NANAIMO CHILD DEVELOPMENT CENTRE
Opening Doors®

TILLICUM LELUM ABORIGINAL FRIENDSHIP CENTRE

LaFF
LADYSMITH FAMILY + FRIENDS RESOURCE PROGRAM

NANAIMO LADYSMITH PUBLIC SCHOOLS

CONNECTING WITH THE COMMUNITY
NANAIMO, LADYSMITH AND SURROUNDING AREAS

NOVEMBER 2024

THE FEDERATION of COMMUNITY SOCIAL SERVICES of BC

BC Association of Aboriginal Friendship Centres
BCAAFC

BCACDI
The BC Association for Child Development and Intervention

inclusion BC

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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) across British Columbia. In response, individuals and organizations throughout the province advocated for a framework that would be informed by the real-life experiences of families and children with disabilities or support needs.

After this announcement, the BC Association of Aboriginal Friendship Centres (BCAAFC), the BC Association of Child Development and Intervention (BCACDI), the Federation of Community Social Services, and Inclusion BC came together to:

- Assess the strengths and potential of the proposed framework.
- Express concerns about whether the anticipated changes would effectively address the needs of children, youth, their families, supporting organizations, and communities.
- Propose a province-wide engagement to MCFD, focusing on community development, to shape the transformation of B.C.'s support system.

In response, MCFD awarded a grant to these organizations—referred to as the Provincial Working Group—to lead a provincial engagement initiative guiding the CYSN service transformation. This effort, known as the Community-Led Collaboration Project, launched in the fall of 2022.

Initially, six communities were selected to begin engagement activities, and the grant was later extended to potentially include up to 30 additional communities across British Columbia. In March 2024, Nanaimo-Ladysmith received a grant to explore the needs for services and supports for children and youth with disabilities and support needs.

This report highlights the challenges, aspirations, and expectations that families and community service providers discussed in Nanaimo-Ladysmith, and neighboring communities regarding the future of services and supports.

THE APPROACH

The Provincial Working Group of the Community-Led Collaboration Project partnered with communities across B.C. to create an inclusive, culturally respectful, and accessible engagement process. They established four guiding principles to shape their approach:

- **Collaboration**: Engagement is co-designed with community members to explore how B.C. communities can strengthen service networks and support systems for children and youth with disabilities or support needs, as well as their families.
- **Community-Driven Change**: The project builds on the strengths of B.C.'s existing support system, identifying necessary improvements to better serve children, youth with disabilities or support needs, and their families.
- **Reconciliation & Decolonization**: The project's approach to engagement is rooted in reconciliation and decolonization, aiming to be inclusive, accessible, and culturally safe. This includes creating space for historically excluded voices and perspectives.
- **Transparency and Timeliness**: Engagement summaries are shared promptly with participants to keep them informed and ensure that community perspectives are accurately reflected.

In Nanaimo-Ladysmith and surrounding areas the engagement process was:

1. In person meeting with community wide invitation to service providers. Develop a timeline with the Nanaimo partnership (NCDC, Tillicum Lelum, LAFF, and School District #68)
2. Creation and Distribution of community-wide survey for both families and service providers. Survey was developed in partnership with Discovery Research (3rd party agency).
3. In person parent session – hosted at Tillicum Lelum by Nanaimo partnership- professionally facilitated by a 3rd party agency (Upwords)
4. Virtual service providers session- professionally facilitated (Upwords)
5. In person community session – distribution and discussion of family and service provider survey
6. Virtual Follow up with community parents
7. In person service provider meeting to review research findings and develop solutions table
8. Deliver report and findings back to community. Report back to MCFD

SAFE SPACES FOR COMMUNICATION

In Nanaimo and Ladysmith, a partnership was developed from initial meeting with Nanaimo Child Development Centre, Tillicum Lelum, Ladysmith Family and Friends and School District #68.

Local families and service providers were invited to participate in these ways:

- Personalized emails to community service providers
- Emails to families from their connected agencies
- In person invites to families and service providers
- Agency Social Media posts
- Information Posters provided to Local Community Agencies

What Participants were offered:

- Childcare honorariums and onsite childcare (NCDC childminders)
- Financial support and booking of transportation from anywhere in the communities
- Food at every event
- Gift cards and raffle baskets at both in person family events
- Various avenues to engage in the opportunity to share families and service providers thoughts and ideas
- Virtual sessions for those unable to attend in person sessions

ABOUT NANAIMO

Nanaimo, a vibrant city located on the eastern coast of Vancouver Island in British Columbia, Canada, is known for its natural beauty, cultural history, and community-focused lifestyle. With a population of approximately 100,000 people, it serves as a gateway to Vancouver Island, attracting tourists, families, and professionals alike. Surrounded by scenic mountains, forests, and coastal views, Nanaimo offers a mix of urban and natural attractions, including parks, waterfront promenades, and easy access to outdoor recreational activities. The city has a strong sense of community and an increasing focus on inclusivity, particularly in supporting children and youth with disabilities and special needs.

Nanaimo's population is diverse, encompassing families, young professionals, and retirees, and is characterized by a mix of different cultural backgrounds. Indigenous communities, including the Snuneymuxw First Nation, play a significant role in the area's cultural and historical landscape. The city has been growing steadily over the years, attracting new residents who appreciate its mild climate, and access to both natural and urban amenities.

The Early Development Instrument (EDI), a research tool developed by the Human Early Learning Project (HELP) at the University of British Columbia (UBC), is used to assess healthy child development in British Columbia. According to EDI data, childhood vulnerability rates vary widely across the province, with rates ranging from 21.8 percent in some communities to as high as 72 percent in others.

In Nanaimo/Ladysmith, 34.5% or 362 of 1050 children are vulnerable on one or more scales of the EDI upon entry into kindergarten, this is higher than the mean average of 32.9% across the province.

On the EDI, children are considered vulnerable if, without extra support and care, they are more likely to face challenges during their school years and beyond. There is a need to understand healthy child development and the factors influencing it in our community. It serves as a foundation for discussions and actions that are locally focused, tailored to the specific needs of children in your area, and driven by community advocates.

This statistic is sourced from the Early Development Instrument(EDI) which is composed of the five measures of vulnerability in children entering kindergarten in British Columbia. The EDI is the tool that has been used by the Human Early Learning Project (HELP) at the University of British Columbia for over two decades to monitor children's development at school entry (https://earlylearning.ubc.ca). The EDI looks at five domains of child development including: physical health and well-being, social competence, emotional maturity, language and cognitive development, and communications skills and general knowledge.

Early Development Instrument, online: https://earlylearning.ubc.ca

ABOUT LADYSMITH

Ladysmith, a charming town located on the eastern coast of Vancouver Island in British Columbia, is known for its rich history, small-town charm, and active community. Located about 25 kilometers south of Nanaimo, Ladysmith is known for its heritage buildings, scenic waterfront, and welcoming community atmosphere. Its historic downtown and surrounding natural beauty attract both residents and visitors, making it a desirable place to live.

Ladysmith has a population of approximately 9,000 people and is growing as more people are drawn to Vancouver Island's lifestyle. The town has a relatively balanced age distribution, with many families, young professionals, and retirees. The Indigenous Stz'uminus First Nation, whose traditional territory includes the Ladysmith area, plays a central role in the cultural and historical identity of the region. The population in Ladysmith tends to be diverse, and community efforts emphasize inclusivity, especially for families and individuals with varying needs.

WHAT WE HEARD IN NANAIMO AND LADYSMITH

Community engagement began in May 2024 through a collaboration between the Nanaimo Child Development Centre, Tillicum Lelum, Ladysmith Family and Friends (LAFF), and School District #68. Together, they organized:

An online survey available from May 21 to July 30, 2024, accessible both virtually and in-person, to gather feedback from parents/caregivers, youth, and service providers. A total of 276 surveys were completed, including 230 from parents, 38 from service providers, and 6 from youth (ages 13-19). Additionally, an in-person survey session took place on July 21, 2024, at NCDC's annual Silly Boat Regatta, with 70 families participating.

An in-person family event at Tillicum Lelum on June 19, 2024, which included dinner, entertainment, and a bouncy castle. This session, facilitated by Upwords, a professional facilitation company, enabled 16 families to participate in 10-minute interviews.

An online discussion board for service providers, held from June 25-27, 2024, with participation from 21 providers.

In each session, including the survey, participants explored family needs, available community services, gaps in services, and aspirations for future support.

What is working well in our community:

> *"A mother who was a refugee from a central American country was here alone with her globally delayed son. He was high needs and she couldn't work or even make any social connections for support. I was able to connect her with the family resource navigator who linked her with a multicultural society to help her navigate housing and work. The NCDC was also able to find her clinicians who spoke her native language, even ones that were in the Lower Mainland. I was also able to liaise with Child and Youth with Support Needs, even though the child had not yet been able to receive an assessment for diagnosis, and they agreed to fund some services and respite and connect her to the At Home Program for incontinence supplies. This mother went from being locked in and alone with a high-needs child to finding help for him, support for herself, social connections, and eventually work." – Provider*

- Current service providers are dedicated and work diligently to support the diverse needs of children.
- Specialized schools, learning centers, and private tutors help address some service gaps.
- The early intervention programs at NCDC are valued by the community.

- Parents rely on social media, word of mouth, and advice from medical professionals to find resources.
- Collaboration around individual clients exists to some extent, with connections fostered through Early Years Partnerships and community events.
- The NCDC is appreciated by internal professionals, parents, and some service providers for its family-centered approach, compassionate care, multidisciplinary teamwork, resource navigation, flexibility, professionalism, and expertise

What is not working well in our community:

> *"The [service] that I would love to have – [because] I think it would benefit him, us and the school – is behavioral therapy. But that's not covered unless you have an autism diagnosis.*
>
> *And I currently don't work right now, because I need to be available almost every day of the week in case something happens at school where he can't stay. So, we're a one income [household] right now. … And that's gotten really tough. And even though my husband has benefits, most benefits don't cover that. And we just can't afford it. … Even counseling, we put him in, but we were paying fully out of pocket, and we had to stop because we couldn't afford [it anymore].*
>
> *So, a lot of it has to do with lack of funding for the kids that don't fall into a certain area." – caregiver*

- There is widespread dissatisfaction with the accessibility of community services across all areas.
- Significant frustration exists regarding service availability, long waitlists, and high costs.
- Other issues include gaps in information, limited support, and a lack of connection among services.
- Therapy options are limited, and sessions are often infrequent.
- Service hours are restricted, with no availability outside of school hours.
- Transportation to clinics and services is lacking.
- There is a shortage of qualified staff in all areas.
- Private therapy is costly.
- Parents face a substantial burden in advocating for themselves and their children.

