There are no toddler groups running and the playground in the community needs to be updated to be accessible for toddlers and for children with mobility challenges and/or other disabilities.
- The dock is a barrier to travel, as it is steep and slippery when there is any rain making it difficult to handle strollers and wheelchairs or for anyone with mobility issues.

A VISION FOR SUPPORT IN OPITSAHT

As part of the conversations in Opitsaht, 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:

A service hub in Opitsaht

so families no longer need to travel to receive supports. The service hub would ensure access to full-time service providers that community members could build solid and trusting relationships with over time.

Collaboration, coordination and strong communication among service providers to organize family supports. An early intervention team so families get the supports they need before their children enter Kindergarten (and can let schools know about the required supports before their children start in elementary school).

More community support groups including prenatal and postnatal groups, baby groups, toddler groups, family support groups, parenting groups and youth groups. Consistent (weekly)
mental health services in
the community that are
culturally safe, and traumainformed.

Education and resources for families to learn how to best support their children who often don't receive the therapies and supports they need.

A trusted navigator who comes regularly to the community to connect families to supports and help them navigate the medical system and paperwork.

Transportation supports for families, including
medical travel supports in a
variety of options (funds in
advance, transportation
service with a van, etc.)

Safe and affordable housing in the community to attract service providers and therapists to live permanently in or nearby the communities.

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.

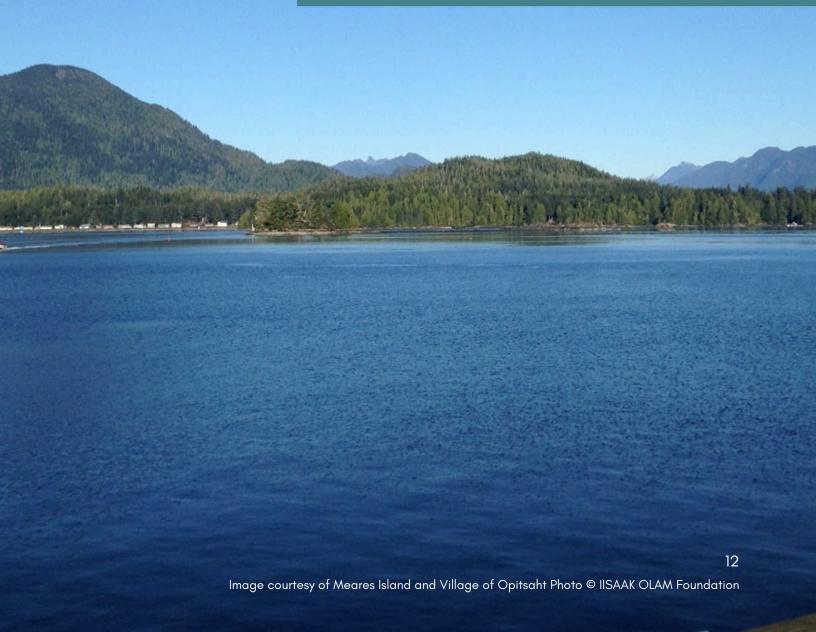
In all cases, the outcomes of the Community-Led Collaboration Project belong to the communities. The hope is that participants' ideas and experiences will serve as a tool for B.C. communities as they work to build and advocate for better networks of services and supports and make changes in their community 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>.

IN SUMMARY

Please find a plain language summary of key findings from the Opitsaht engagement on the following pages.



WHAT WE HEARD IN

Opitsaht

Opitsaht is located on the unceded and traditional territory of the Tla-o-qui-aht First Nation of the Nuu-chah-nulth Peoples.

Opitsaht is an Indigenous community located on the West Coast of Vancouver Island just across the harbour from Tofino. Opitsaht has a population of approximately 150. Children, up to the age of 14 years, make-up one third (35.5 percent) of the population. Opitsaht is only reachable by boat from Tofino. A facilitator held a conversation at the Meares Island Culture Centre with 18 local families, 14 community service providers and an Elder.

What's working well in Opitsaht

- There is a strong sense of community connection, with families relying on one another for support.
- Wickaninnish Elementary School in Tofino is recognized as a "great place" for children with support needs
- Local support workers take on various roles and collaborate to provide the best support for local children and youth while advocating for their needs

Opportunities for change

Families struggle to access supports

Families aren't aware of or don't have time/resoruces to access supports.

Families are struggling to fill in paperwork to get funding or supports for their children. Families also share they're not aware of all available supports and are challenged by waitlists.

Lack of services

Families need to travel to get supports and there are no physiotherapists (PTs), speech and language pathologists (SLPs), doctors or nurses that come to the community community.

One parent said, "Having

a doctor coming to our community would save a lot of trips..." Medical "...having that one travel funds are available, but the process is cumbersome for families and requests aren't processed in a timely to have." " manner.

trusted person who helps navigate it all and support the family's journey would be a great support system

- Family member /caregiver

Connection and communication

There is a lack of connection and communication between available services and local First Nations.

Community members find it difficult to know who is doing what and who comes to community. People also expressed the wish for more groups to enhance connection such as pre- and postnatal groups, baby groups, toddler groups, family support groups, parenting groups and youth groups.

Mental health supports

There is a lack of culturally safe mental health supports in the community.

Counsellors and youth workers don't come into the community and there are no mental health services for younger children. Community members want regular and consistent mental health services operating out of a culturally safe place using trauma informed practices, learned from the Nuuchah-nulth culture and beliefs.

Transportation challenges

Families want service providers to come to their community so they don't have to travel.

Transportation to get children to services and supports is a huge barrier for families. Many families need to travel to Tofino, or further, to get the supports they need. One family member said, "What are people supposed to do when they do not have a vehicle to bring them to appointments out of town?"

Visions and Solutions

During the conversations in Opitsaht, parents/caregivers, community service providers and an Elder 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.

A local service hub

A service hub in Opitsaht.

Families want a service hub in Opitsaht with access to full-time service providers that community members could build solid and trusting relationships with over time.

A trusted navigator

A navigator to connect families to local supports and services.

Families want a navigator who can act as a liason between families and serivce providers helping them nagivate the medical system and support them with paperwork.

Transportation supports for families

Families want transportation supports including medical travel supports available to them.

Families, specifically, want travel supports to get to appointments. One community member said "There would be a system in place where you could book a van, with a driver to take you to your appointment within 24 hours. Since the bus service got taken away from us, I see so many people hitchhiking to get to their appointments."









