











Community-Led Collaboration Project2024

The Voice of Sooke, West Shore and Surrounding areas

With thanks to the traditional territories of the Coast Salish: T'Sou-ke Nation, Sc'ianew Nation, Esquimalt Nation, Songhees Nation, and the Nuu-chah-nulth: Pacheedaht Nation.









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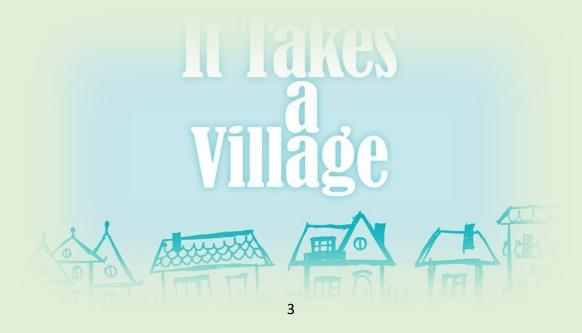


Project Background

The Community-Led Collaboration Project (CLCP) provided communities in British Columbia the opportunity to engage in meaningful and inclusive conversations about how to create a better network of services for children and youth with disabilities and/or support needs and their families. Notes from all the conversations have been compiled into this report. The results from all the conversations will be part of a report that is being submitted by Inclusion BC and the CLCP Grant Committee. This and other community reports will be shared with the Ministry of Children and Family Development (MCFD) with the intent of helping develop the future of services for Children and Youth with Support Needs (CYSN) in BC. All personal information in this report is confidential, and no individual names or identifying characteristics have been used.

The Community-Led Collaboration Project aims to build on the existing strengths of community-based models and explore what truly collaborative and connected networks can achieve by working together for children and youth with support needs and their families. The community conversations that are included in this report focuses on children and youth who are under the age of nineteen, have an undiagnosed or diagnosed disability, need supports, and/or have possible developmental delays.

These conversations, which were conducted in partnership with West Shore, Sooke and surrounding areas, will help inform an inclusive, culturally safe, needs-based approach to providing supports and services that consider the specific circumstances of the young people in need of supports and their families who live in these communities, and, importantly, the voices of people who historically have not been represented.



About the West Shore, Sooke and Surrounding Areas

The Western Communities, (which include Metchosin, Highlands, Langford, and Colwood) and extend from Sooke to Port Renfrew, are located on Southern Vancouver Island, on the unceded traditional territories of the Coast Salish: T'Sou-ke Nation, Sc'ianew Nation, Esquimalt Nation, Songhees Nation, and the Nuu-chah-nulth: Pacheedaht Nation. This region is surrounded by forests, ocean, mountains, and lakes and is located to the west of Victoria, the capital city of British Columbia.

The town of Sooke is located approximately twenty-five kilometres west of the West Shore towns. Port Renfrew is located seventy-two kilometres to the west of the town of Sooke. Public transportation west of the West Shore is limited.

According to the 2021 census, this area is home to approximately 88,442 people; 5.9 percent of people living on the West Shore and surrounding communities identify as Indigenous.₍₁₎ The Sooke School District (SD62), which serves students in the region, has approximately 13,250 students enrolled.₍₂₎ In 2023, 4,378 students (33.04 percent) received support through SD62's Inclusive Education Services Department.₍₃₎ Additionally, there are approximately 4,670 children, under the age of four, living in the Western Communities.₍₄₎ The Local Health Area Profile for the region states an expected population growth of 53 percent over the next twenty years.₍₅₎

According to the Early Development Instrument (EDI), a research tool used by the Human Early Learning Project (HELP) at the University of British Columbia to help understand healthy child development in the province, childhood vulnerability rates vary significantly across BC. According to HELP, "We consider a rate of 10 percent to be a 'reasonable' benchmark for child vulnerability. With this in mind, the current [provincial] vulnerability rate [in one or more areas of development] of 33.4% is over three times higher than we would consider acceptable." (6)

In the West Shore, 25.25 percent of 655 enrolled kindergarten children are vulnerable on one or more scales of the EDI upon entry to kindergarten.₍₇₎ From Sooke to Port Renfrew, 32 percent of 186 kindergarten children are vulnerable on one or more scales of the EDI upon entry to kindergarten.₍₈₎

EDI research indicates that these high percentages show that West Shore and Sooke children are vulnerable in one or more areas of development. Social, emotional, physical health, and well-being are the highest areas of vulnerability in this region. These percentages of between 25 and 32 percent are far above the rates HELP considers "reasonable." (9)

The Process of Engagement

Pre-Engagement and Engagement Planning

On April 25, 2024, a pre-engagement planning session was conducted to share information on the Community-Led Collaboration Project and gather community input into the planning process on how to best reach communities to participate in the engagements. Valuable input was provided by British Columbia Aboriginal Network on Disability Society (BCANDS), Métis Nation BC, educators, community agencies, Island Health, parent representatives from the District Parent Advisory Council (DPAC) for SD64, and the FamilySmart and Family Support Institutes. In addition, some parents and family members who work in the field and have lived experiences with the challenges that are faced by children and youth with disabilities and/or who need supports, contributed invaluable feedback for how to plan the engagements.

