



**clements centre**  
for FAMILIES

# Cowichan Community Conversations

COWICHAN, PENELAKUT, AND SURROUNDING COMMUNITIES



**Findings from the Community-Led Collaborations Project in Cowichan, Penelekut, and surrounding areas.**

The Cowichan Valley is located on the traditional and ancestral territories of the Lyackson, Stz'uminus, Puneluxuth', Meluxuh, Halalt, Dididaht, Pacheedaht, Pauquachin, Quw'utsun, and Ts'uubaa-asatx people.



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**COWICHAN INTERCULTURAL SOCIETY** where cultures connect



Canadian Mental Health Association  
Cowichan Valley



Speech-Language Pathology & Behaviour Consultant Services

# About Cowichan

The Cowichan Region is centrally located on Vancouver Island between Nanaimo and Victoria. We are grateful and honoured to provide our services on the traditional and ancestral territories of the Lyackson, Stz'uminus, Puneluxutth', Meluxuh, Halalt, Dididaht, Pacheedaht, Pauquachin, Quw'utsun, and Ts'uubaa-asatx people. We acknowledge the rights, interests, priorities, and concerns of all Indigenous Peoples (First Nations, Métis and Inuit), respecting and acknowledging their distinct cultures, histories, rights, laws and governments.

The Cowichan region includes the communities of Chemainus, Lake Cowichan, Duncan, Cobble Hill, Shawnigan Lake, and Mill Bay, as well as the aforementioned Nations. In 2021 it had a population of 89,013 (Stats Can 2021 Census). Children up to the age of 14 make up 14.2 per cent of the population of Cowichan (Stats Can 2021); 12.6 per cent of the population are Indigenous.

According to the Early Development Instrument (EDI), a research tool used by the Human Early Learning Project (HELP) at the University of British Columbia (UBC) to help understand healthy child development in British Columbia, childhood vulnerability rates vary significantly across the province, ranging from 21.8 per cent in some B.C. communities to 72 per cent in others. In School District 79, 34%—or 199 of 592 children are vulnerable on one or more scales of the EDI upon entry to kindergarten. This compares to 32.9 per cent of all kindergarten children across B.C. being vulnerable on one or more scales. The longer-term trend shows that 26% of children were vulnerable in Wave 2 and 34% were vulnerable in Wave 7. This represents a meaningful increase in childhood developmental vulnerability for this time period. In addition to these vulnerabilities, according to Nourish Cowichan over 4,100 children in the Cowichan Valley live in poverty – about 30% of children living in the area. The combination of vulnerabilities as indicated on the EDI and food insecurity indicate the need for robust child development services to mitigate these challenges to the healthy development of the children in our community. These conversations will inform how we can improve services to support that development.

# Project Background

In the fall of 2021, the Ministry of Children and Family Development (MCFD) introduced a new framework for delivering services to Children and Youth with Support Needs (CYSN) in British Columbia. This announcement sparked confusion and concern throughout the province, along with calls for more extensive consultation. Individuals and organizations across B.C. emphasized the need for any changes to be shaped by the lived experiences and insights of families and children and youth with disabilities or support needs.

In response, several key organizations—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.

MCFD responded by providing these organizations (referred to as the Provincial Working Group) with a grant to carry out a provincial engagement project, which began in fall 2022 and was known as the Community-Led Collaboration Project.

As part of this effort, the Clements Centre was one of several organizations across the province that received funding from the Provincial Working Group to lead community discussions on CYSN services. Our project, focusing on the Cowichan region, was led by a team that included representatives from Hiiye'yu Lelum (House of Friendship), Cowichan Valley Youth Services, the Canadian Mental Health Association, Cowichan Intercultural Society, Penelakut Tribe (Spune'luxutth), Bridges Speech-Language Pathology and Behaviour Consultant Services, and Our Cowichan Communities Health Network.

This report outlines the challenges, hopes, and expectations for CYSN services and supports as expressed by families and community service providers in the Cowichan Valley.