Hopes for the future of services:

> *"A centralized service hub that accepts referrals from walk-in clinics, schools, family doctors, and self referrals (plus more I'm sure) and has access to all step-up and step-down levels of care. Intake social workers who connect families with holistic supports - respite, mental wellness, food security, therapy, schooling options, assessment, testing. Overseen by a multidisciplinary, multi-employer leadership model, with regional or departmental teams. Integration would be seamless, and wait times would be short." – provider*

- An ideal service network should be **centralized**, **holistic/multidisciplinary**, **connected**, and **well-informed**.
- **Centralized**: Comprehensive information about all available services should be easily accessible, allowing providers to make direct referrals and enabling parents to prioritize and choose the services they need.
- Families should have the option to **self-refer** or be referred by service providers to a central hub for all necessary referrals. Intake information would be shared across services to prevent families from repeatedly sharing their stories.
- **Shared information and records** would allow better coordination, with collaborative meetings and joint visits among service providers.
- **Co-location of services**: All providers would operate under one roof, ideally located near public transit, with satellite branches as needed. Parent services would be offered at the same location as children's services.
- **Holistic/multidisciplinary approach**: All professionals involved in a child's development—covering medical, physical, mental, emotional, and social needs—would be part of this network, supporting children from birth to 19 years of age.
- More **networking and training opportunities** would strengthen collaboration and promote information sharing.
- Improved **integration of private providers** within daycare and school environments.
- **Ongoing input** opportunities from families, providers, and the community.
- Enhanced **communication** among providers about individual clients, including clarity on each team member's role.
- A focus on **mental health services** for the entire family.
- Increased **support for parents and youth** and expanded **respite care** options.
- **Social groups** for children and parents to connect with peers.
- **Access to needs-based services**, moving away from a purely diagnosis-based model.
- **Outreach services**: Therapy would be provided where needed—in homes, schools, daycares, and other community spaces. A mobile unit with multiple service providers could also be considered.

SOLUTIONS

Between May and November 2024, sessions were held to examine existing services, identify gaps, and discuss participants' ideas for advancing community services—essentially, solutions to address these gaps. After initial in-person and virtual sessions in May, June, and July, parents and caregivers were invited to a virtual follow-up meeting to review what had been learned, identify any remaining needs, and discuss possible next steps. Unfortunately, no caregivers or guardians attended this meeting, held on October 10, 2024.

A final in-person meeting was then conducted with local service providers. Attendees, who represented 11 community organizations—including Kwumut Lelum, Métis Nation, Central Vancouver Island Multicultural Society, United Way, Boys and Girls Club, Island Health, Vancouver Island University, School District #68, City of Nanaimo, and Nanaimo Child Development Centre—received detailed research findings (Appendix A) beforehand and were asked to come prepared with ideas for solutions.

The engagement sessions led to the following key solutions and vision for future community services:

1. **Collaborative Team Approach**: All service providers would work together within a coordinated team structure, meeting regularly for collaboration.
2. **Centralized Service Hub**: A single, accessible location where all community services and resources are available, offering guidance for both service providers and the families they support.
3. **Centralized Referral and Intake System**: A unified intake system that manages referrals for all community services a family may need, so parents/caregivers only need to make one call to connect with various services.
4. **Unified System for Family Files**: A shared system where service providers can update family files, schedule meetings, see team members and their roles, and include medical personnel. A dedicated navigator would manage this database.
5. **Family Registry for Waitlists**: A single registry for waitlisted services, especially childcare, to eliminate the need for families to join multiple waitlists and to streamline how new openings are allocated.
6. **Flexible Service Delivery Locations**: Services (both public and private) provided in all necessary settings, including home, school, daycare, and other community spaces.

7. **Up-to-Date Resource Database**: A central database where service providers can submit the latest information about their services and other resources, accessible to families and providers. A dedicated navigator would manage this database.
8. **Flexible Service Hours**: Extended hours for services to accommodate family needs beyond the school day.
9. **Integrated Family Services Location**: Centralize services for all family members, such as providing parental mental health support in the same location as children's therapy services.
10. **Expanded Scope at Early Years Tables**: Include all team members, including medical professionals, in Early Years tables, which would also offer education on local services and resources for providers.
11. **Additional groups** – social groups, parenting groups, peer support groups, youth peer support groups
12. **Needs-based service-** All children and youth, regardless of diagnosis, will receive the services they need when they need them. This approach will be applied to all ages, from 0 to 19.

Across all proposed solutions, participants agreed that the government must reevaluate the funding structure, formula, and allocation for children and youth with special needs, making them a priority. It was also evident that multiple ministries are involved in providing services to this population, making inter-ministerial collaboration essential to ensure services are sustainable, valuable, and effective.

WITH THANKS AND APPRECIATION

The Nanaimo-Ladysmith Community-Led Collaboration Project extends its sincere gratitude and appreciation to the families, youth, and service providers who generously contributed their experiences, insights, and perspectives on future needs. The information gathered through this collaboration is invaluable and will be instrumental in shaping a service model that effectively supports children and youth with diverse needs, empowering them to achieve lasting success.

Appendix A: Detailed research findings

Gaps in services for children with special needs in Nanaimo & Ladysmith, BC

Quantitative & Qualitative Research Findings

May – September 2024

upwords
Discovery Research

Nanaimo Child Development Centre
Opening Doors

With funding from:

BC Association of Aboriginal Friendship Centres
BCAAFC

The Federation of Community Social Services of BC

BCACDI
The BC Association for Child Development and Intervention

inclusionBC

INSIDE THIS REPORT

PROJECT DETAILS

Background, Methodology, Respondent & Participant Details

What we need to **FIND OUT**

In partnership the Nanaimo Child Development Centre with Tillicum Lelum, School District 68, and LAFF (Ladysmith Family & Friends) received a grant from the Inclusion BC to conduct research that will help identify gaps in services for children with diverse needs.

This research explored the following for children with diverse needs:

- Needs of their families
- Gaps in service
- Hopes for future services

Research aimed to target:

- The families of children with diverse needs, and
- Agencies that provide services to families with diverse needs.

Research addressed both current funding streams:

- Early intervention (children not yet attending school)
- Needs based (school aged children 6-19 years)

HOW WE WENT ABOUT IT

QUANTITATIVE*

PHASE 1: Online Survey

Survey Distribution

- The online survey was developed in collaboration with Nanaimo CDC
- QR code and survey link were provided to be advertised to appropriate audiences
- The survey was available from May 21, 2024, through to July 30, 2024

Coding: Open end responses were reviewed, and code frames created to facilitate quantifying the responses.

3 primary targets:

- Parents/Legal Guardians
- Youth
- Service Providers
- Others were also able to take the survey to account for other family members involved in care.

QUALITATIVE*

PHASE 2: Interviews with Caregivers

~10-minute interviews with 16 parents or caregivers

- June 19
- at Community BBQ event organized by NCDC

PHASE 3: Online Discussion Board with Service Providers

1 hour of engagement from each participant within a 3-day period (June 25-27)

- **Asynchronous** (not in real time): activities were programmed ahead of time
- All activities except one were **completed independently** to eliminate bias, influence and group think
- A professional moderator probed for clarity and detail

21 service providers completed all activities (+3 more completed over 90% of activities)

- 8 participants were from Nanaimo CDC / 16 from other organizations
- Good mix of years worked in field (from 1-44 years)

HOW TO **INTERPRET THE QUALITATIVE FINDINGS**

These findings are qualitative in nature and represent our interpretation of the views of a small group of caregivers and service providers in the Nanaimo area.

While they are not intended to be statistically representative of the population, they provide **valuable direction and insight** into the issues discussed.

*Icons identify slides with findings specific to quantitative or qualitative methods throughout the report

QUANT FINDINGS

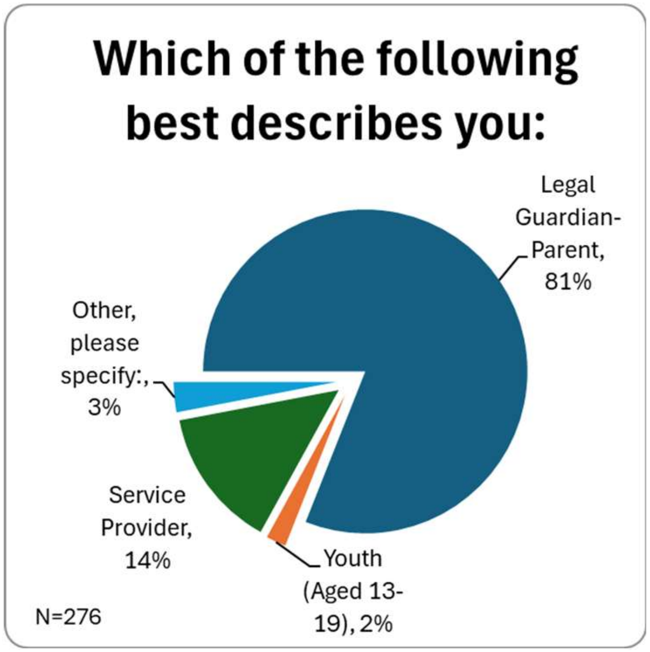
Respondent Details – Summary Overview

An online, quantitative survey was made available by Nanaimo CDC for Parents/Guardians, Youth, Service Providers and others involved in care to complete.

A **total of 276** online surveys were completed.

- **230 Parents, Guardians, and other respondents** completed the survey – **these will be referred to as 'Caregivers' throughout the rest of the report**
  - Other respondents included grandparents, siblings, and aunts and were included with Parents/Guardians in the analysis.
- **38 Service Providers** from various local companies completed the survey.
- **6 Youth** (aged 13-19) completed the survey.

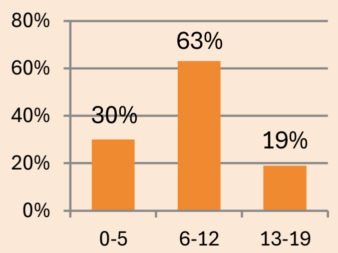
Note: A margin of error cannot be associated with a non-probability sample.



Respondent Details

Caregivers (n=230)

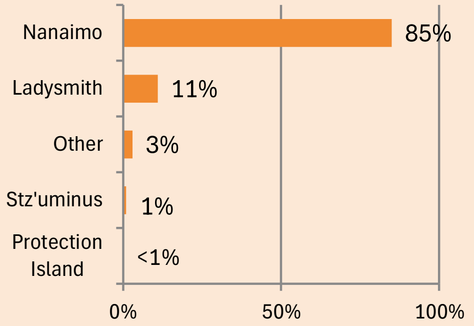
Q: What age bracket does your child/youth fall into?



Responses: 259 | Base: 230

Note: Percentages sum over 100 as multiple responses were allowed

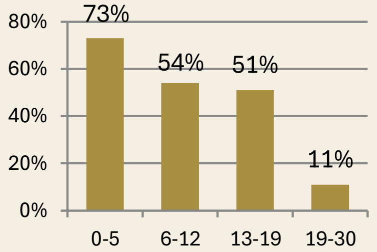
Q: What area do you live in?



N= 220

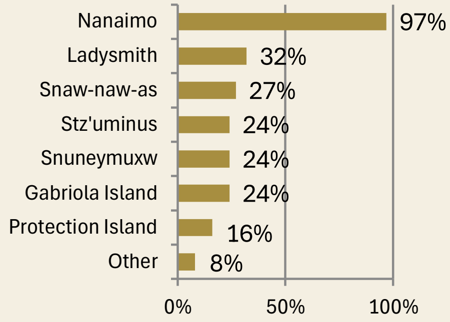
Service Providers (n=38)

Q: What ages do you support?



