Powell River
Educational Services Society

Community Consultation on
Services to Children and Youth with a Disability in qathet Regional District

November 2024

CONTENTS

Reporting Agency: PRESS

Community Profile: qathet Regional District

Planning & Design of Consultation

What we heard – Family Conversations & Input

What we heard – Agency Conversations & Input

Reporting Agency: PRESS

SOCIETY PROFILE

Powell River Educational Services Society ("PRESS") is a BC-registered, Indigenous-led, non-profit society incorporated in 2008. The society was originally created to manage the diverse social and economic benefits to Coast Salish communities that emerged through an innovative partnership between educators, the private sector, and Klahoose First Nation.

Today, PRESS continues to implement community-centred educational, social, cultural, and economic initiatives in the traditional territories of the Tla'amin and Klahoose Nations through imaginative approaches and partnerships in education and training, and the creation of broad-based stakeholder groups around specific aspects of our mission statement.

A core intent of the society is to assist vulnerable, marginalized, or at-risk individuals and groups to overcome social and economic barriers by learning meaningful skills in diverse settings. Those we serve include persons with disabilities, youth, seniors, women, First Nation communities and individuals, people on low fixed income and individuals and families at risk of homeless.

By brokering strong and effective working partnerships between government, First Nations, educators, local communities, and the private sector, PRESS delivers innovative and successful educational, cultural, employment and economic development initiatives in coastal BC.

As an Indigenous-led non-profit we integrate multiple interests and activities within our agency's vision of a community and region where every person is valued, and all individuals and groups have genuine opportunities to realize their full potential. PRESS, historically, has had two broad service mandates:

- Empower vulnerable individuals and groups
- Revitalize economic and cultural foundations

Our services, programs, and initiatives in support of empowering vulnerable people encompass the following service areas:

- Adults with disabilities
- Families on limited income
- At risk children
- Indigenous individuals & communities
- Seniors
- Tiny business owners
- Local and regional economy

Community Profile: qathet Regional District

GEOGRAPHICAL LOCATION AND SIZE

The qathet Regional District (qRD) is situated in the traditional territory of the Tla'amin, shíshálh, Klahoose, Nanoose, and K'ómoks First Nations. In 2017, elders from the Tla'amin Nation gifted the name 'qathet' ("working together") to the Regional District. qathet (pronounced "KAW-thet") encompasses roughly 5,000 square kilometres of land including Texada, Savary, and Lasqueti islands, and mainland BC coastal areas from Toba Inlet in the north, to Saltery Bay in the south. The community is accessible only by air or water.

GOVERNANCE & JURISDICTION

Five different levels of government have jurisdiction in the region:

- Tla'amin First Nation
- City of Powell River
- qathet Regional District
- Province of BC
- Government of Canada

There are complex overlaps and gaps in the jurisdiction and authority of these multiple levels of government. While provincial and federal governments enact broad social policies (housing, minimum wage, income assistance, criminal code, transportation, infrastructure, etc.), the funding from these levels of government has seen significant cuts, leaving local governments in a difficult position.

GENERAL POPULATION

The more than 21,000 residents of qathet RD live on First Nation lands (1,200), in the City of Powell River (14,000), or in one of five rural electoral areas of the district (5,800). This population:

- Has seen little growth over the past 25 years and is expected to increase very little over the next 20 years
- Is predominantly Caucasian:
    - Only 8% within the RD / 5% within the city identify as Indigenous
    - Only 3% within the RD / 4% within the city identify as other belonging to other racial groups[1] (Filipino, Chinese, Black, Korean, South Asian, and Southeast Asian are predominantly represented within this small group

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[1] VS 30% in BC and 22% in Canada

- Has a relatively stable composition, with a turnover rate of only 15%
    - 94% of these new arrivals have come from within BC or Canada, and only 6% from other countries

CHILDREN AND YOUTH

Number of children and youth[2]

The qathet Regional District is home to 3,525 children and youth, aged 19 and younger:

AGE	qathet RD	Tla'amin	City of PR	Rural areas
All children & youth in each area	3525	170	2435	920
Preschoolers	735	40	505	190
5 to 9 years	915	45	615	255
10 to 14 years	960	50	655	255
15 to 19 years	915	35	660	220

Child well-being and vulnerability[3]

In 2019 within the qRD:

- 35% of children aged 6 and under were considered 'vulnerable'
- 31% of kids ages 6-12 were considered 'low' in well-being.

