



THRIVE



Community-Led Collaboration Project 2024 Victoria and the Greater Victoria Area



With thanks to the traditional unceded territory of the Lkwungen (Lekwungen) peoples.



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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 from the Victoria and Greater Victoria communities have been compiled into this report. After hearing the concerns of these communities, recommendations are being brought forth that will be part of a report that is being submitted to 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 explores 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 focus 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 the Victoria and Greater Victoria communities, 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 Victoria and Greater Victoria Area

Located on the southern tip of Vancouver Island, Victoria is part of the traditional unceded territory of the Lkwungen (Lekwungen) peoples. As settlers in this region, the Greater Victoria and Victoria Community-Led Collaboration Project wishes to acknowledge that we are guests on these lands. We thank the Lkwungen People, also known as the Songhees and Esquimalt First Nations communities, for their continued stewardship, care, and leadership of these lands.

The City of Victoria is just 19.5 square kilometres; however, the Greater Victoria area includes the municipalities of Esquimalt, View Royal, and Oak Bay. It boasts a diverse demographic profile reflective of its rich history and cultural heritage.¹ With a 2023 population of approximately 398,000 residents, Victoria is characterized by a range of diverse cultures. Although, Victoria has a large number of European descendants, there is an increasing population of Asian, African, and other racial groups in the City. According to figures released in 2022, approximately five percent of the population is Indigenous.²

The Greater Victoria School District (SD61) has twenty-eight elementary schools, ten middle schools, and seven secondary schools. There were 20,855 students enrolled in the 2023-24 school year in SD61. According to the Enhanced Student Learning Report, published by SD61, approximately 15 percent of all SD61 students in that calendar year had a disability, were experiencing developmental delays, and/or had learning challenges. This means that during the 2022-23 school year, there were approximately 3,026 students with extra support needs enrolled across the district out of a total of 20,855 enrolled students.³ There are four alternative education programs in the district to support diverse learners, including programs for students with high medical and complex needs and for students who are not able to thrive in traditional school settings.

Due to its status as the capital city, there are a wide variety of other resources available in the City of Victoria. It is home to all provincial government offices. There are two hospitals. Victoria also boasts over 200 day care centres serving over 2,800 children; however, there is a shortage of over 4,800 children unable to be placed.⁵ There is easy physical access to mental health services, psychiatry, pediatric care, youth groups, behaviour intervention support centres, and psychological therapy centres; however, there are lengthy waitlists to access some of these services.



The Approach to Engagement

The Community-Led Collaboration Project came together to create four guiding principles of inclusive community conversations as a benchmark for the working groups:

Reconciliation and Decolonizing: Reconciliation and decolonization guide our approach to community engagement, which is designed to be inclusive, accessible, and culturally safe, with an approach that makes space for historically excluded voices and perspectives.

Collaboration: The best engagement occurs when all members of a community actively work together to plan an engagement that will inform how they can create improved networks of support for children and youth with disabilities and/or support needs and their families. Inclusive communities are healthier communities, and building inclusive communities is a shared responsibility.

Community-Driven Change: This project presents an opportunity to build on the existing strengths of British Columbia's current system, and challenges each community to address the changes needed to best support children and youth with disabilities and/or support needs and their families.

Transparency and Timeliness: Timely summaries of engagement will be circulated to keep participants informed, which will also help ensure that this report is capturing what is most important to the community.



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 the 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.

From June to October 2024, numerous community engagements took place, with the participation of families, self-advocates, service providers, and educators. The Community-Led Collaboration Project created safe spaces for conversations and utilized methodologies of an in-person world café format, surveys, and both virtual and in-person discussions for those who preferred not to meet in a group.

Family Engagement

An in-person engagement session was hosted for families residing in Victoria and the Greater Victoria area on June 24, 2024. Eighteen parents attended the session at the Victoria Scottish Community Centre.

Five in-person interviews were also conducted: Three interviews took place with parents who have diverse needs and two additional parents were interviewed whose children have complex care needs and receive health and mental health supports.

Surveys

Seventeen family surveys were completed. These are families that could not attend in person sessions but provided valuable feedback.