# Cowichan Community Conversations, 2024

## Introduction

The conversations and collaborations which took place as part of this project led to twelve recommendations. There was a consistency between the participants and the communities which was not initially anticipated. It was clear that there are significant unmet needs across our region, both on the part of families and of service providers. The participants were focused on these shortfalls and were committed to working with whoever can assist in overcoming them.

“Without interventions at the right time, how are they expected to become healthy, contributing members of society? How much will it cost later on if they don’t get these services.....”

## Description of project

The Cowichan Valley community led collaboration with families and service providers of infants and children with disabilities took place over eight weeks in the spring of 2024. Meetings were held in community centres across the region plus two First Nations, Cowichan Tribes and Penelakut. We asked 4 questions at each session:

1. What services and supports are currently working well?
2. Is there anything missing?
3. What would an ideal network of services and support look like?

And :

4. Any other comments?

“Every child matters in the future, not just the past”

The meetings were marked by the strong engagement of participants. Honest, straight forward opinions by 67 individuals were shared in seven in-person and one virtual meeting plus ten online surveys. Participants included mothers, fathers, recent immigrants, Indigenous, grandparents, foster parents, and service providers. Service providers included a wide range of agencies with a cross section of professional skills such as occupational, speech and physical therapists, early childhood educators, nurses and teachers.





## Things that are working

Families who were receiving help were happy with the quality of the services being provided in the community. Use of the Hul'q'umi'num language where appropriate was appreciated.

Although individual funding covers only a portion of the costs many of those receiving the funding found it is working, In particular participants felt that the individual funding for children with autism worked well, provided families had the cognitive, emotional and executive skills to initiate the services.

"Our autism funding gives our family hope..."

Concerns were not expressed about the quality but about the availability of services.

## Things that are missing

Seven themes stood out overall. These were consistent between groups and participant backgrounds but with additional needs expressed by families with older children.

"I don't think it is fair that people either go broke (paying for private assessments) or wait"

### 1. Barriers to accessing care and supports

There are significant barriers and delays for accessing assessment with most parents reporting waiting for more than two years for assessment or needing to pay significant amounts for them in the private system. Once there was a diagnosis the wait for services was frequently longer than two years. With the funding cut off at age six and the initial recognition that a child may need support often not taking place until they are two years or older these delays mean many families lose the opportunity for intervention and support at a critical age as the result of a lack of funding.

Increasing the frustration is the inability to know where they sit on the wait list. The primary cause for the delays was believed to be the lack of staff and resources. The shortage of speech therapists was especially noted.

"There needs to be a process, pre-kindergarten process, so young children can get help early."



Another cause for frustration and stress was the lack of access to knowledgeable child development professionals. The increasingly reduced contact with public health and the lack of parent support groups in the early years have meant that families may not recognize their child's development challenges. It may not be until the child enters childcare, preschool or kindergarten that they learn that the child requires additional supports.

Parents described the significant cost of private assessment and the burden these costs put upon the family. This placed greater pressure on them to work while at the same time they needed to care for their child. "You are expected to parent like you don't work or work like you don't parent." The barriers were not just cost but included technology such as computer access and transportation, especially accessible transportation, from outlying areas, from on reserve and from Penelakut Island. The lack of resources is described as resulting in not just a gap in service but in fewer appointments farther apart in time. Parents are expected to take over the therapy and may not have the capacity in terms of knowledge, capacity or time. This in turn may lead to families withdrawing from services.

## **2. Knowledge of existing services**

Accessing supports and services requires knowledge of what exists and how to access them. There was a near universal request by both families and service providers for a system with an online and in person central information centre and access to a navigator with knowledge of what resources exist, where, who qualifies for the service, and how are they funded. Even service providers and foster parents with extensive experience in the work, and in the community, struggle to know what supports are provided, by whom and how to access them. "Need places to send parents – need resources. Don't know where to send families..." . Ideally this central hub would also provide information on social support groups, counselling resources and respite supports. It would also facilitate networking between agencies and professionals.