Child poverty[4]

The families of many local children struggle financially. In 2021, the poverty rate for children and youth [age 17 and under] was 24.7%[5] compared to BC (18.5%) and Canada (17%). If we apply this poverty rate to available 2021 census data, this means that roughly 800 local children live in poverty in our community. And it's important to note that this poverty rate statistic does not capture the depth of the poverty that may be experienced by these children.

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[2] Table created from multiple 2021 census tables for region

[3] https://powellriver.civicweb.net/document/87572/

[4] https://powellriver.civicweb.net/document/87572/

[5] https://campaign2000.ca/wp-content/uploads/2021/11/BC-First_Call_Report_Card_2021_Nov_23_web.pdf

If they are part of a household whose main income is social assistance, then finances are inadequate to raise their families out of poverty: there is a major and constant struggle to meet their basic needs.

For example, in 2019, combined income from social assistance benefits, child tax benefits, GST rebates and other related income supports from both the federal and provincial governments would have provided:

- A total income of $21,395 for a single parent with one child living in BC, which is $10,450 *below* the after-tax poverty line for this type of family
- A total income of $28,162 for a couple with two children living in BC - $16,874 *below* the poverty line for this type of family.

qATHET SCHOOL DISTRICT (SD47)

qathet School District (SD47) and its over 400 employees serve the school-aged population of more than 3,000 students, including 679 students with special needs. The district offers its educational programs in:

- Five elementary schools
- One remote island elementary school
- One regional online learning school
- An alternate school
- One secondary school

The district offers additional programs and services including:

- Strong Start & Strong Start Go Mobile Programs
- Before & After School Programs
- Seamless Kindergarten Program
- Elementary Reading Intervention Program
- Summer Learning Programs
- Provincial Auditory Outreach Program
- Speech Language Therapist
- Occupational Therapist
- Educational Assistants
- Powell Lake Ecological and Outdoor Learning Centre

Total school aged children[6] in qRD

qathet RD	Tla'amin	City of PR	Rural
2790	130	1930	730

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[6] This is an approximation, based on all children aged 5 to 19 in each area

SD47 enrolment, 2023/2024[7]

SCHOOL-AGED KIDS IN qRD	# IN REGULAR SCHOOLS	# IN ALTERNATE SCHOOLS	# IN ONLINE SCHOOL[8]	# HOME SCHOOLED	TOTAL SD47 ENROLMENT
2790	1999	22	1016	5	3,038[9]
TOTAL CHILDREN WITH SPECIAL NEEDS (SN) IN qRD	TOTAL SN STUDENTS IN REGULAR SCHOOLS[10]	TOTAL SN STUDENTS IN ALTERNATE SCHOOLS[10]	TOTAL SN STUDENTS IN ONLINE SCHOOL[10]	TOTAL SN STUDENTS HOME SCHOOLED[10]	TOTAL SN STUDENTS IN SD47[10]
NO DATA	350	20	309	0	679

BC Ministry of Ed Funding for Special Needs Students

The Ministry of Ed Funds SN Students according to the following levels and categories: [11]