From June to October 2024, numerous community engagements took place, involving families, self-advocates, service providers, and educators. Participants were informed through various methods such as personal invites, posters, Facebook posts, a digital newsletter mail out, Community Living and community partners' websites, and through their children's caregivers. The Community-Led Collaboration Project created safe spaces for conversations by offering locations to meet that were comfortable for the participants, providing childcare, and making translation supports available where needed. The engagements utilized methodologies of an inperson world café format, surveys, and both virtual and in-person discussions for those who preferred not to meet in a group.



Family Engagement

Engagement Sessions for Families:

Sooke session, July 4, 2024: Four families registered; two attended West Shore session, July 11, 2024: five families registered; three attended

Family Focus Groups

Sooke Family Resource Society, July 17 and 24, 2024: neurodivergent family play group; thirteen families participated

Military Family Resource Centre, July 31, 2024: eight families participated

Supported family Interviews/ Surveys

Sooke Family Resource Society, family support outreach to Port Renfrew/Pacheedaht First Nation, supported survey completion, August and September 2024: three families participated

Island Metis Family and Community Services Society, supported survey completion, August and September 2024: three families participated (from the West Shore, Saanich Peninsula, and Victoria communities)

Service Providers Engagement

Engagement Sessions for Service Providers:

Sooke session, June 6, 2024 : 18 people registered, 11 attended West Shore session, May 30, 2024: 17 people registered, 16 people attended

Service providers who attended the engagement represented the following groups:

Sooke Family Resource Society, Island Metis Community Services, Boys and Girls Club of South Vancouver Island, Always Active – accessible sports and recreation, Military Family Resource Centre, Thrive Social Services Association, Kingfisher Preschool, Family Smart, Metis Nation BC, Little Steps Therapy Services, Wild Seeds Speech, Language & Supported Learning Services, Victoria Speech and Language, Blossom Behaviour Services
Island Health – Public Health and Supported Child Development
Island Health – Supported Child Development
Community Education supports

Surveys:

Family Surveys (Sooke – 3 families; Westshore - 4 families) Service Provider Surveys (Sooke – 1 survey; Westshore - 2 surveys)

What We Asked

In all engagements, participants were asked the following three questions:

- 1. What services and supports for children and youth with support needs are working well in your community?
- 2. What are the gaps in services and supports for children and youth with disabilities or support needs and their families? What is missing or hard to access in terms of services and supports in your community?
- 3. What does a better network of services and supports look like? What changes or improvements would you like to see in your community so that children and youth with support needs and their families can thrive?



What We Heard

The following are the overarching conversation themes that arose from the engagements with Sooke, the West Shore, and the surrounding communities:

CONVERSATION	SUPPORTING DETAILS
THEMES	
"We need a 'family-centred approach' with a dedicated case manager who understands both the system and specific needs of families, ensuring parents are heard and supported."—Family member	 There is a desire for more trust and more listening to families and children regarding their preferred types of services and care philosophies. The opinion was voiced that many services and funding models are deficit based. Neurodiversity affirmation acknowledges the challenges neurodivergent children face with speech or sensory regulation, while also recognizing the disabling role deficit-based policies and practices play in shaping the services that these children receive through CYSN, MCFD, and Autism Funding Unit (AFU). Use of language within systems (communications, website, pamphlets, etc.) is perceived as frequently being deficit based, which may not reflect how families would like to have their children discussed. Language and cultural barriers can prevent families from having choices or understanding choices. Child and family-centred supports and planning should be at the forefront. Lack of resources, type of supports, and funding models can limit choices available to families: "There is a lack of informed choices and options for families and wrap-around supports are insufficient. The available services often offer prescriptive rather than individualized options."—Service provider
Access to services/inclusion "Often supports are time-limited, waitlists are lengthy, and [there is a] lack of respite services. Families often have to pay out of pocket for supports and there is frequently a lack of communication	 It was expressed that there are many gaps in both infrastructure and services that do not promote inclusion, i.e., lack of accessible playgrounds, safe places to play, sensory-friendly places, lack of recreation, community groups, and supports for children nine to eleven years old. There can be inequities in accessing childcare, especially for children who need supports: "[It's] difficult to work outside of the home because waitlists for childcare spaces for kids who need support are longer, kids with support needs have more appointments and are sometimes only offered half-day spots in kindergarten because support needs can't be met in the school system."—Family member