Service Providers Engagement

On June 3, 2024, an in-person engagement session was provided at Queen Alexandra Centre for Children's Health. Facilitated by Lori Frank Mediation, the meeting was comprised of forty clinicians including behaviour analysts, speech language pathologists (SLPs), occupational therapists (OTs), a physiotherapist (PT), children and youth psychologists, Island Health and its Supported Child Development and Early Intervention programs.

In addition, four service provider surveys were completed.

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 in Victoria and the Greater Victoria area:

Conversation Themes

THEMES	SUPPORTING CONVERSATIONS
<p>Family Centred Support—Provide Help When Parents Need It</p> <p><i>“I wish there was someone who would be the point person to help me figure out what therapies my children need and how to allocate the funding.”</i> —Parent</p>	<ul style="list-style-type: none"> • There is a substantial hope from many families for funding mechanisms that are not only more accessible and less bureaucratic, but also more reflective of actual cost and needs for families, especially with the increases in cost of living: <i>“I would like to see the system simplified. Having actual people to talk to in person—you can’t go anywhere and just ask one question. Make services more based on need.”</i>—Parent • Some families would like to see a broadening of service types and delivery methods to accommodate diverse needs, especially in the educational settings and in respite care. • Several families are concerned about the drastic drop off in funding and supports for school-age children and then through transitions because it impedes therapies and the supports needed. • Families voiced a desire for support for a variety of reasons, whether it be filling out forms, understanding the systems, dealing with their own marginalization. They would like more support to help them navigate and access what they need: <i>“Navigating through the system can be very hard. I am not from Canada originally, and things are very different here. We don’t know what supports we are eligible for.”</i>—Parent
<p>Funding</p> <p><i>“Funding should be linked to the needs of the child, not diagnosis. Right now my child needs lots of therapies, but we get no extra funding for them, and I am</i></p>	<ul style="list-style-type: none"> • Funding models do not support enough access to child, youth, and family-centred supports. They are deficit based and crisis driven. <i>“Some therapies work well for us, but they are not covered and we can’t afford to continue accessing the help.”</i>—Parent

<p><i>missing a lot of work.”—Parent</i></p>	
<p>Coordination, Communication, Collaboration</p> <p><i>“Navigating through the system can be very hard. I am not from Canada originally, and things are very different here. We don’t know what supports we are eligible for.”</i> —Parent</p>	<ul style="list-style-type: none"> • There is often a lack of communication, information sharing, and transparency across different systems, which can result in families requiring additional advocacy and navigation supports. • Families don’t always know where to turn. Developing clear and effective navigation aids could be useful in helping families access needed services quickly and efficiently. • In particular, some families feel that accessing medical travel funding and preparing for appointments in Vancouver is incredibly daunting. <i>“Medical travel funding can be very confusing. There are so many things that families need to do to prepare for medical travel to BC Children’s Hospital (e.g., booking accommodation, TAP form, scheduling appointments together). There are multiple people to contact, and it can be very stressful. There are a lot of tasks to do, while you are worrying about your child’s health.”</i>—Parent
<p>Mental Health and Complex Care</p> <p><i>“My work of supporting my child by attending workshops, professional meetings, hospital visits, making phone calls and internet research is a full-time job, Not to mention the stress that this causes.”</i> —Parent</p>	<ul style="list-style-type: none"> • Complex care often involves working with children and youth with multiple diagnoses. • Some families see their children dismissed by mental health providers. They feel there is a lack of understanding of the supports that children and youth who struggle with mental health and diverse abilities require. It appears to them that there is a lack of specialized resources or collaboration among systems for solution-focused teamwork. This creates a barrier to equitable mental health supports for children and youth with diverse needs: <i>“If we received help when I started seeking, I think my child wouldn’t have gotten worse and require more services or more resources (police, medical, and outpatient services).”</i>—Parent • Families who are supporting a child or youth with complex needs also struggle. Many take time off work, pay out of pocket, and the added pressures can take a toll on relationships and others in the home. It was felt that many families are not well supported to care for their own mental health. <i>“For a child with severe anxiety who cannot be comfortable with support workers, 80 percent of the AFU [Autism Funding Unit] funds are largely unusable for us. As a single parent with no family in the area, exhaustion is unmeasurable.”</i>—Parent • It was voiced that families want to see a strengthening of mental health supports and the creation of more inclusive environments that cater to the diverse needs of all children and