N=37

Q: Where are your services located?



Responses: 94 | Base: 37

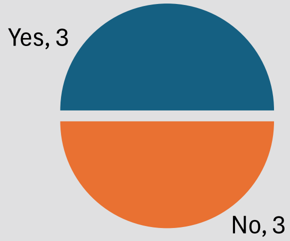
Q: What is the name of the company/agency you work for?	
Nanaimo Child Development Centre	15
Tillicum Lelum Aboriginal Friendship Centre	5
School District 68	3
WorkBC	3
Independent Child Care	2
BGC of Central Vancouver Island	1
Central Vancouver Island Multicultural Society	1
Enchanted Moments	1
Jolly Giant Childcare	1
Little Legacies ltd.	1
McElhanney	1
MNBC - Metis Family Connections	1
Nanaimo Innovation Academy	1
Sprouting Tigers	1
Vancouver Island University	1

Youth (n=6)

Due to the low number of completes, we are sharing actual counts, as percentages cannot reliably be interpreted.

SERVICES RECEIVED

Q: Are you currently participating in any community services such as respite, private therapies or behaviour intervention?



Q: What area do you live in?	
Nanaimo	4
Protection Island	1
Other	1

Q: What diagnoses do you have?	
Not Yet Diagnosed	2
Mental Health	2
Prefer not to say	1
Learning Disorder(s)	1
Developmental Coordination Disorder	1
Global Developmental Delay	1
ADHD	1
Autism	1
Muscular Dystrophy	1

KEY INSIGHTS

3 Key Learnings

1

Top Issues: wait times and cost of services

- **65% of caregivers are dissatisfied with wait lists and availability of services.**
- **Four in ten caregivers report that their child does not receive ANY services**, mostly because:
  - they do not qualify (partly due to lack of diagnoses) or
  - cost of services.

2

There are Support Gaps

- Kids falling through the cracks:
  - **Diagnoses or needs other than ASD;**
  - **Those with lower needs;**
  - **Ages above 5+;**
  - **Newcomers** to the area or to Canada
- Service Gaps:
  - **Mental health** supports for kids and parents
  - **Inclusive childcare options**
  - **Therapy in child's 'natural environment'**
  - **Recreational programs**
  - Other **support for parents** (e.g., system navigation, respite, ...);
  - **Dietitians**
  - **'Creative" therapy forms**
- Other Limitations & Barriers
  - Limited availability
  - Parent's effort required to access services
  - Lack of collaboration among providers

3

Some things are working well

- Existing service providers are **dedicated and work hard** to support children's diverse needs
- The **Nanaimo Child Development Centre** (CDC) is appreciated for its early intervention program
- **Specialized schools, learning centres or private tutoring** are filling the gap for some who have access.
- Parents have some resources to learn about available services:
  - pediatricians,
  - nurses at Island Health,
  - word of mouth or Facebook Groups.

3 Key Opportunities

1

Service overview and system guidance needed

- Caregivers and providers wished for an **overview of services** to mitigate lack of knowledge about what is available.
  - Caregivers need help navigating the system
  - Not all providers (e.g., those new to the area) know who to refer to
- Possible formats for an overview of services:
  - **Online repository** – regularly updated; could also include a page where providers can post updates or invitations for events
  - **Printed pamphlet/information package** for families
  - **Networking events** for service providers to introduce themselves to others

2

Collaboration and centralization

Various aspects/'steps' to centralization:

- Centralized **intake and/or referral system**
- Centralized **record-keeping or file-sharing** and/or **more collaboration** for individual children
- Centralized **location**
- Fully **integrated agency** with **centralized management**
  - Watchout: some private providers expressed strong hesitation about this last 'step'

3

Shift to needs-based vs. diagnosis-based access to services

- Many providers called for a **shift to more needs-based access to services & funding.** They highlighted the faults of the current diagnosis-based funding structure and service access which leads to increased wait-times for assessments due to increased number of people seeking diagnosis, over-diagnosing, and lack of fairness in distribution of funding.
- ASD diagnosis and the associated funding can lead to inequity in access to services – no funding and therefore less services available for other diagnoses (e.g., ADHD, CP, FASD, Down Syndrome …) or those with needs but no diagnosis.

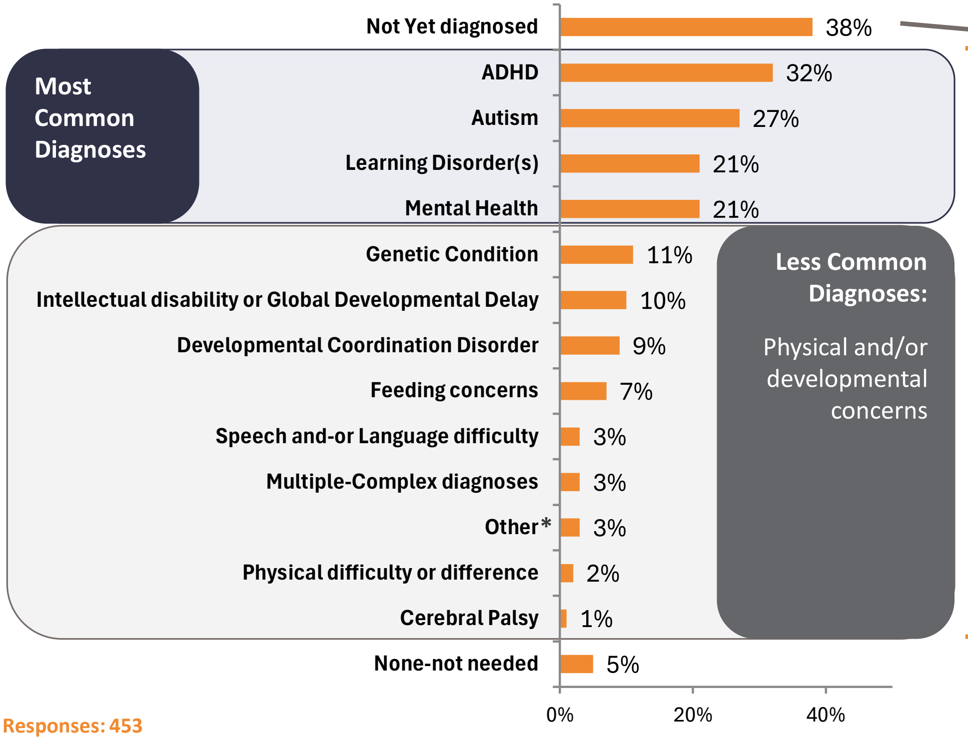
DETAILED FINDINGS

Overview of Current State

Needs within the community are diverse; many children are still awaiting formal diagnosis, while others are living with a range of developmental, learning, and health conditions.

Child(ren)'s Diagnoses

Q: What diagnoses do they [your children] have?



Responses: 453
Base: 229 [Parents, Guardians, and other respondents (non-guardian caregivers)]

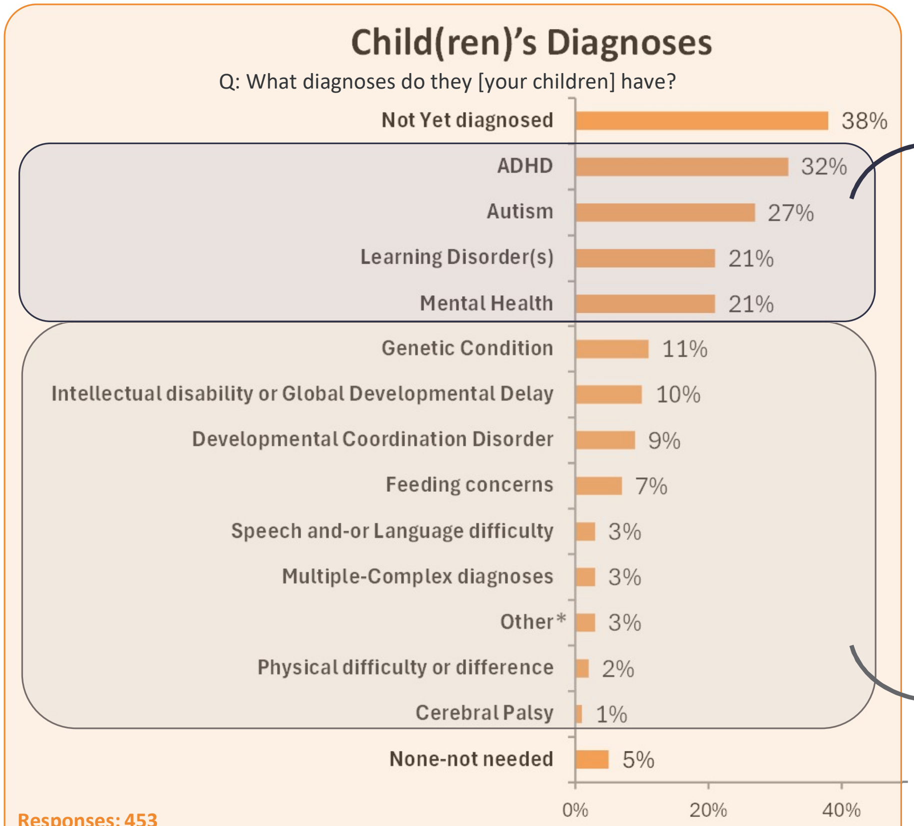
Undiagnosed Cases: A significant portion of the children (**38%**) are reported as **not yet diagnosed,** highlighting the ongoing need for assessments.

- **Among parents with children 0-5 years old**, the percentage of undiagnosed cases is 55%, emphasizing the need for early intervention services.

Multiple Diagnoses:
41% of caregivers report dealing with **2 or more diagnoses, highlighting a need for multidisciplinary treatment approaches.**

* See Appendix or Notes section for "Other" Diagnoses specified

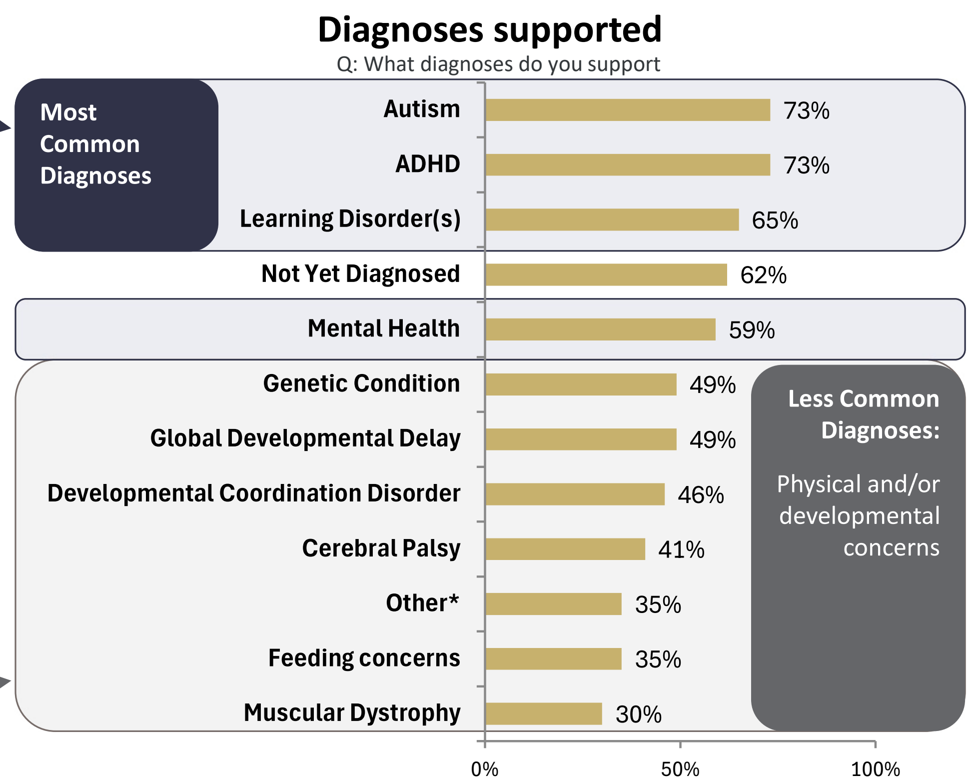
Reported support for diagnoses by service providers generally aligns with Parent/Guardian reports of current diagnoses.