INCIDENCE		LEVEL	CATEGORY	DESCRIPTION	SUPPLEMENTAL FUNDING PER STUDENT
LOW INCIDENCE	A relatively low incidence of students compared to the general school population	**Level 1**	A	Physically Dependent	**$49,070**
			B	Deafblind	
		Level 2	C	Moderate to Profound Intellectual Disability	**$23,280**
			D	Physical Disability or Chronic Health Issues	
			F	Deaf or Hard of Hearing	
			G	Autism Spectrum	
		Level 3	H	Needs Intensive Behaviour Interventions or support for Serious Mental Illness	**$11,760**
HIGH INCIDENCE	A higher prevalence of students in these categories.	**Level 4**	K	Mild Intellectual Disability	**No supplemental funding**
			P	Gifted	
			Q	Learning Disability	
			R	Has moderate need for Behaviour Support or support for Mental Illness	

NOTE: This table shows the model for funding to the District, not a spending formula for individual students. The ministry expects that these students may need more or less spending based on their individual needs.

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[7] This is an approximation, based on Ministry of Ed final operating 2023/24 grant for qathet SD. https://www2.gov.bc.ca/assets/gov/education/administration/resource-management/k12funding/23-24/23-24-sd-47-june-2024.pdf

[8] The district operates a regional online school with intake outside the qathet RD. We were not able to obtain clear numbers for local vs regional students in this online school.

[9] Online school has regional enrolment – multiple students

[10] This information was generously provided to us by the District Head of Special Services

[11] A detailed description of the different Levels of Special Needs starts on page 40 of the BC Ministry's Special Education Policy Manual: https://www2.gov.bc.ca/assets/gov/education/administration/kindergarten-to-grade-12/inclusive/special_ed_policy_manual.pdf .

SD47 Special Needs students in 2023/24

679 = Total K-12 ENROLMENT of students with special needs

- 161 enrolled across 6 elementary schools (24% of total SN students)
- 189 enrolled at Brooks Secondary (28%)
- 20 enrolled in Westview Learning Centre (3%)
- 309 enrolled in PIE, locally and regionally (45%)

524 = Total K-12 FUNDED STUDENTS with special needs

- Only 77% of ALL identified special needs students are funded[12]
- 9 SN students assessed & funded as Level 1 (1%)
- 348 SN students assessed & funded as Level 2 (51%)
- 167 SN students assessed & funded as Level 3 *(25%)*
- *155 SN students assessed as Level 4 receive no additional funding (23%)*

HEALTH SERVICES FOR CHILDREN & YOUTH

Vancouver Coastal Health

qathet Regional District is served by the Vancouver Coastal Health Authority. VCH is one of five publicly funded regional healthcare authorities within BC and provides essential health services for people with a disability, emphasizing accessible care in a rural context. Key health services include primary, specialized, and community-based care, which can be customized to meet the specific needs of individuals with physical, intellectual, and developmental disabilities.

Tla'amin Health

Tla'amin Health provides a full range of primary, secondary, and tertiary health services for community members living within the Tla'amin Nation and to First Nations people in the remote coastal communities in the Powell River area. Tla'amin Health works in collaboration with a variety of other organizations including Vancouver Coastal Health, the Ministry of Child and Family Development, School District 47, Inclusion Powell River, First Nations Health Authority, Inter Tribal Health Authority, Health Canada, Klahoose First Nation, and Homalco First Nation, among others. Tla'amin's public health services include:

- Nurse Practitioner
- Registered Nurse
- Chronic Disease Nurse
- Social Worker
- Mental Health Worker

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[12] https://www2.gov.bc.ca/assets/gov/education/administration/resource-management/k12funding/23-24/23-24-sd-47-june-2024.pdf (This is the final 23/24 operating grant for SD47)

  - Medical transportation support, including rides, escorts, flights, taxis and accommodations.
  - Child development Resource Centre A range of services and support for children and families
  - Health Promotion: a range of programs to foster healthy habits including pre-natal gatherings, cooking with kids, community kitchen, and exercise programs

qathet Division of Family Practice (qathet DoFP)

The qathet Division of Family Practice is part of a province-wide initiative aimed at strengthening primary health care. The division collaborates with family physicians, nurse practitioners, allied health professionals, Vancouver Coastal Health, and other community organizations to address local health care needs.