	families, including neurodivergent individuals and those with complex needs.
Support Through Transitions	<ul style="list-style-type: none"> • Many teens struggle with transitions as they see their peers mature and move on to jobs, higher education, and relationships. This creates additional social anxiety and depression. <i>“The mental health of our youth is paramount and the lack of social opportunities and supports to nurture youth transition to adulthood is missing.”</i>—Service Provider • There is a huge gap in services and supports for youths age thirteen and up, particularly for non-Autism Spectrum Disorder (ASD)-related needs. <i>“We need better middle school after school supports.”</i> And: <i>“Make sure the after-school care continues after age twelve.”</i>—Parents
Shortage of Workers and Resources <i>“Services are stretched so thin that help is given to those needing obvious help. It’s like hospital triage.”</i> —Parent	<ul style="list-style-type: none"> • Families are experiencing long wait lists, especially for assessments that determine what supports might be available. • There is a shortage of qualified workers everywhere, and this seems especially evident in the adolescent years. <i>“There is minimal to non-existent supports/ resources for children ages thirteen to nineteen years of age.”</i>—Parent Resources are mostly based on deficit-funding models and are not necessarily family and child focused or flexible to adapt to the changing needs of the families. • Families particularly feel like schools are especially short staffed when it comes to supporting students who have complex needs. <i>“There is not enough workers with high-level skills to support children in school.”</i>—Family



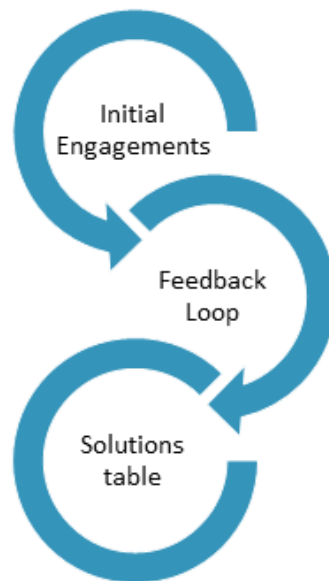
Victoria and Greater Victoria

Solutions Table Recommendations

During the Victoria 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, a diverse and small group of community members. This group consisted of parents, a youth self-advocate, educators, 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. This group had the opportunity to discuss recommendations to improve services and supports for children and youth with support needs In Victoria and Greater Victoria.

The Solutions Table identifies recommendations as important to improving supports for children and youth. These recommendations align with promoting a holistic, accessible, and a collaborative system for families.



Vision #1 – Families have barrier-free access to receive supports for their children and youth, when and how they need it.

What Steps/ Solutions Are Required to Achieve this Vision?	Who Needs to be Involved to Bring These Solutions to Life
<p>Address Gaps in Funding for Children and Youth with Support Needs: Autism Funding Branch (AFB) Children and Youth:</p> <ul style="list-style-type: none"> • Recommend that MCFD provides individualized funding, indexed for inflation, starting at current starting rates of \$22,000 per year for children under the age of six and \$6,000 per year for those over the age of six. • Ensure AFB funding remains flexible, accessible, and responsive to each child’s unique needs, providing stable support for autism-related therapies and services. • Guarantee funding continuity by maintaining access regardless of fluctuations in service usage, recognizing that a child or youth’s support needs can vary over time. <p>Enhancements to Non-Autism Funding Branch (non-AFB) for Children and Youth:</p> <ul style="list-style-type: none"> • Recommend that MCFD extends individualized funding, indexed for inflation, at equivalent rates to those provided for autism-related support: \$22,000 per year for children under the age of six and \$6,000 per year for those over the age of six. • Recommend that access to non-AFB funding be based on functional support needs as determined by a standardized screening process, ensuring equitable funding for children with diverse support requirements. 	<ul style="list-style-type: none"> • MCFD budget and finance teams for funding allocation and indexing • AFB administrators for overseeing autism-specific funding distribution • Non-AFB program administrators for managing individualized funding for children qualifying through functional needs assessments • Community Living BC (CLBC) for consultation on the administrative funding model • Supported Child Development (SCD) teams, childcare providers, and community agencies for supporting inclusive childcare environments • Family advocates and caregivers to provide feedback and insights on funding effectiveness