Child(ren)'s Diagnoses

Q: What diagnoses do they [your children] have?

Responses: 453
Base: 229 [Parents, Guardians, and other respondents (non-guardian caregivers)]



Diagnoses supported

Q: What diagnoses do you support

Responses: 246
Base: 37 [Service Providers]

* See Appendix or Notes section for "Other" Diagnoses specified

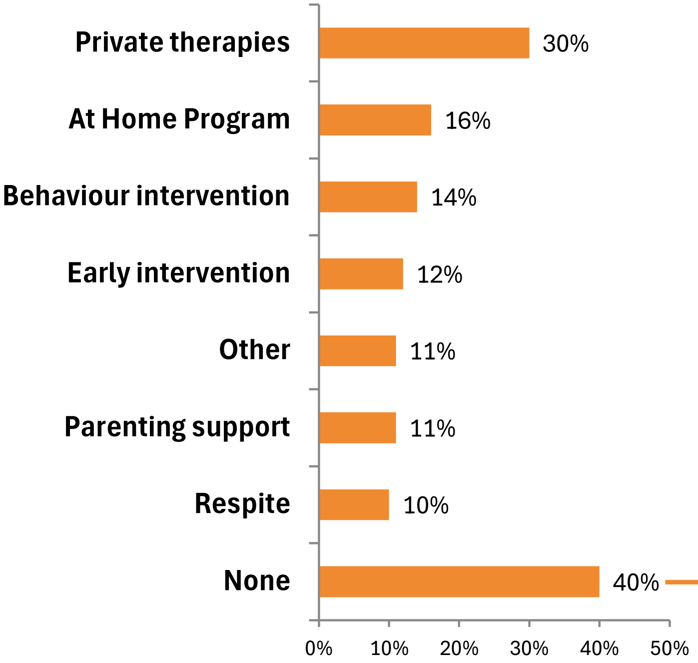
QUANT FINDINGS

CAREGIVER PERSPECTIVE

Four in ten caregivers report that their child does not receive ANY services.

Services received

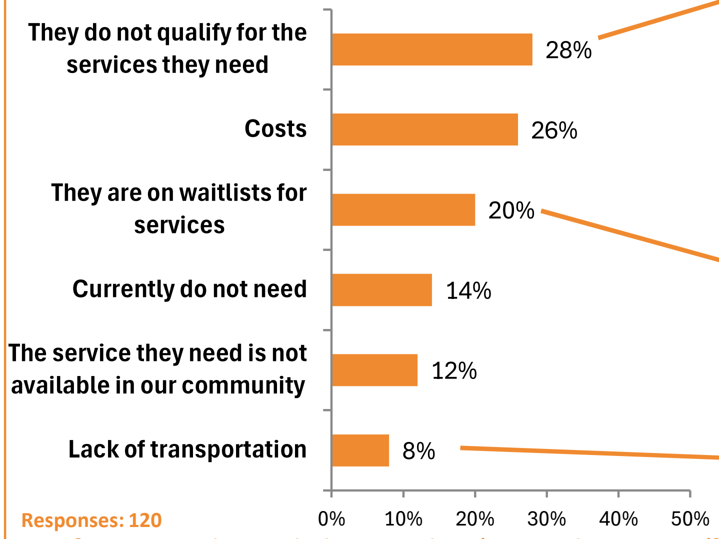
Q: Which community services does your child/youth currently receive?



N=230 [Parents, Guardians, and other respondents (non-guardian caregivers)]

Reasons for no services

Q: Why do you not receive any services?



Responses: 120

N=92 [Parents, Guardians, and other respondents (non-guardian caregivers)]

Of those not currently receiving services, 45% are not yet diagnosed, 26% are diagnosed with ADHD, 20% are diagnosed with a learning disorder, and 17% have a mental health diagnosis. **

Differences by ages*:

47% percent of those with children 13-19 not receiving services indicated it was due to not qualifying for the services they need.*

Only 6% of caregivers with children 0-5 not receiving services selected waitlists as the reason.*

18% percent of caregivers with children 0-5 not receiving services identified lack of transportation as the reason.*

***Note: Percentages for subcategories by child's age should be interpreted with extreme caution.**

- Children aged 0-5 not receiving services: N = 17
- Children aged 13-19 not receiving services: N = 17

**See Appendix (slides 45 & 46) for full breakdown of reasons by age groups, and diagnoses of those not receiving any services.

upwords

DISCOVERY RESEARCH

Providers reported some collaboration around individual clients and some general connection through the Early Years Partnership and events.

What Connection & Collaboration currently looks like:

Meetings for one client

- E.g., IEP meetings, goal planning, discussing treatment options, transition planning
- Happening among OTs, PTs, SLPs, Behaviour Analysts, pediatricians
- Collaborative care plans with Island Health Dietitians, Private Behaviour Consultants & Daycare Providers

Referring clients to another provider or program

- The ICY holds a weekly referral screening table attended by SD68, Island Health, and CYMH

Information Exchange

- Sharing reports or requesting information from other providers
- Providing consultation to support workers for a child
- ED of one local resource centre (LaFF) sits on various boards for other organizations to get information and ideas about what is happening

Joint therapy or activities

E.g.,

- running groups in collaboration
- joint event to orient families to school system
- partnering for community events
- Working on joint appointments between Island Health & NCDC

Sharing own space/providing outreach therapy in other agencies' spaces

E.g.,

- Therapy & consultation in daycares, preschools & schools
- Pediatrician letting other providers work out of own office

Early Years

- Early Years Partnership: all early-years service providers (not limited to diverse needs) meet ~5x per year
- Early Years Events where many resource providers gather in one space for families to access

Lack of time and knowledge about each other, as well as competitive attitudes are among the barriers to collaboration.

Barriers to Collaboration:

Time Constraints

- Meetings hard to fit into busy schedule; difficult to find time that works for everyone
- Networking is unpaid time; time spent on collaboration with provider team may need to be billed to client family
- Lack of staff (unable to recruit & high turnover)

Lack of knowledge

about other organizations or service providers and what they do

- Hard to know who, and how best to work with different groups, get access to contact info (especially for service providers who are new to the area)
- When partnerships do occur, the information stays with the person meeting and is not shared with the team

Competitive attitudes

- Competing for funding (e.g., losing short-term contracts if referring to another service); seeing services as a business
- Not recognizing/valuing contributions of other service providers
- CDC participants also mentioned that different philosophies and intervention models prevent agencies and service providers from establishing shared goals for the community

Lack of team communication

- Not looping all providers into communication with client
- Some restrictions due to confidentiality & privacy; lack of consent forms that allows providers to share information

> *" I think **there are a lot of 'cooks in the kitchen'**. So for example, I might e-mail a family some information and then a social worker connected with them and then a DL, and then the PT, and **if we all just connected together in one e-mail chain, it would be amazing!**"* – Provider

Lack of LOCAL networking and training opportunities

(in Vancouver if offered by the MFCD)

> *"[Professional Development] seems more available from a provincial level which does involve 'location' not always being ideal; i.e., attending PD and workshops in Vancouver. Would be nice to see more of that closer to our area."* – Provider

QUAL FINDINGS

PROVIDER PERSPECTIVE

*“**Our services are often competing**, and it takes away from the ability to provide wrap around service.*

*I find the **lack of interagency partnerships** leaves a lot of referrals in limbo as **both sides are unaware of the services available in the community**.*

*This **lack of communication and-information sharing** means there are a lot of families missing out on services they are perhaps unaware of in the community.”*

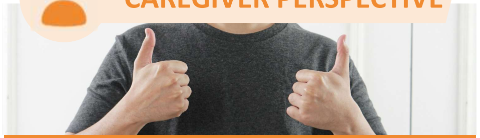
– Provider

The Highs & Lows

What’s working well & what’s missing

Early Intervention program at CDC, informal information sharing among parents, and alternative education programs were mentioned as working well currently.

CAREGIVER PERSPECTIVE



Parents appreciated Early Intervention program and ways in which they heard about services.

- ✓ **Early Intervention** (0-5 years) **at CDC**
- ✓ Information exchange about services through **Facebook Groups** or **word of mouth** (personal relationships)
- ✓ **Pediatrician or nurses** at Island Health **recognizing needs and recommending** services
- ✓ One parent appreciated having **support provided in childcare setting**

PROVIDER PERSPECTIVE

Many service providers show dedication and hard work

- ✓ Working very hard and go above and beyond to support families, often taking on more than they can handle due to their compassion.

School alternative programs or private learning centers seem to be in high demand

Strengths & Benefits:

- ✓ much-needed break for parents
- ✓ small group settings
- ✓ especially appealing for families who cannot or do not want to be the therapist

Example learning centres:

- ✓ Let me be me
- ✓ Claro
- ✓ NUKO
- ✓ Blackbird

Certain 'pockets' of kids with 'right' diagnoses or demographics are best able to access supports they need

- ✓ **Kids with ASD diagnosis AND low needs** can usually get the support they need with the funding available.
- ✓ **Indigenous children** who can utilize **Jordan's principle** are able to access services much faster than others.

- ✓ One parent mentioned that the **Outreach program** (by School District) has been successful for children with severe school avoidance for various reasons (usually disabilities) – it's **less noisy;** someone there to form a relationship with

Example Success Stories… in their words:

"One student I have worked with for several years had been removed from several elementary schools because of unsafe behaviours. His needs made it very difficult for him to participate in activities in a group setting. ***By partnering with MCFD*** *in finding a care provider, and* ***registering him with our distributed learning school,*** *he has been* ***able to find a balance of at-home learning and interactions with peers in a less demanding setting and is having tremendous success****. This partnership involved school staff, district specialist staff, MCFD social workers, a care provider, medical professionals and the parent."*

- Provider

"A mother who was a refugee from a central American country was here alone with her globally delayed son. He was high needs and she couldn't work or even make any social connections for support. I was ***able to connect her with the family resource navigator*** *who* ***linked her with a multicultural society*** *to help her navigate housing and work. The NCDC was also able to* ***find her clinicians who spoke her native language,*** *even ones that were in the Lower Mainland. I was also able to* ***liaise with Child and Youth with Support Needs,*** *even though the child had not yet been able to receive an assessment for diagnosis, and they agreed to fund some services and respite and connect her to the At Home Program for incontinence supplies. This mother* ***went from being locked in and alone with a high-needs child to finding help for him, support for herself, social connections, and eventually work."***

- Provider

The Nanaimo Child Development Centre was appreciated by the providers working there, parents and some external service providers.