between supports and services."—Parent	 Families who need to move to another region may lose supports and may require being put on waitlists for services and medical supports in their new communities. Forms can be complex and difficult to understand and complete. For newcomers and new immigrants, connecting with resources can be confusing and often they do not know how to access resources. Families who live in rural areas may struggle with lack of local services, and transportation to access supports can be expensive. It was mentioned that assessments do not always mirror the actual needs and support. Often there are long waits for assessments and having one does not necessarily mean that help will follow. How can we ensure that assessments are available for everyone who needs them? Supports and services should be as diverse as the needs of those accessing them. It was voiced that there is a shortage of skilled workers. Services provided in each community should be accessible to all and ideally should focus on universal supports starting from infancy through preschool. It appears that there is a lack of resources for families who wish to have supports in their homes. This often seems to be a low priority.
Coordination and	have supports in their homes. This often seems to be a low priority.
Coordination and Communication We "hope for improved continuity of care across systems."—Family member	 Families often face numerous roadblocks when trying to access help. Reasons for this could include segmented services, a lack of communication between service providers and across systems, with each other and with families. The complexity of navigating systems leaves many families confused and unsupported. More coordination and facilitation to support informed collaboration and networking across systems for complex situations is needed. It was voiced that to better support families, supports should focus on building relationships and trust, that listening and learning would lead to better supports. Increase availability of translator services across public and private agencies. A centralized resource hub to keep stakeholders updated on available services was suggested. This could also include work or waitlists from other provinces, countries, or health regions, ensuring that the system does not create barriers.
Mental Health "I am very concerned about the unrelenting stress families are facing and the lack of adequate supports it is a recipe for tragedy."—Service provider	 Participants spoke about a lack of support for children/youth with multiple needs, including in the mental health, substance use, and sexual health areas. Significant concerns voiced by participants are long waitlists, inadequate support for children/youth with complex needs, and the failure to include diverse communities effectively in service delivery. It was mentioned that mental health supports could be more accessible, especially for neurodivergent individuals and individuals with multiple support needs.

	 It is important for mental health to be an integral part of holistic support planning along with trauma-informed practices. Robust mental health supports should ideally include the entire family.
Support through transitions We need to "improve the continuity of care across different systems to ensure seamless transitions and consistent support."—Service provider	 It was voiced that support during transitional stages is needed for more families, ensuring continuity of care. Families need additional support to prepare and manage transitions. Communication and collaboration between systems could be improved, especially during transitions.

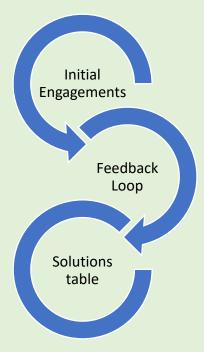


Solutions Table Recommendations

During the Sooke, West Shore, and surrounding areas engagements, families, self-advocates, and members of the community explored what is working well, where there is room for improvement, and what they envision for the children and youth with support needs in their community.

After the initial engagements were conducted, a follow-up loop took place to ensure that the voices of each person was heard clearly and accurately. Notes of all of the engagements were gathered, and the key findings were brought forward to a Solutions Table working group, consisting of parents, a representative for military families, speech and language pathologists, and community care providers. Each member has been actively involved in the Community-Led Collaboration Project and is well-versed and knowledgeable about children and youth with disabilities and/or who have support needs. The group discussed the themes brought forward from all the community conversations and surveys.

The Solutions Table that this group came up with identifies recommendations as important to improving supports for children and youth in Sooke, on the Westshore, and in surrounding areas. These recommendations align with promoting a holistic, accessible, and collaborative system for families.



Key Findings for the Solutions Table

Vision #1

Families are passionate to see their children and youth with diverse abilities thrive in a community where they have flexibility to choose the types of supports they need that align with their interests, goals, cultural preferences, and lifestyle.