<ul style="list-style-type: none"> • Suggest implementing policies to secure uninterrupted funding for non-AFB children, allowing consistent access to necessary services. <p>Additional Solutions for Both AFB and Non-AFB Funding Recipients:</p> <ul style="list-style-type: none"> • Allocate supplementary funding for administrative overhead to agencies to support operational efficiency, using rates comparable to the CLBC model. • Expand the At Home Funding Program to accommodate applications for children over the age of six with complex needs who require funding beyond \$6,0000, based on assessed impairment and health/safety needs. • Create two additional assessment categories to include mental health and behavioural needs to ensure comprehensive eligibility criteria. • Recommend that MCFD and Supported Child Development (SCD) provide sufficient funding for supports, enabling all children with support needs be able to access preschool or daycare. 	
<p>Make Assessment Processes More Helpful and Accessible</p> <ul style="list-style-type: none"> • Implement an accessible assessment pathway that includes multiple entry points: <ol style="list-style-type: none"> 1. Direct referrals by GP, pediatrician, or nurse practitioner for autism or other diagnoses 2. Direct referrals by child and youth professionals (i.e., social workers, 	<ul style="list-style-type: none"> • MCFD and health authority (Island Health) assessment teams • Professional organizations for OTs, PTs, SLPs, behaviour analysts, and social workers • Family representatives and advocates for children with support needs

<p>childcare providers, schools, OTs, PTs, SLPs) for functional needs assessments</p> <p>3. Referral to diagnostic assessments following functional assessment</p> <ul style="list-style-type: none"> • Structure assessment system to allow children to qualify for support services based on functional needs, enabling timely intervention without requiring specific diagnoses. • Recommend that MCFD and Island Health collaborate to conduct functional and family needs assessments, ensuring comprehensive understanding of support needs. • Expand the list of qualified professionals who can conduct functional assessments to include occupational therapists, BCBAs, PTs, SLPs, social workers, and other trained child professionals. • Automatically qualify children with birth-related diagnoses (e.g., Down Syndrome and other genetic conditions) for support funding, ensuring immediate access to resources. 	
<p>Review and Make Changes to Respite Funding</p> <ul style="list-style-type: none"> • Reinstate the Community Respite Service, funded by MCFD and administered by community agencies (e.g., The Cridge Centre, Community Options for Children and Families), to offer respite care to all families with identified needs. • Allocate sufficient funds to ensure all qualifying families, identified through functional assessments or diagnoses, can access respite services. 	<ul style="list-style-type: none"> • MCFD and community respite agencies • Respite providers and training organizations • Families, support networks, and community advocates

<ul style="list-style-type: none">• Use a health- and safety-based priority screening tool to ensure timely access for families.• Set compensation for respite providers at a competitive level to attract and retain qualified providers.• Provide MCFD funding for comprehensive training programs to equip respite providers with the skills necessary to support diverse family needs.	
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Vision #2 – Systems work well together with family-centred supports for children, youth and their families. As children mature they are able to access complex care, mental health support and aid with transitions

What Steps/Solutions Are Required to Achieve this Vision?	Who Needs to be Involved to Bring These Solutions to Life?
<p>Recommend Funding Navigators, Based in Community Non-profits, Through MCFD to Guide Families in Understanding and Accessing Services, Applying for Support, and Navigating Complex Systems. Suggest Structuring Funding to Support:</p> <ul style="list-style-type: none"> • Small caseloads (maximum forty families per navigator) • Competitive salaries for navigators to attract professionals with experience in child development, disabilities, and service systems • Annual professional development to keep navigators informed of updated systems and best practices • A diverse team of navigators, reflecting the cultural backgrounds of families in the region and fostering collaboration based on varied experiences 	<ul style="list-style-type: none"> • MCFD, community-based organizations, and family support services • Navigators with backgrounds in child development, disabilities, and family advocacy • Family representatives and advocacy groups
<p>Streamline Mental Health Services</p> <ul style="list-style-type: none"> • Streamline transition processes within Island Health, ensuring that children are automatically eligible for the next level of service as they grow or transition. • Fund transitional support for up to three months following major transitions (e.g., from Ledger House to community care, hospital discharge to home) to facilitate continuity of care. • Remove diagnostic restrictions that prevent children with intellectual disabilities, autism, or other conditions from accessing mental health services. 	<ul style="list-style-type: none"> • Island Health mental health teams and administrative staff • MCFD, community health practitioners, and family representatives