▮ **Internal Comments** ▯ **External Comments**

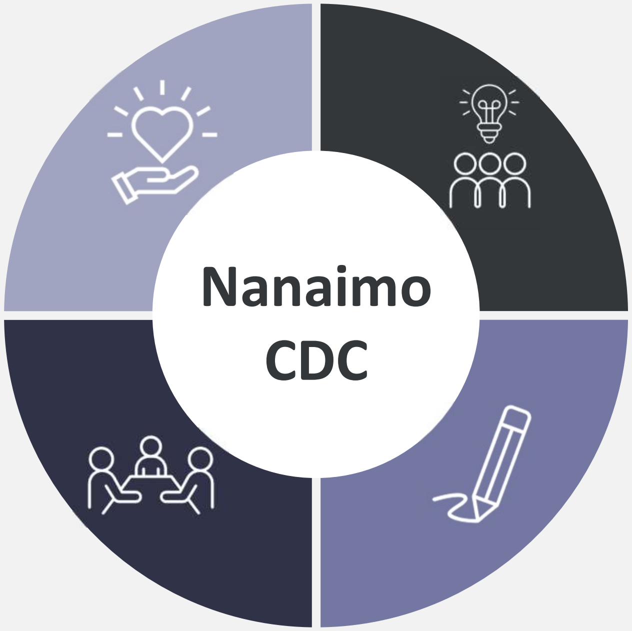
Care & Compassion

- Caring, devoted, passionate staff
- Going above and beyond to meet families' needs
- Friendly, kind, and compassionate

Collaboration & Teamwork

- Multidisciplinary, team-based service
- Collaborations with provincial and community service providers

- Joint efforts with other agencies (e.g., Ladysmith Family & Friends Resource Centre)
- Family Resource Navigator appreciated for linking caregivers to resources



Approach to Services

- Family-centered, aligning services with family goals
- Flexible service delivery (in-home, daycare visits etc.)
- Low barriers to referrals (accepts self-referrals, doctors and daycare providers)
- Referrals based on needs not diagnosis

- Consultative service model is valuable
- Social Groups

Professionalism & Expertise

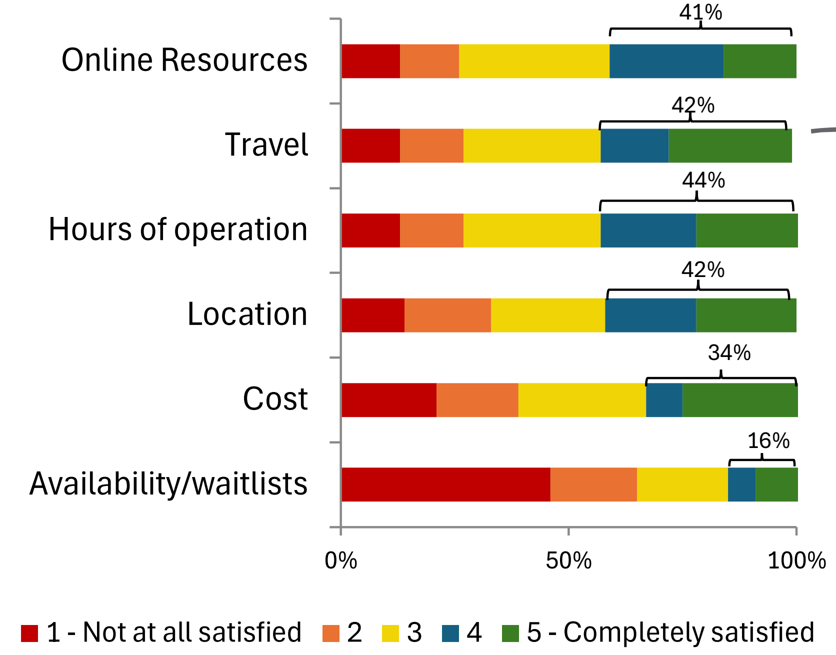
- Skilled, regulated professionals with up-to-date training
- CARF accreditation
- Continuity of care (from birth until 18)
- Long-term staff
- Large size helps secure essential funding to support services

> *"**The support from the CDC has been fantastic**, I must say. In a sense, communication was good. We could get in touch with them. They would give us advice, but give us good advice. It was always good advice."* – Caregiver

Overall lack of satisfaction: Less than half of Caregivers are satisfied with accessibility of community services in all areas; the greatest dissatisfaction is in availability, waitlists and costs.

SATISFACTION WITH SERVICES

Q: How satisfied are you with the accessibility of community services in the Nanaimo/Ladysmith area?



N=202 [Parents, Guardians, and Other respondents (non-guardian caregivers)]

While some aspects of accessibility are working somewhat well, **cost and availability** are significant concerns.

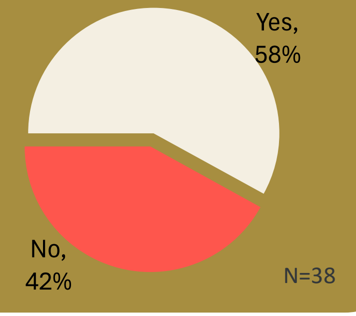
Travel: Satisfaction was lower amongst respondents living outside of Nanaimo (33% satisfied).

PROVIDER PERSPECTIVE

42% of service providers also did not think there were appropriate community services available.

- Outside of Nanaimo, 60% of providers said there were not appropriate services available.**

Q: Are there appropriate community services available for the child/youth that you support?



**Note: Due to low response numbers, any breakdowns among service providers should be interpreted with caution.

“The [service] that I would love to have – [because] I think it would benefit him, us and the school – is behavioral therapy. But ***that's not covered unless you have an autism diagnosis.***
And ***I currently don't work right now, because I need to be available*** *almost every day of the week in case something happens at school where he can't stay. So, we’re a one income [household] right now. … And that's gotten really tough. And* ***even though my husband has benefits, most benefits don't cover that****.* ***And we just can't afford it****. … Even counseling, we put him in, but* ***we were paying fully out of pocket, and we had to stop*** *because we couldn't afford [it anymore].*
So, a lot of it has to do with lack of funding for the kids that don't fall into a certain area."

– Caregiver

"We've only been here for two years. We had come from the interior. So, ***we're still on a waitlist for speech. So that's been a year and a half, waitlist****. And on a waitlist for a pediatrician."*

- Caregiver

Beyond long wait times and lack of funding, current services also fail to address additional shortcomings, including:

- **Information Gaps**
- **Connection Gaps**
- **Support Gaps**
  - Certain kids "fall through the cracks"
  - Lack of certain types of services

> *"We have a child with diverse needs (ODD, ADHD, querying ASD), who has been turned away at CYMH, is not attending school due to integration issues and safety concerns, is living in poverty, and the* ***parent cannot take them to appointments****. They* ***lost their SLP and OT when they aged out of NCDC care****. They aren't a strong candidate for clinical counselling, but they are struggling, and our youth support worker is trying to provide connection, but the* ***parent has no resources for respite, support, or private services****. The child expresses suicidal ideation and wants to talk to a counsellor, but our* **waitlist** *is long and CYMH, who currently have NO WAITLIST,* ***will not take the child because of their multiple diagnoses****."*
>
> – Provider

The greatest service gaps stem from a lack of information and connection.

INFORMATION GAPS

Parents expressed a lack of knowledge about what services “are out there” or what a service actually does

> ***“The supports are there, we just don’t know how to properly utilize them.”***
> – Caregiver

Providers:

- Especially those new to the area do not know what’s available or who to refer to
- Seasoned providers may have outdated information

CONNECTION GAPS

More collaboration wished for among providers, e.g. team meetings

- **Lack of seamless collaboration** between agencies – unable to access same records easily or share information

Parents wished for more opportunities to connect with other parents & share experiences

OPPORTUNITY / IDEA FOR PEER SUPPORT AND MENTORSHIP:

A **volunteer network** could pair parents who have some experience with the system to ‘newer’ parents.

- This would help fill both INFORMATION & CONNECTION gaps.

"We had a bunch of different services being provided to us. And one of them was OT. … And ***it was really just not made clear what exactly their role was, and what they did. They just kept asking us: 'What would you like us to work on?'*** *…* ***We don't really know, we [said] we need help with a lot of things.*** *… I don't know if it was the person or if it's just [that] there's not enough information for parents on what the therapies are.* ***[It] almost felt like there needs to be some initiative on the OT's part.*** *'I've done the assessment, or he's been assessed, and I think you guys might want to look at this area here.' Or maybe like, 'Is he dressing himself? That's something I work on. Is he going to the bathroom? These are areas that I do that I can help you with.' Maybe like pinpoint some areas, then we'd be like, 'Oh, well, he isn't dressing himself. You can work on that?' …*
I feel like there's a lot of information that you have to try and understand. With an autistic child and many other different challenges, you're learning as you go as a parent and trying to like remember all the parts and pieces of the therapies and what does what, and trying to figure out like, what he needs help in. There's just a lot of things happening fast, a lot of questions coming at you. And you're still just trying to process a lot. …
The supports are there, we just don't know how to properly utilize them."

– Caregivers

To fill the information gap, both parents and providers wished for an overview of all services available.

Information about available services needs to include **a general overview of all providers,** as well as **timely communication about one-time events or seasonal programs:**

1. **Summary overview** of all services available that should:
   - be regularly **updated**
   - include **detailed information**: name & contact info, description of service, how to access, waitlist times, costs of service
   - allow **filtering** (e.g., by location, type of service, type of need, public/private,…)

Formats:

- Most envisioned an **online repository**
- **Pamphlet:** One provider suggested having a printed version that could be distributed through providers as well as other public services

> *"Every child deserves support and every family needs to be able to access without barriers. So many families are overwhelmed and* ***do not know where to start. Having a pamphlet to help sort the road map to supports,*** *should be user friendly and accessible through the SD 68/69 and VIHA, library, etc."* – Provider

2. **Information about upcoming programs** (e.g. summer camp) sent via email with enough notice

> *"****It would be nice if there was a list, like a little 'menu'*** *… an* ***option to see everything that's available****, and then ask if we can be in certain groups or even if there's a waitlist for something. ….* ***I'd like a little paragraph, or like a little snippet, like on a menu, like this has this sauce****. I think that would be good. … [Then I could] reach out and say, 'Hey, I think that's what we need right now, that could help my child.' "* – Caregiver

> *"We got an email* ***about a city camp*** *that's hosted by the city, but it wasn't email, it was sent to us by mail.* ***There was only two weeks notice, and they were on vacation at that time****. So we really didn't even have an opportunity to get them involved in that.* ***I think something like that should be sent in an email, there should be a website where we can go, or even [that] we should be informed about stuff like that well ahead of time****. I mean, a few months is reasonable. And the other aspect is, even this camp that we got him in, I mean,* ***we got lucky, we got an email. We acted on the email within a day, and there was only one spot left,*** *so we got him in, but* ***there should be a website where everything is disclosed, all the information, all the camps, everything's updated constantly****."* – Caregiver

Support gaps exist in current service offerings for specific needs or age groups, and certain types of services are unavailable.