What Steps/Solutions Are Required to Achieve This Vision?	Who Needs to be Involved to Bring These Solutions to Life?
Implement a Community-Based Systems Navigator Program Create a well-funded, community-based systems navigator program where navigators have manageable numbers of families they work with, are impartial, and support families holistically. The navigators should be embedded within community agencies and be accessible to families on an as-needed basis to ensure continuity in care and support with case management/coordination of services.	 MCFD and cross systems navigation partnerships with Ministry of Social Development and Poverty Reduction (MSDPR), Child and Youth Mental Health (CYMH), CYSN Indigenous Child and Family Service agencies and/or Child Protection Services in BC as a service file option Health authority (Island Health), MSDPR, and Community Living BC (CLBC) for youth in transition Community partners and families
 Strength-Based, Affirmative Funding, and Programming Models Shift the approach to funding and programming from a deficit-based model to one that affirms neurodiversity and individual strengths. This should include resources tailored to specific cultural preferences, goals, values, and interests to provide meaningful and personalized supports for children and youth. These should be person and family centred and flexible to support needs and preferences; honouring family choice and experience in knowing what they need for their children/youth. 	 MCFD, including CYMH and CYSUN Child Protection Services in BC Ministry of Education and Child Care; individual school boards Health authority (Island Health)/Ministry of Health Community partners and the families they serve
Increased Financial Support for Travel in Remote Communities	MFDC; MSPDR; FNHA; community partners and the families they serve

- Providing this would include explaining resource options to families and working from the understanding that families are the experts in their own lives. Offering additional funding for families in small or remote communities to cover travel costs to access essential programming and resources would ensure equitable access to services, regardless of location.
- For those who don't qualify for federal or provincial travel benefits, access to direct funding would provide flexibility to use the funds or engage with community partners to discuss funding a program that would provide supporting individuals in need for each community.

Network and Peer Support Opportunities

- Establish a HUB (centre), similar to Alberta's Parent Link Centres, providing wrap-around supports from agencies, where families can network and share experiences. These spaces should provide information about available choices and services, fostering community-driven decision-making.
- HUBs are a place where community agencies share space and families have options. HUBs have a coordinator that works to bring agencies and resources together to update and share information so families face less barriers, are well connected, and are well informed. Ensure there are navigators who support connecting with families and coordinate services that truly meet the needs of families and their children/youth. Navigators would also fill a valuable role, listening to families.

- MCFD; MSDPR
- Health authority (Island Health); FNHA
- Delegated Aboriginal agencies and other organizations who may provide funds, along with community supports and other outside agencies

Accessible, Flexible, Family-Centred Support Options

- Offer a flexible support system that includes both prescriptive and individualized services. Families should have the flexibility to choose services based on their evolving needs, which can include respite care, therapy, and recreational programs.
- MCFD to provide family-centred and child/youth-centred funding options
- Individual agencies to ensure their processes are family centred

- Ensure that services and planning are child and family centred. Service providers should involve families in decision-making processes, allowing their voices to shape the support options available to them. Further, there should be a feedback loop and quality assurance to ensure that this collaboration is happening
- Family driven, family developed, family consultation, family review...

Culturally and Linguistically Inclusive Services

- Ensure services and communication materials are available in multiple languages and are culturally sensitive.
 Provide translation services as needed to eliminate language barriers that prevent families from accessing appropriate care.
 Make translation services for children and their families available for all services they may access. Professional translators should have experience to understand health and industry language and how to best translate information to families.
- Federal refugee funding as well as all the government resources listed above, plus Inter-Cultural Association of Greater Victoria (ICA)
- All agencies and care providers should have access to educated translators, similar to the translation resources available through Island Health and schools.

Vision #2

Families in the Westshore, Sooke and surrounding areas are informed, connected and have the inclusive and barrier free access to the supports they need regardless of diagnosis.

What Steps/Solutions Are Required to Achieve This Vision?	Who Needs to be Involved to Bring These Solutions to Life?
Support Is not Reliant on a Medical Diagnosis: Shift to a Social Model of Assessment Adopt a social model of assessment that focuses on the child's environment, relationships, and functional needs, rather than a purely medical diagnosis. This approach ensures that children and families receive individualized support based on actual needs, including social and family needs, rather than age or diagnostic criteria. Remove barriers such as diagnostic or age requirements for accessing funding and services. Create a needs-based approach that ensures collaboration with families and professionals to determine appropriate levels of support. Flexible and Adaptable Funding Options Allow families to choose between individual funding, hub funding, or a hybrid of the two, depending on their evolving needs. This flexibility enables families to adjust their funding models as circumstances change, ensuring their ability to access necessary supports. This includes decreasing supports when they	MCFD, including CYMH and CYSN Child Protection Services in BC Ministry of Education and Child Care; individual school boards Ministry of Health; health authority (Island Health) Community partners and the families they serve MCFD and service providers
are not needed with the assurance of ease to request supports as needs change.	
Design funding and support determinations that take into account the entire family's needs, including factors such as childcare availability, full-time work, single parenting, and remote locations.	MCFD and service providers