Powell River Child, Youth and Family Services

Powell River Youth and Family Services offers psychological support services to families with children aged 8 and younger, including a neurodiverse playgroup as well as programs supporting youth mental health.

Inclusion Powell River (IPR)

All of the following programs are provided to children with a disability free of charge. Referrals to these programs can be made by:

- Family doctors or nurse practitioners
- Public health nurses
- Midwives
- Childcare providers
- Counsellors
- Social Workers
- Parents

INFANT DEVELOPMENT PROGRAM

The infant development program is a free, home-visiting program to support families with children aged birth to three years. It is designed to help them promote their child's learning and development, especially if their child is experiencing or is at risk for developmental delay. This program is free to everyone in Powell River and qathet.

SUPPORTED CHILD DEVELOPMENT PROGRAM

The Supported Child Development Program (SCDP) is a community-based program that supports children who have or are at risk for a developmental delay, behavioural concerns, or need extra support to attend a public program like preschool. The program supports children up to 12 years old (and 13 -19-year-olds on a case-by-case basis). There is no fee.

COMPLEX DEVELOPMENT BEHAVIOURAL CONDITION PROGRAM

The Complex Developmental Behavioural Condition (C.D.B.C.) program supports children up to the age of 19 with confirmed or suspected complex behavioural conditions, offering:

- Personalized one-on-one support to families
- Skills-based group programming.
- Advocacy for accommodations for sensory issues
- Education for families and professionals regarding invisible brain-based disabilities
- School-based team meeting support
- Assistance to obtain assessments or referrals to other resources

OCCUPATIONAL THERAPY AND PHYSICAL THERAPY

Occupational therapy and physical therapy can significantly improve overall quality of life for babies, children, and teenagers with special needs:

- Promoting inclusion through sports, recreational activities, and education with other children
- Helping to prevent secondary complications like muscle tightness or lung infections
- Enhancing motor skills, such as balance, coordination, strength, endurance, and mobility
- Improving mental health from lowered stress, anxiety, and social isolation, while increasing self-confidence, and the ability to handle challenges.

EARLY INTERVENTION ENHANCEMENT PROGRAM

The Early Intervention Enhancement Program (EIE) is a voluntary program for families with children aged birth to five years that supports the development of good mental health and wellness for before school-aged children.

CHILD / YOUTH COMMUNITY-BASED SERVICES

Ministry of Children and Family Development

The Ministry of Children and Family Development’s primary focus is to support all children and youth in British Columbia to live in safe, healthy, and nurturing families and be strongly connected to their communities and culture. The ministry supports the well-being of children, youth, and families in British Columbia by providing services that are accessible, inclusive, and culturally respectful

- Assessing and supporting your child's development
- Autism spectrum disorder
- Complex health needs
- Deaf, hard of hearing, deafblind, blind and partially sighted
- Fetal alcohol spectrum disorder (FASD)
- Intellectual disabilities

Inclusion Powell River

CHILD AND YOUTH WITH SUPPORT NEEDS PROGRAM

The Child and Youth with Support Needs (CYSN) program supports parents with children between the ages of 6 and 12 who have been previously diagnosed and qualify for CYSN services through the Ministry of Children and Family Development (MCFD). No fee. Must be referred by the MCFD CYSN Social Worker for qathet regional district.

YOUTH OUTREACH PROGRAM

The Youth Outreach Program supports children and youth between the ages of 13 and 19 who have been designated as a Child or Youth with Support Needs by Ministry of Child and Family Development (MCFD. No fee. Must be referred by the MCFD CYSN Social Worker for qathet regional district.

Powell River Therapeutic Riding Association

PR Therapeutic Riding Association provides access to trained horses and side walkers to enable children with special aged 5 to 19 to enjoy riding uses horseback riding to improve their physical, emotional, and social well-being. Children benefit from the horse's rhythmic movement, enhancing muscle tone, balance, coordination, and posture. It also builds confidence, self-esteem, and emotional connections.