"I couldn't articulate what I needed. 'Here is a binder of what is available ...' I don't know what she needs!"



The need for a navigator to help find the way through the maze of service options was particularly voiced by parents struggling to understand how to complete the required paperwork and dealing with the challenges of parenting. The current system requires access to technology and a level of comfort finding your way through complex systems and forms that is beyond what many families can manage both in terms of time and of education. There are limited or no supports in place for parents who face challenges of their own such as low literacy and numeracy.

There needs to be consistency so trust can develop. Not all families and all communities will access services in the same way and at the same time. Navigators will need to be culturally knowledgeable and trusted. They also need the skills to do appropriate outreach to families facing additional barriers.

The navigator could also assist with transitions as children move between supports including the transition to school which was described as difficult or unsuccessful and transitions into adult supports as they age out of the child support system. One difficulty is the abrupt transition at age 18 as a child with disability may be forced to make a transition out of the school system when they would have benefited from remaining an additional year or two. It is "just as overwhelming knowing J is going into adulthood as it was when he was first diagnosed."

"I don't have time to do all this paperwork. ... busy managing meltdowns. Managing is a full time job."

### **3. Information sharing**

There is a need for more frequent engagement and information sharing, i.e. more of a team system. Specifically the need for a central charting system was expressed, where providers are able to review assessments, test results and therapies provided by other professionals. Families are challenged trying to be the 'go between' as they may not have been given the full information and are not always believed. The importance of relational connection between service provider and child also results in challenges when the service provider isn't a consistent presence for the child who relies on and trusts the relationship built with the provider



This is made worse by the lack of consistency of providers. This results in a lack of response or ill-informed responses from support workers who are constantly new. Children who struggle with change do not cope well with a constant change in therapists and service providers.

“Relationships are important to our kids who thrive on stability”

#### **4. Flexibility**

One size does not fit all. Some children do better with in home therapy as they cannot manage the extra stimulation of a centre or a school. Some families require supports outside of normal working hours. Other families may need support for transportation such as a bus monitor to assist during school bussing.

#### **5. Social Needs**

Parents feel their child is not able to fully participate in life. The need for social interaction including play spaces which are accessible for children with disabilities and which have fences and gates for those children who are elopers. There were clear and consistent requests for access to recreation and social supports including music and art therapy. Summer and end of school camps may not accept children without additional staffing supports. “....sports when child is disabled .... kid gets dropped or kicked out”. Therapists make recommendations for swimming and gymnastics but programs and staff are not available. All children have a need for social interaction and this increases as they become teenagers. The lack of programming for peer interaction was noted by several parents with recognition that this may require behaviour support in community.

“Parents are treated like we are crazy rather than the expert on their kids”

“need more sports... as my son has a lot of energy”



## 6. Schools

A strong majority of parents described local public school-based programs as not working. Not having funding attached to the child has resulted in a lack of transparency. It appears to many families that the funding is redirected by the school to general supports and is not used for their child's needs. Families home school often not by choice but by necessity. "Children need to be able to attend school regularly so they can be set up for success."

"..had to the leave the school system as my kids were falling through the cracks. One was being severely bullied with little consequences for bullies or understanding of her needs....refused an IEP despite her diagnosis."

Home schooling restricts the ability to work. Private specialized schooling where available is an alternative but expensive and require a level of support not available to all families. "We had to refinance our home to put our kids in private school as they were being traumatized and not supported in public."

## 7. Parent and family support

Parents struggle with self-care and with finances. "There are next to no supports for parents who are in burnout." Trying to work and support their child(ren) when they have limited or no respite supports adds a tremendous burden. "... I can't leave work to deal with my disabled child or I'll lose my job"

"Current model: Having the school have the majority of the funding means my daughter has no supports because they have no resources for her – then I have to use my funding and take time off work to take her to private [services]..."

"Parents should not have to choose between the wellbeing and welfare of their children and poverty."

"Even as it stands, I can barely find wiggle room for my own self-care because I have to work to keep us remotely above water financially and then I have to take the children to all of their interventions..."