Integrated Consent Across Systems to Improve Support

- Develop mechanisms for systems (e.g., health, education, social services) to communicate and share necessary information efficiently. Create a system where families can give a single consent to allow relevant information to be shared across agencies, eliminating duplication and gaps in service.
- Allow across the board consent so that families do not need to repeat histories.
 For example, when a family applies for the Affordable Child Care Benefit, they are able to check a box that allows the Canadian Revenue Agency (CRA) to access information for the application.
 Cross consents would also be very helpful for CLBC and Persons With Disabilities (PWD). Simplifying processes across different systems would make it easier for families to access supports.
- Establish a process to ensure the parent/caregiver providing consent is well informed and their rights are protected.

- Various ministries, including MCFD, CRA, CLBC, PWD, Information Management & Technology
- Health authority (Island Health), CYMH

Trauma-Informed, Holistic Mental Health Supports

Provide robust mental health supports integrated into the broader support network for children and families.

Services should be trauma-informed and include counseling for families, recognizing that the entire family system is impacted when a child has support needs. Currently, many families are not supported with mental health needs until there is a crisis.

 Provide better training for service providers. MCFD could support establishing a standard of traumainformed practice such as what Child and Youth Mental Health Services (CAYMH) provides. Agencies should ensure that staff are well trained and their programs provide emotionally safe and welcoming places. MCFD and outside agencies

- Improve quality insurance. Prevention, understanding of trauma informed care, and support should be the drivers in providing mental health supports for children/youth.
- Provide a standard of training that demonstrates a true understanding and knowledge of what it means to be trauma informed. Consider having support workers complete Adverse Childhood Experience (ACE) training to better understand children/youth being served.



In Summary

What We Heard in Sooke, on the West Shore and in Surrounding Areas

While gathering information from the West Shore as well as smaller communities like Sooke and surrounding areas, it was discovered there was a resounding similarity across the board:

Families want flexible, accessible, wrap-around supports close to home. They want services that are family centred and support the whole family.

Families want their children to grow up in a society where neurodiversity is embraced

"We hope that MCFD/CYSN/AFU removed all deficit-based policies and procedures to allow room for neurodiversity/ diversity affirming principles and practices to be the foundation of services for children with support needs". – Self-Advocate

What is Working Well

- Many of the community agencies have a great relationship with families
- Early years programs are supportive
- Additional models of services such as the Disability Resource Center, Foundry and Diabetes Management Support have been helpful
- Families who are able to access Family Support, say the worker roles is an appreciated model of support
- When families have input to the design and choice in what service looks like for their children and supports in accessing the services, it makes a positive difference to the care of the children/ youth and their families.

Opportunities for Change

- Families want choice. There is a desire for more trust. Families and their children want to be listened to regarding their preferred types of services and care philosophies.
- Access to supports and services is particularly difficult in remote areas.
- Families struggle to navigate complex systems that don't communicate with one another. "We hope for improved continuity of care across systems." Family member
- The entire community feels that more mental health support for children and youth with diverse abilities and their families is urgently needed.
- Transitions can be difficult and confusing. It is imperative to "improve the continuity of care across different systems to ensure seamless transitions and consistent support."
 Service provider

Visions and Solutions Summary

Vision 1: Families are passionate to see their children and youth with diverse abilities thrive in a community where they have flexibility to choose the type of supports they need that align with their interests, goals, cultural preferences, and lifestyle.

Solutions:

- Implement a community-based Systems Navigator Program.
- Build strength-based, affirmative funding and programming Models.
- Increase financial support for travel in remote communities.
- Provide network and peer support opportunities—Establish a Resource HUB.
- Offer accessible, flexible, and Family-Centred support options.
- Provide culturally and linguistically inclusive services.

Vision 2: Families on the Westshore, in Sooke, and in surrounding areas are informed, connected, and have inclusive and barrier-free access to the supports they need, regardless of diagnoses.

Solutions:

- Ensure support is not reliant on a medical diagnosis: Shift to a Social Model of Assessment.
- Offer flexible and adaptable funding options.
- Provide Family-Centred Needs Assessments.
- Improve communication across systems and develop an Integrated Consent Systems to improve support across Systems.
- Provide Trauma-Informed, Holistic Mental Health Supports by standardizing tools such as ACES to be a requirement of training when working with families.

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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 the West Shore, Sooke and surrounding areas look at ways to best support children and youth with disabilities or support needs so they can thrive now and into the future.