SUPPORT GAPS

Kids that "fall through the cracks":

- **Diagnoses or needs other than ASD** (e.g., ADHD, CP, DCD, Down Syndrome, cognitive needs)
- **No diagnosis** (but same needs as kids with diagnosis)
- **Multiple diagnoses** – some services have exclusion criteria
- **Lower needs** (e.g., tutoring for learning disabilities)

> *"A lot of [the services] are directed to higher needs kids, like for example autism or developmental, more physical developmental disabilities.* ***There don't seem to be a lot for ADHD, or the dyslexia****, like [help with] schoolwork, or tutoring. There has been no support groups or community groups I've found that have offered advice or anything."* – Caregiver

- **Primary school-aged** (5-13) - some support is offered in high school

> *"When you transition from the CDC,* ***when your child starts going to school, it's like the Wild West, no one knows what's happening****."* – Caregiver

- **Older youth** (end of high school)
- **Newcomers** to the area or to Canada

Service gaps:

- Not enough **private practitioners**, especially OTs and speech language practitioners (SLPs)
- **Mental health** supports for kids and parents
- **Inclusive childcare options**
- **Therapy in "natural environment"**
  - e.g., supports within childcare, private providers allowed into schools, outreach therapy in-home
  - Especially schools lack sufficient resources and support
- **Recreational programs** (e.g., camp, dance, fitness, etc.)
- **Support for parents** – system navigation, respite, education how to help child at home, additional assistance (e.g., transportation, housing, etc.)
- **Dietitians**
- **"Creative" forms of therapy:** Play, Music, or Outdoor therapy (e.g., a nature program)

"I definitely think more support [is needed] for parents so that they're better educated to [help] their own kids at home, because I think that's the most important thing, because that's where they are most, at least for my kids, they're home with me, so just being able to have more tools and education to kind of feel like I can do better for him here at home."

- Caregiver

"When we look at things like infant/child mental health or family mental health - there aren't enough services available to support families. How can we address other therapy needs like physiotherapy if they aren't in a mental space that allows them to accept it and implement things? Families are under stress - perhaps they have housing or food insecurity that I cannot address - how can physiotherapy be a priority when they have to meet their family's basic needs first?"

- Provider

*"Nanaimo may be **missing support services to children with diverse needs related to nutrition** (i.e., neurodiversity, eating disorders, nutrition-related trauma, allergies and intolerances...). ... to be honest, **many of the organizations/services provided to children with diverse needs would benefit from having a dietitian on staff**. ... If a child is not able to benefit from early intervention for whatever they need, related to nutrition, **the impacts can be several, but mainly it can impact their eating habits into adulthood, their nutritional status and health (i.e., malnutrition), their mental health and social health**."*

- Provider

Limited availability of services, combined with cost and effort required by parents prevent optimal support for children with diverse needs.

AVAILABILITY

- **Limited therapy length or frequency** – they're "just scratching the surface"
- No services available **outside of school hours** – difficult for working parents
- **Transportation**: Having to travel to clinic vs. service in home

> "Many families have funding (e.g. for private therapies) but cannot find someone able to see their child outside of school hours."
> – Provider

- **Lack of qualified staff overall** – a few providers pointed out that **there aren't enough providers in the area, even if funding was available to access a service.**

Suggested solution [starting point]: partnering with universities to offer programs locally (on the island) and offer local placements to connect students right away

> *"The biggest improvement we could make is having more clinicians which is **prevented by both the availability of clinicians** and the lack of funding for these positions."*
> – Provider

> *"Our biggest challenge is **recruiting therapists to come to Nanaimo**. We have all the processes in place, just no manpower."*
> – Provider

COST

- **COST:** can't afford to pay for private assessment or therapies
  - Especially difficult for those unable to work due to care-needs of child

EFFORT

- **Having to advocate for oneself and child:** a few caregivers mentioned that they needed to make "a lot of noise" or be "a squeaky wheel", had to reach out over and over again
  - Felt to be impossible for someone with cognitive barriers or psychosocial issues to navigate the whole process & system

QUAL FINDINGS PROVIDER PERSPECTIVE CAREGIVER PERSPECTIVE

"I have several ***patients who have severe ADHD which impacts their academic, emotional, and social success.*** *Schools will not provide support or adaptations because it is not a recognized condition for designation in the school system. And* ***most children with ADHD have at least one parent with ADHD, making their ability to access complicated systems and resources more challenging****. Many of these children go on to suffer anxiety, skip school, self-harm, and self-medicate with substances. And even at that point, access to mental health services is scant at best unless a child is in crisis. Fixing broken children is far more difficult that keeping them intact and supported."*

– Provider

"[I needed to make] lots of noise, *just telling the school I'm totally exhausted, like, what do I do? … And it's annoying, because* ***it's like the squeaky wheel thing. No one likes the squeaky wheel. But that's how you get the feedback****.*

But ***if I wasn't able to advocate for myself and my child, if I had any kind of cognitive barrier myself****, or if I had any other, like psychosocial issues, to navigate that whole process,* ***it would be impossible."***

– Caregiver

Wishes for the Future

The IDEAL Network

QUAL FINDINGS

PROVIDER PERSPECTIVE

An IDEAL network of services should be:

- centralized
- holistic/multidisciplinary
- connected
- informed

“I would want to see a ***network of service providers that can address the multitude of needs*** *for the youth and their caregivers. This network should also be* ***free to collaborate with medical and education professionals*** *so that* ***a child's full team understands and provides feedback*** *as to the support needs and success of interventions.*

It would be ***funded by government*** *- probably a partnership of various ministries - child & family development, mental health and addictions, education, and* ***could include non-profit fundraising so that the community also feels a sense of ownership****.*

The network would ideally provide ***regular opportunities for direct face to face collaboration*** *- team assessment and treatment delivery - and* ***further education and training that includes a variety of service providers****.* ***We learn a lot when we learn about other clinician's roles and skills.***

This should be ***overseen by a board that includes medical, allied health, educator, parent, and youth with lived experience members*** *- we need involvement of all of those affected by the service to ensure all needs are recognized and met.”*

– Provider

QUAL FINDINGS — PROVIDER PERSPECTIVE — CAREGIVER PERSPECTIVE

Providers and Caregivers wished for more centralization in one or more aspects.

Many providers (especially from the CDC) called for more centralization.

Some Caregivers also wished for a “one-stop shop”

Least intensive

CENTRALIZATION ASPECTS

Most intensive

INFORMATION

about all available services (public & private)

- For providers to make direct referrals
- For parents to pick services they want to pursue

> "So many families are overwhelmed and **do not know where to start.** Having a pamphlet to help sort the road map to supports should be user friendly and accessible through the SD 68/69 and VIHA, library, etc.“
>
> – Provider

INTAKE/REFERRAL SYSTEM

- Families would self-refer or providers would refer families to a central place to figure out next steps & provide further referrals to ALL services they might need
- Need a navigator/case manager who is knowledgeable about child development as well as all services in and outside their own agency
- Intake: shared initial conversation to avoid need to retell stories

INFORMATION SHARING/ SHARED RECORDS OR FILES

- Sharing information about a child’s progress, whether through providers able to access reports from other providers directly (with consent) or parents sharing it in a central location that all providers can access

Collaboration of service providers during treatment

- Joint appointments
- Team meetings

> "Maybe a coordinated portal (electronic). The case manager from different agencies could support the family to decide what information goes into the portal and what other agencies have access to that information. … I do not want to suggest that all of a child's counselling, therapy or behavioural intervention notes would be on this portal, but at least their current goals and who is doing what. Then if a new person gets involved the list of providers gets updated and we can spend less time in meetings just getting updated contact info. I have to emphasize the parents would need to be in control of what specific information is shared in this portal” – Provider

LOCATION

All providers under one roof with:

- proximity to bus route
- satellite branches
- services for parents (e.g., mental health counselling) in same location as services for their children

INTEGRATED MANAGEMENT

WATCH OUT!
some private providers are not willing to join such a fully centralized place!

> "I understand that a lot of people are wanting a central organized facility. I find this very interesting, as **all of the service providers that I have talked to have said that they would not work at one of these**. I know **personally, I would not,** and I would rather leave the field, than go and work for a specific organization again. So there would have to be some serious discussions with actual therapists to see if they would actually go and work in a facility like everyone is describing. As I said, I personally would not.“
>
> – Provider

upwords   DISCOVERY RESEARCH

An ideal network should also be holistic, multidisciplinary, connected and informed.

Holistic & Multidisciplinary

- **All professionals** involved in a child's development should be included – medical, physical, mental, emotional, social
- **Continuity** – same network for all ages (from birth to 19)

Connected

- Non-CDC provider participants especially wished for **networking & training opportunities** to strengthen collaboration and information-sharing. Specific ideas included:
  - ➢ Online service provider forum, including a space to post brochures or flyers
  - ➢ Event with presentations (in-person or Zoom) with educational content or sharing successes with each other
  - ➢ Information events for families
  - ➢ Regular newsletters
- **Better integration of private service providers into daycares and schools**
  - One private OT was unaware they could apply to provide services within school district)

Informed

- Wish for increased communication
  - between service providers about individual children
    - ➢ **consent would need to be built into referral process**
  - about other service providers' roles and skills

- **Opportunity for ongoing input from ALL parties** (providers, educators, families, youth)
  - Important to include voices from those with lived experience (caregivers and/or youth)
    - ➢ Could take the form of a **board of directors** overseeing the network or on a (paid) parent advisory panel to give feedback on service plans

*"A **centralized service hub** that accepts referrals from walk-in clinics, schools, family doctors, and self referrals (plus more I'm sure) and has **access to all step-up and step-down levels of care**. Intake social workers who connect families with **holistic supports** - respite, mental wellness, food security, therapy, schooling options, assessment, testing. **Overseen by a multidisciplinary, multi-employer leadership model**, with regional or departmental teams. Integration would be seamless, and wait times would be short."*

\- Provider

*"I think the starting point [would be for] it to **have a main organization being the backbone** and supporting this network, **having someone (one or more staff) dedicated** to the network and optimizing its functioning, and build on collective capacity and power (i.e., apply for funding)."*

\- Provider

[Q: what would you say is missing?]