They juggle appointments, therapy, behavioural challenges while trying to work. “We have no marriage. It’s crisis management every minute of every day.” Current funding, where available, does not recognize that inflation has increased costs while wages have not kept pace. Disability supports and payments are not enough to manage and the income cut off line is very low. Review of current funding must incorporate consideration of the difficulties caused by the reduction in services which results from these pressures.

“Have one place to access all information and someone to guide us through the different stages of services/funding/organization as our kids grow”

Living with a child with a disability impacts the lives of their normally developing siblings. Supports such as counselling and peer groups are needed. The costs of supporting a disabled child reduce access to resources for the other children in a way that is not often recognized

## What would an ideal system look like?

1. A system which is equitable, immediate and flexible. That provides access to quality services which are not diagnostics based but based on child and family needs.
2. A central hub providing up to date information on what services are available and where. The hub or portal ideally would be easily accessible by both service providers and families. “Need places to send parents – need resources. Don’t know where to send families...” Ideally this would include a navigator program where staff with knowledge of available supports, funding and therapy are able to assist families with form completion and assist with navigating the numerous barriers to accessing available programs and funding. Ideally this would also provide supports to families with low literacy, those whose first language is not English, and those, who are newcomers to the country.
3. Culturally appropriate, knowledgeable and skilled Navigators who are able to develop relationships with families and help them with completing forms, finding resources, locating therapists, and managing transitions. Recognizing the overwhelming challenges faced by families of children with disabilities, a navigator service would reduce stress, increase system efficiency and provide ongoing support. This should also support transitions into adulthood.



4. A community of care with transparency, continuity of care with a shared data base and a consistent sharing of child centred and child focused messaging. The current silos of information relate to what services are available and also the information specific to each family and child. Establishing a safe system which would permit service providers to learn what others have recommended and what supports have been provided would reduce duplication, reduce time spent on intakes, shorten wait times and improve the quality of service.
5. Funding by need and severity not by diagnosis, recognizing that the diversity of symptoms and challenges faced by families may not align with a narrow diagnostic definition. This includes recognizing the impact of gender differences.

“Every time a family has to divulge the very same info, this is TRIGGERING!!”

6. Funding of service providers to permit adequate levels of wages and supports, and encourage job retention.
7. Supportive services and counselling to be available during the long delays in receiving diagnosis and therapies. This would include social groups where families can network and share knowledge.
8. Adequate mental health services which are publicly funded for all family members, including counselling and social groups for parents and siblings. This should be ongoing as the challenges change over time. Parents of children with disabilities face stresses financially, physically and socially. Supports for counselling, increased levels of respite and social networking opportunities were requested.
9. Increased staff and programs. There is a significant shortage of staff in all related professions and at all levels. This increases wait times and reduces the availability of one-to-one supports. This may require an increase in salaries and payment schedules.

“We have no marriage. It’s crisis management every minute of every day.”



10: Increased training access. The current online training opportunities were appreciated but there was a strong request by both professionals and families for more training opportunities, including training for staff providing a variety of community programs across the region. Families would like to have the opportunity to learn more to support their children as well as to have appropriate tailored education for their pre/post pubertal children such as hygiene and sexual education specifically created for youth and young adults with disabilities. This should include a transitions program to educate families about how to transition from school age to adulthood, particularly geared to those who are not in the public school system, due to complex health needs.

Professionals of all fields would like to increase their skills and those of their coworkers specific to a variety of disabilities. This training should be trauma informed and culturally sensitive. It was suggested a wider recognition of the skills of immigrants may assist in staffing shortfalls.

11. Improved access needs to be provided to recreation and social needs with a special emphasis on summer programs for school aged children. Access should be available across the region, including outlying areas, to specialized playgrounds with fences and gates, with ramps and lower swings and climbing apparatus. Access, including to a diversity of programs which meet the varying needs of individuals. Programs in small communities as well as central ones, such as art therapy, music, gymnastics, swimming, soccer and clubs which help in socialization. Access to these programs may need supported transportation for parents who work.