<ul style="list-style-type: none"> • Develop a Foundry-style mental health day program for youth ages fifteen to nineteen at Royal Jubilee Hospital, funded by Island Health. • Conduct a community engagement process to gather input on the mental health system, focusing on identifying service gaps and aligning with family needs. 	
<p>Expand Parent Supports</p> <ul style="list-style-type: none"> • Fund a parenting support program through MCFD, using a model that combines group classes with one-on-one in-home support from facilitators for all parents and caregivers requesting additional supports. • Expand CLBC Funded Parent Support Program to ensure all parents and caregivers have adequate supports. 	<ul style="list-style-type: none"> • MCFD and CLBC • Community agencies, family support specialists, and parent advocacy groups • Parents and caregivers seeking support services
<p>Offer Range of Service Provider Options to Ensure Families Have Choices</p> <ul style="list-style-type: none"> • Maintain existing public services and provide individualized funding for private service providers, allowing families to have greater choice when choosing which funding model they prefer. 	<ul style="list-style-type: none"> • MCFD, families, community agencies

In Summary – What We Heard from Victoria and Greater Victoria

What Is Working Well

1. Funding models emphasize parent choice and control, allowing for a diverse selection of services and support, including travel and educational assistance.
2. Community support through social media groups and other local networks help families navigate challenges effectively.
3. There is strong community dedication, with numerous experienced professionals, deeply committed to their roles.
4. The integration of family input and local knowledge into care processes ensures that services are tailored to the specific needs and cultural backgrounds of families.

Opportunities for Change

- Ensure that family-centred support and help is available when needed.
 - Families are requesting funding to access supports to match the increases in cost of living.
 - Complex systems can be simplified and help provided to families to navigate systems.
- Children/youth should be able to access the care they need without barriers.
- Families, youth, and children should have support to access mental health services that is diverse and inclusive. These services should be provided in a timely manner without cost.
- Additional supports are necessary especially in the area of child/youth transitions.
- More availability of family-centred skilled workers and resources are needed.



Visions and Solutions Summary

Vision #1- Families have barrier-free access to receive supports for their children and youth, when and how they need it.

Solutions:

- Review MCFD funding to ensure that it is inclusive for all children and youth with support needs and that it is family centred.
- Update assessment processes so that they are accessible through many entry points, are inclusive of all children with support needs, and that they are child and family centred.
- Review respite funding, ensuring that it is timely, adequate to give families a break, and that incentives are put into place to attract skilled workers.

Vision #2: Systems work well together with family-centred supports for children, youth, and their families. As children mature, they are able to access complex care, mental health support, and aid with transitions.

Solutions:

- Fund navigators to guide families in understanding and accessing services, applying for supports, and navigating complex systems.
- Streamline mental health supports, remove diagnostic restrictions, and focus on providing mental health services to children and youth.
- Expand parenting supports with classes and one-on-one in-home support programs.
- Offer a range of service provider options to ensure families have choices, allowing them to choose which model works best for their child/youth.

References

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- ⁴ School Enrolment Numbers, Greater Victoria School District, 2024-25 School Year, <https://www.sd61.bc.ca/schools/school-enrollment-numbers/>.
- ⁵ Child Care in Victoria report, compiled by the City of Victoria, 2022, <https://www.victoria.ca/media/file/child-care-victoria-report>.

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 Victoria and Greater Victoria look to find ways to best support children and youth with disabilities or support needs so they can thrive now and into the future.