*"I think **a one-stop shop, one center** that connects you, like basically, **you can do an intake** and they can say, 'Okay, your child might qualify for a special needs amount'', **your doctor just signs a form.** … Or here's an **advocate who can help you with the disability tax.** … Having **one person to be like, 'Here, we're gonna get you connected to all these people. And we're going to help you knock all these things off your list.'** Otherwise, you're doing it and … it's super overwhelming."*

– Caregiver

In summary, parents and providers identified a need for mental health services, additional support for parents and older teens as main areas of opportunity.

When asked about their wishes for new community services or improvements to current services, the most important areas identified included*:

Access to funding - affordable services	**14%**
Inclusive spaces and programs	**14%**
Reduce Wait Times	**14%**
Specialized services	**14%**
Mental Health support ★	**12%**
In-school Support	**12%**
Improve assessment/diagnostic services	**9%**
Parental Support ★	**8%**
Professional development and training	**8%**
More providers	**7%**
Youth Support ★	**7%**
Camps for diverse kids	**7%**
After-school and out-of-school care	**6%**
Respite care ★	**6%**
Autism Services and Programs	**4%**
None - everything is good	**4%**

★

Opportunity Areas

- **Mental health services** a priority for all: requested for children/youth but also for the parents/guardians and service providers that are supporting them
- **Unmet need for parental support & respite services** – consequences of that service not being available include parent burnout

To help solve this need, one provider called for **more university programs on the island** to educate more OT, PT, SLPs. A closer partnership with educational programs could focus on creating internship opportunities, with the additional benefits of new clinicians learning on the job and providing lower cost care

★

Teens and young adults are an underserved population with a particular **need for services targeting the transitions** associated with that age group such as working, moving, and attending post-secondary, **e.g.,**

- **job readiness training**
- **supported first employment**
- **learning activities of independent daily living** (e.g. cooking, cleaning, finances, transportation)

* See Appendix or Notes section for full list and percentages of mentions

Additional wishes identified through the qualitative research included social groups, needs-based access to services, and more services in a child's 'natural environment'.

Social Groups

- Many caregivers additionally wished for a **'safe spot' social group,** both for kids and parents to relate with their peers with similar needs and experiences

Needs-based service access

- Many providers also called for **a shift to more needs-based access to services & funding** instead of diagnosis-based. They highlighted the faults of the current diagnosis-based funding structure and service access which leads to:
  - increased wait-times for assessments due to increased number of people seeking diagnosis
  - over-diagnosing
  - lack of fairness in distribution of funding

> *"School age children receive funds based on having a specific diagnosis where other children receive little to no funding or supports. Even though their abilities in our community are often higher. There are youth who have jobs and can drive a car receiving Autism funding, while non-verbal kids without Autism sit at home."*
> – Provider

Outreach services

- **Providers wished for more outreach services** or supports delivered in child's 'natural environment'; e.g.,
  - Therapy options integrated in daycare, school, home, or community (whether individual or group-based therapy/intervention)
  - Hubs in different communities or a Mobile Unit with multiple service providers available for different time slots at different locations (e.g. SLP, OT, Dietitian, Jordan's Principle application help)

THANK YOU

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upwords

APPENDIX

Additional Details from Quant Survey

“Other” Child Diagnoses specified

Parents, Guardians, and other respondents (non-guardian caregivers)

“Other” Diagnosis	Count
Anxiety	7
Speech disorder	6
ODD	5
FASD	3
Cerebral Palsy	2
Deaf Blind	2
Down syndrome	2
Agnenis of corpus callosum, polymicrogyria	1
ARFID	1
Born prematurely	1
Brachial-Plexus Injury	1
Brain aneurysm muscular effects	1
Cavus Foot (pain & sore for walk or do exercise)	1
Complex Neurological developmental disorder	1
Charge Syndrome	1
Difficulty integrating visual input with motor output	1

“Other” Diagnosis	Count
Flat head	1
Giftedness	1
Glut I	1
Hereditary Angioedema	1
Intellectual disability	1
Language disorder	1
Missing right hand	1
Muscular Dystrophy	1
Pandas	1
PANS	1
PTSD	1
Sensory Processing Disorder	1
Spinal injury	1
Unknown cause of paralysis	1

“Other” Diagnoses supported specified

Service Providers

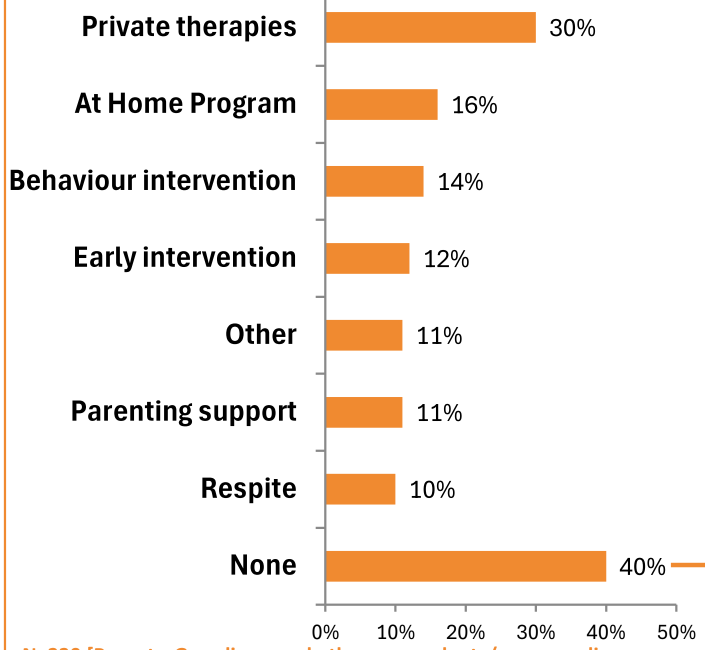
Other Diagnoses supported specified:

- A variety. We work towards being inclusive.
- Addiction
- Employment readiness
- FASD
- General movement disorders, seizure disorders, orthopedic conditions (Juvenile arthritis, arthrogryposis, spina bifida, congenital limb differences, etc.)
- I support parents who have any questions about services for their families.
- Psycho-social emotional
- Support for Parents
- Trauma related disorders
- We are a parent child group so we will support every child no matter their condition

Four in ten caregivers report that their child does not receive ANY services.

Services received

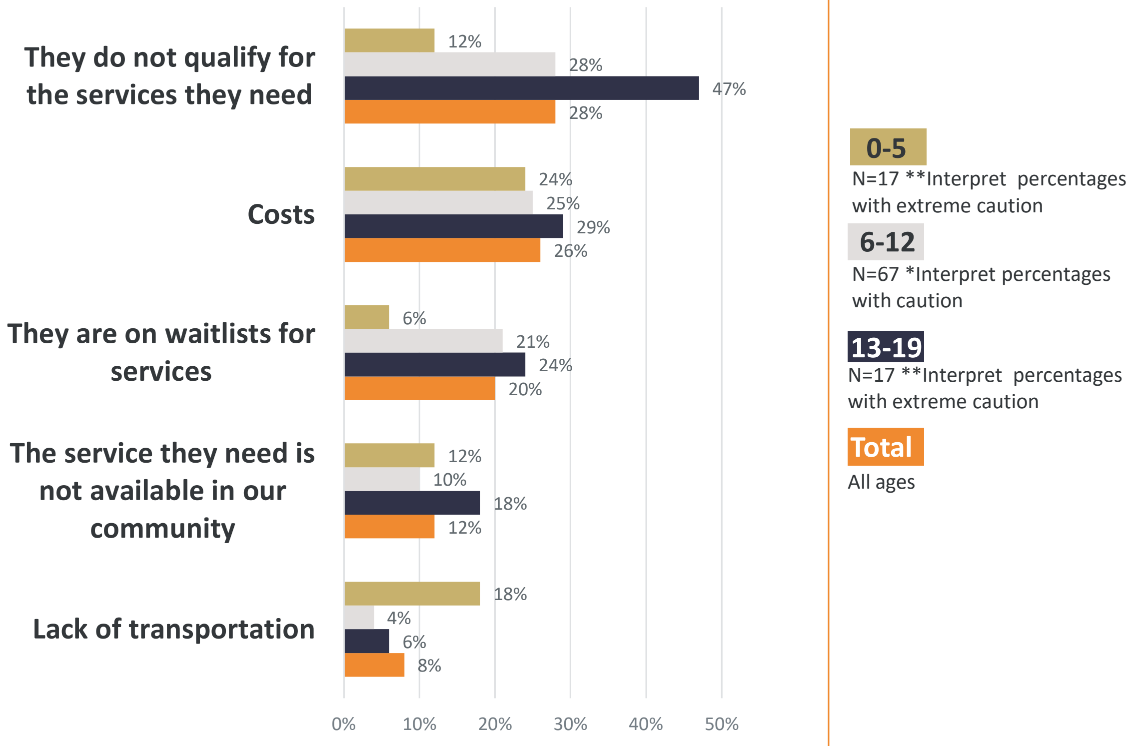
Q: Which community services does your child/youth currently receive?



N=230 [Parents, Guardians, and other respondents (non-guardian caregivers)]

Reasons for no service by Age of child

Q: Why do you not receive any services?

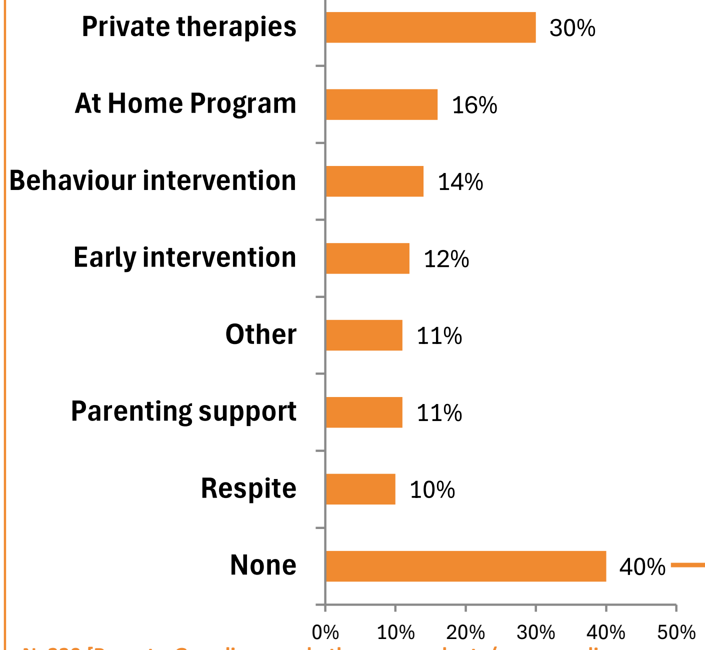


Base=92 [Parents, Guardians, and other respondents (non-guardian caregivers)]

Four in ten caregivers report that their child does not receive ANY services.