Powell River Public Library

The library provides a range of programs and resources for children, teens, their families & caregivers and educators:

UNDER 13 PROGRAMMING

- Upcoming Events
- School Tours
- Preschool Storytime
- More to Explore
- Summer Reading Club
- Literacy Resources
- Resources for Early Childhood Educators
- Recommended Reading for Kids
- Recommended Websites for Kids
- Kids & Online Learning

The library has a **Children's Program Attendance Policy:**

This policy requires that *all* children who use the library and attend programs must be under the supervision of an adult. This supervision may take the form of an adult co-attending a program or remaining within the library for the duration of a program. In either case, caregivers are responsible at all times for the safety and behaviour of their children in the library and must be available to provide any necessary support to their child in library programs. PRPL does not provide childcare through its services and programs and cannot assume responsibility for children left unattended in the library or at a program. Children who wish to leave a library program may choose to do so and will not be accompanied by staff.

TEEN PROGRAMMING

- Teen Volunteer Opportunities
- Technology Resources
- Role Playing Game Kits
- Library Programs
- Young Writers' Group

Parks, Recreation & Culture

The City of Powell River's Parks, Recreation & Culture department has a mission to enhance the quality of life for all citizens in a positive, healthy, and equitable manner, by:

- Maintaining parks, green space and playing fields
- Operating facilities that support a variety of indoor recreational activities, including an aquatic centre
- Cooperating with multiple community organizations, such as Powell River Special Olympics
- Providing community recreation services and programs:
  - **CHILDREN'S PROGRAMS (0-12 YEARS)** The *Children's Recreation Programs* are intended to provide a safe, fun, and inclusive environment for children aged 0-12 years to participate in leisure and recreational activities, building on every child's capacity to learn, play and be active. Summer Camps, arts, holiday and year-round programs are offered.
  - **YOUTH & TEEN PROGRAMS (13-18 YEARS)** The city's youth programs are designed to provide youth and teens with some fundamental learning and leadership opportunities within our community. Programs include:

Family Place Resource Centre

Family Place welcomes all families with children on a drop-in basis, Tuesday to Friday, 10am to 2pm. Drop -n programmes include

- Baby-time Drop-In
- Toddler-time Drop-in
- Storytime.
- Open Space Parent-Led Programming
- Group field trips
- Seasonal celebrations

Staff are also able to assist families with completing applications for services or funding. the centre's fax machine, printer, computer/scanner and phone are available for families to use for completing applications.

GRANTS FOR SPECIALIZED THERAPIES

Variety, the Children's Charity of BC

Variety offers grants for specialized therapies for children with a disability who are aged 0-18, and whose family's total annual household income is $85,000 or less. The therapies funded by Variety (to a top value of $2,500 annually), include:

- Occupational therapy
- Physical therapy
- Speech & language therapy
- Music therapy
- Equine therapy

Planning & Design of Consultation

CONDUCT ENVIRONMENTAL SCAN

To create a foundation for the consultation process, PRESS staff conducted an initial environmental scan:

- To determine what if any recent related studies or initiatives had been completed, or were under way or soon to be started
- To create a working picture of local services to *all* children, which should, in principle, be accessible to children with special needs
- To create a preliminary picture of local services dedicated to children with special needs
- To gather information to help us determine the most logical approach to the consultation
- To identify organizational partners for the consultation
- To help create a comprehensive community profile for our final report

IDENTIFY RELATED STUDIES & INITIATIVES

2019 Powell River Childcare Planning Project

This 2019 study determined that less than 16% of the more than 2800 children and youth in the qathet Regional District had access to licensed childcare.