“More structured collaboration is needed with funding/ contracts given to centres/providers who...attain measurable outcomes.”

12. Bi-annual networking meetings. Family members and service providers frequently expressed appreciation for the networking and learning opportunities the focus group meetings provided. There were numerous requests for similar meetings to be held regularly in the future, perhaps annually. During the larger focus groups the parent and caregivers shared knowledge and resources amongst themselves. The families had children across a wide spectrum of ages and abilities and most had not had a prior opportunity to meet or discuss with others sharing their experiences. It was the first opportunity that most families have had to learn from others with shared experiences.

The service providers' meetings also provided a significant opportunity for participants to learn about the services available in the community, to meet the people who provide them and to network. It was requested that at least bi-annual meetings to network specifically on this issue.



## **Conclusion**

The community conversations met a need both for the gathering of information and for critical networking between and among families and service providers. The conversations were often both impassioned and detailed. The information provided by the participants has been collated as clearly as possible. All who participated felt that there is a need to go beyond research to action.





Speech-Language Pathology & Behaviour Consultant Services



Canadian Mental Health Association  
Cowichan Valley

Community-Led Collaboration Project

# We want to hear from families with children and youth with disabilities or support needs.

Families in The Cowichan Valley are invited to participate in a conversation about services and supports for children and youth with disabilities or other support needs in your community.

We want to know what is working for families, what is missing and what a better network of services and supports could look like in The Cowichan Valley.

## Family Session #1

May 14th 2:00-4:00pm  
Shawnigan Lake Community Centre



## Family Session #2

May 16th 4:30-6:30pm  
Duncan Community Centre



## Family Session #3

May 21st 10:00am-noon  
Fuller Lake Arena



## Family Session #4

May 22nd 10:00am-noon  
Cowichan Lake Community Centre



## Family Session #5

May 27th 1:00-2:00pm  
Band Office Board Room, Penelakut Island



*\*Scan QR code to register for the session you are interested in*

All these sessions are FREE.

Food will be provided.

Childcare will be available.





Community-Led Collaboration Project

# We want to hear from local community service providers

Local community service providers in The Cowichan Valley are invited to participate in a conversation about how to create a better network of services and supports for children and youth with disabilities or other support needs in your community.

We'll explore what is working for the families you support, what is missing and what better services and supports could look like in order to inform the future of services.

**DATE:** June 10th, 2024

**TIME:** 10:00am - Noon

**LOCATION:** Duncan Community  
Centre

***Service Providers Only***

This is a FREE event  
Food will be provided



Scan QR code to register



Speech-Language Pathology &  
Behaviour Consultant Services



Canadian Mental  
Health Association  
Cowichan Valley

Community-Led Collaboration Project

# We want to hear from families with children and youth with disabilities or support needs.

Families and service providers are invited to complete a survey about services and supports for children and youth with disabilities or other support needs in our community.

We want to know what is working for families, what is missing, and what a better network of services and supports would look like in the Cowichan Valley.



*\*Scan QR code to be  
taken to the survey*





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Si'em Lelum Gymnasium  
5574 River Rd, Duncan, BC

Tuesday, July 2nd  
Noon to 3pm

To register or for more information  
please call or email:

250-715-1024

[anita.seymour@cowichantribes.com](mailto:anita.seymour@cowichantribes.com)

\*Lunch and childcare provided







## Improving Services for Children and Youth Survey

Families and service providers are invited to complete a survey about services and supports for children and youth with disabilities or other support needs in our community.

We want to know what is working for families, what is missing, and what a better network of services and supports would look like in the Cowichan Valley.

Please send completed surveys to [info@clementscentre.org](mailto:info@clementscentre.org) or drop off at the Clements Centre (5856 Clements Street). Thank you!

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1. What services and supports are currently working well?

2. Is there anything missing?

3. What would an ideal network of services and support look like?

4. Any other comments you'd like to share?