Services received

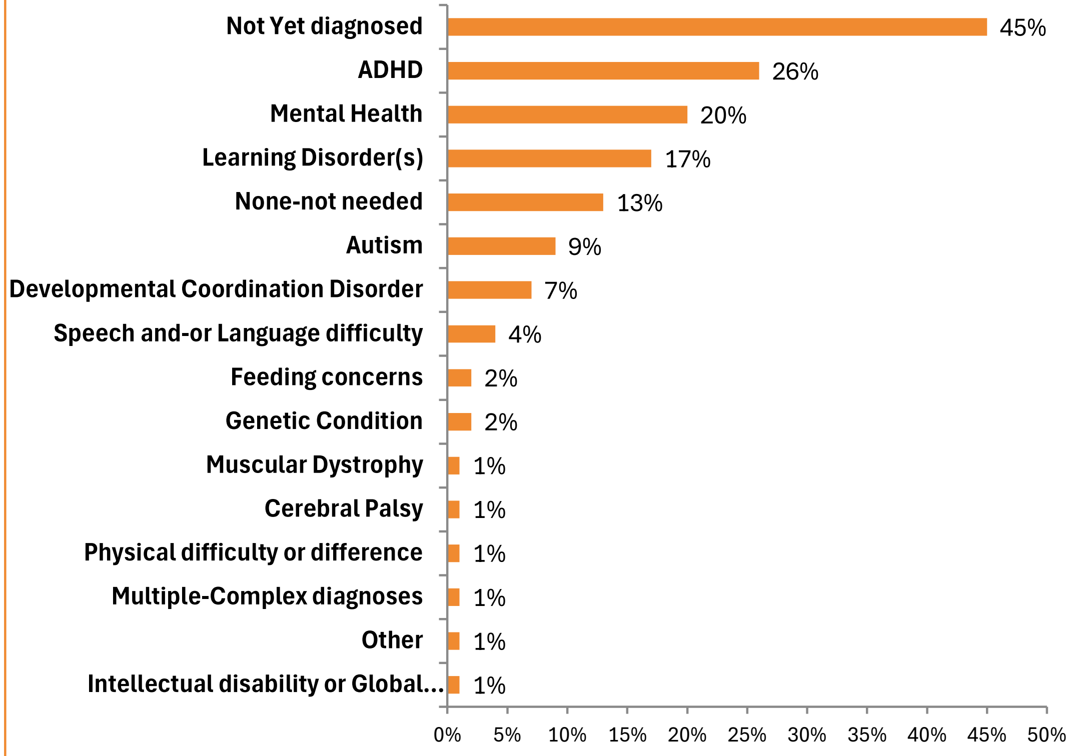
Q: Which community services does your child/youth currently receive?



N=230 [Parents, Guardians, and other respondents (non-guardian caregivers)]

Diagnoses of those not currently receiving services

Q: Why do you not receive any services?



Base=92 [Parents, Guardians, and other respondents (non-guardian caregivers)]

Parents, Guardians, and Other respondents (non-guardian caregivers)

Satisfaction with Services

Respondents that indicated being dissatisfied in any category were asked to outline why they were dissatisfied. The primary explanations included:

- **Long Wait Times:** Parents face extensive wait times for assessments, therapy services, and pediatric appointments, often spanning months to years. This delay exacerbates the challenges children face, particularly in critical developmental periods.
- **Financial Strain:** The high cost of private therapies and assessments is unaffordable for many families, leading to significant financial stress. Many are forced to pay out of pocket for essential services that they feel should be accessible.
- **Limited Availability of Services:** There is a shortage of specialized services, particularly for speech therapy, occupational therapy, and mental health support. This scarcity is further compounded in smaller or more rural communities.
- **Inadequate School Support:** Schools lack sufficient resources and support for children with learning or behavioral difficulties. The process to secure necessary accommodations is often lengthy, leaving children without the help they need.
- **Work-Life Balance Challenges:** The limited hours of operation for services (typically 9-5) make it difficult for working parents to attend appointments without missing work, adding to the stress and financial burden.
- **Lack of Information and Coordination:** Parents struggle to navigate the system due to a lack of clear information about available services and how to access them. This leads to frustration and feelings of being left to manage complex needs on their own.

All Respondents

Looking to the Future

This question provided valuable insights into the community's priorities for the future of services for children and youth with diverse needs. The most important areas identified included:

Specialized services, including SLP, OT and targeted services not including Autism were mentioned by **14%** of respondents. **Seven percent** also noted needing **more providers** in general.

Reducing wait times was also frequently mentioned (**14%**), particularly for obtaining a diagnosis so that services could be accessed and/or funded.

Creating more **inclusive spaces and programs (14%)** and ensuring **access to funding and/or affordable services (14%)**.

Increasing **mental health support** for children, parents/guardians, and service providers (**12%**) and increased **in school supports** (**12%**) were also frequently suggested.

Other suggestions included **respite care** (**6%**), more options for **teens and young adults** (**7%**) particularly for transitions associated with that age, and better options for **after school or out of school care** (**6%**).

What new community services, or improvements to current services, for children/youth would you like to see in the future?	
Access to funding - affordable services	14%
Inclusive spaces and programs	14%
Reduce Wait Times	14%
Specialized services	14%
Mental Health support	12%
In School Support	12%
Improve assessment-diagnostic services	9%
Parental Support	8%
Professional development and training	8%
More providers	7%
Youth Support	7%
Camps for diverse kids	7%
After-school and out-of-school care	6%
Respite care	6%
Autism Services and Programs	4%
None - everything is good	4%

List of Service Providers

Comprehensive list of ALL service providers in Nanaimo/Ladysmith area as compiled by provider participants*

General Services focused on Child, Youth or Family (Behaviour or Development Support)

Regional Centres/Associations (Nanaimo or Vancouver Island)

- Nanaimo Child Development Centre
- Ladysmith Family and Friends
- Pacific Care Family Enrichment Society/Childcare Resource and Referral Program (provides information about everything related to childcare)
- Nanaimo and Area Resource Services for Families (harm reduction services)
  - LIFT Program (Living in Families with Teens)
- Nanaimo Youth Services Association (housing services)
- Hope Centre (Gabriola Island)

Provincial or National Organizations (with local services)

- Blind Beginnings BC
- Children & Youth with Support Needs (CYSN) workers – from MCFD
- Child and Youth Mental Health (CYMH)
- Parent Support Services Society BC
- Family Smart (Parent Peer Support)
- Canucks Autism Network
- Autism BC
- ADHD Advocacy BC
- FASD Society for BC
- Canadian Institute for Child and Adolescent Psychoanalytic Psychotherapy

Other General Services for Parents & Kids

- Triple P positive parenting
- Salish Sea Behaviour Consultants
- Boys & Girls Club
- Kidsaction (personalized coaching and resources for physical activity practice at home)

*participants were shown a list of service providers put together by the research team, then asked who was missing

[Continued] Comprehensive list of ALL service providers in Nanaimo/Ladysmith area as compiled by provider participants*

Clinicians

- **Children's Health Centres**
  - NRGH - Paediatric Ambulatory Health Clinic
  - Sunny Hill Health Centre at BCCH
  - Queen Alexandra Centre for Children's Health (including VICAN and Ped. Feeding and swallowing)
- **Private Paediatric Practices**
  - Red Canoe Paediatrics
  - Oceanview Paediatrics
- **Counselling**
  - Paediatric Nutrition counselling services
  - Island Clinical Counselling
  - Blue Heron Counselling
- **Island Health**
  - Discovery Youth & Family Substance Use Services
- Footholds Therapy Centre
- Speak Easy Communication & Education
- Vision Loss Rehab

Childcare/Academic/Learning Supports

- School District 68 & 69
- Amelia Playschool
- Blackbird Academy
- Claro
- NUKO
- Let Me Be Me
- A Taste of Learning
- Fawkes Academy
- Literacy Central Vancouver Island (literacy tutoring)
- Jolly Giant Childcare
- Enchanted Moments
- Strong Start

*participants were shown a list of service providers put together by the research team, then asked who was missing

[Continued] Comprehensive list of ALL service providers in Nanaimo/Ladysmith area as compiled by provider participants*

Indigenous Services

- **Tillicum Lelum** Aboriginal Friendship Centre
  - Including Jordan's Principle Service Coordinator
- **Kwumut Lelum** Child and Family Services
  - Aboriginal Infant Development Program (AIDP)
- **Urban Indigenous Wellness Society**
  - Aboriginal Supported Child Development Program (ASCDP)
- Snaw-naw-as Health Centre
- Snuneymuxw Health Centre
- Stz'uminus Health Centre
- Naut'sa mawt Oceanside Wellness Network
- Island Metis Nation/BC Metis Nation
- First Nations Health Authority
- Aboriginal Head Start
- BC Aboriginal Child Care Society

Other General Public Services (not focused on children)

- Public Health Unit (VIHA)
- Central Vancouver Island Multicultural Society
- Nanaimo Association for Community Living
- Portsmouth Community Care Home
- Brain Injury Society
- Ladysmith Resources Centre Association (LRCA)
- Island Crisis Care Society
- Nanaimo Food Share
- Nanaimo Community Kitchens

Other

Current collaborative teams or partnerships

- Integrated Child and Youth Team (includes MCFD, Min. of Mental Health and Addictions, Island Health and school district)
- Early Years Partnership
- Ladysmith & Stz'uminues Interagency Group
- Gabriola Health & Wellness Collaborative

Other partners to consider including in collaborative efforts

- Vancouver Island University – ECE & CYC departments

*participants were shown a list of service providers put together by the research team, then asked who was missing

Self-identified Strengths & Approaches of each Participant's Organization

Family & Community Engagement

Urban Indigenous Wellness Society:

- Provide family & community connections
- Teambuilding and daily communication

Ladysmith Family and Friends

- Inclusive
- Providing opportunity for resource providers to visit (access to funding)
- Food security program
- Connecting families with each other

Childcare Centres:

- Jolly Giant Childcare: Identifying children that have diverse needs early on
- Enchanted Moments: Commitment to quality outdoor play

Collaboration & Partnership

Island Health

- Large org, more funding support & resources
- Flexibility in offering services based on needs
- Knowledge and education opportunities
- Set up to allow for collaborative/multidisciplinary care
- Public Health Department (Healthy Communities Team): Collaborative – between team members and outside orgs/community partners; able to share a systems perspective (e.g. other impacts such as poverty, food insecurity, unsafe housing, lack of transportation); work is indirect – supporting direct service providers
- ICY team: multiple employers working together – opportunities to remove barriers and do unconventional things

Public School

- Large number of highly committed & specialist staff
- Refined supportive planning processes in recent years – becoming more individualized and supportive
- Great partnerships with other agencies

Private Paediatrician

- Trying to align with community service providers to benefit patients

Flexible and Individualized Support

Private Practice (OT)

- Relationship-based or play-based
- Family-centred

A Taste of Learning

- Individualized, 1:1 or 1:2 programs
- Experiential learning, hands-on
- Trauma-informed practice
- Focus on relationships
- Intimate, small space

SpeakEasy Communication & Education:

- Able to follow clients across age ranges with less bureaucracy

Island Clinical Counselling:

- Creative, flexible services, groups and individuals

Funding and Resources

Urban Indigenous Wellness Society:

- Go above and beyond searching for more funding

First Nations Health Authority

- Community-led – funding, programs, services should be reflective of the wants/needs/requests of community

MCFD/CYSN

- CYSN is catch all from other MCFD services when they are unable to provide appropriate support

Private Paediatrician

- Trying to find resources