> *I am a single parent of a special needs child, and finding quality, affordable childcare has been a major challenge... While I am grateful there is financial aid for childcare, both programs were/are so complicated and hard to access that most care providers will not accept it.*
>
> \- Parent quoted in 2019 childcare report

Community Belonging Team

This initiative was created in November 2023 through a Memorandum of Understanding between the city and the Community Belonging Team and was formally launched in February 2024. The team is currently conducting an environmental scan with a focus on the experience of belonging and participation of pre-school children with disabilities and their families in the qathet region. The members of the Community Belonging Team bring a range of perspectives to this work, and include Janet Newbury and Alison Gerlach (University of Victoria researchers), Meriko Kubota (Vancouver Coastal Health senior policy lead for healthy public policy), and Tabatha Berggren (parent researcher). At the time of the writing of this report (mid-November 2024) no data from the Community Belonging team is yet on public record.

DETERMINE SCOPE OF CONSULTATION

Having completed our environmental scan, PRESS decided to focus this consultation primarily on special needs children aged 5-19, for the following reasons:
- To avoid confusion with the work of the Community Belonging Team
- To avoid duplication of the work of the Community Belonging Team
- To decrease chance of "consultation burnout" of families and agencies, by avoiding canvassing the same people as the Community Belonging team
- To make the best use of the limited time available for the consultation
- The fact that relatively concrete numbers for special needs children aged 5-19 are available at the local School District level

IDENTIFY KEY SERVICE AREAS

Having completed our environmental scan, PRESS decided to structure the consultation across three key service areas:
- Education
- Health Services
- Community-Based Services

This service-area structure was adopted to
- Provide structure and time for in-depth, focused discussions in both family sessions and agency sessions
- Allow families to manage their participation time by taking part only in areas that were of high priority to them
- Minimize in-meeting times for service provider representatives, by focusing their participation on their particular service area
- Give representatives of service providers within the same sector a chance to collaborate about service delivery

IDENTIFY STAKEHOLDER ORGANIZATIONS[13]

Local stakeholder organizations & key individuals associated with those organizations were identified for each service area.

Education

- qathet School District Special Services
- qathet School District Teachers' Association
- CUPE 476 (represents Educational Assistants)
- School Administrators

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[13] The relevant activities of these organizations are described in the Community Profile section, above.

Health Services

- Vancouver Coastal Health
- Tla'amin Health
- qathet Division of Family Practice
- Powell River Child Youth and Family Services
- Inclusion PR

Community-Based Services

- Ministry of Child and Family Development (MCFD)
- Inclusion PR
- Powell River Therapeutic Riding Association
- Powell River Public Library
- Parks Recreation and Culture
- Family Place Resource Centre
- City of Powell River and qathet Regional District[14]

CREATE STRATEGY FOR ORGANIZATIONAL OUTREACH

PRESS compiled contact information for all stakeholder organization, drafted 3 distinct emails for outreach in each service area that included a project description, draft terms of reference and a proposed schedule for an initial meeting.

CREATE FAMILY OUTREACH STRATEGY

PRESS identified specific organizations / individuals across all service areas that would have direct contact – and presumably a relationship of trust – with families of children with a disability, and who might be willing to inform those families about the consultation:

- qathet School District Special Services
- qathet SD school administrators
- MCFD social worker
- Inclusion PR
- Tla'amin Health

To support family outreach from these agencies, we created a 2-page notice about the consultation which included our contact information, as well as a parent participation survey[15] for distribution by these organizations.

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[14] In 2023 The City and Regional District convened an Accessibility Committee in accordance with their newly legislated responsibilities under the *Accessible British Columbia Act*.

[15] This survey gave parents the option of identifying any barriers to their participation, so we could address these in our planning for family sessions as well as the chance to prioritize the service area(s) of most significance to them.

CREATE QUESTIONS FOR FAMILY SESSIONS

We recruited local parents of young adults with a disability, who'd had recent experience of all three local service areas, to draft questions for the three family sessions (education, health, and community) to help start, deepen and sustain family conversations about services in each domain.

CREATE AGENCY WORKING GROUPS

Initially we had a wonderful plan to create three *working groups* around each of the service areas – these would guide and give context to the family consultation for each area and ensure we were working from an open and transparent position.

We did manage to launch the Education Working Group in mid-June as we had planned, giving them the opportunity to review, edit and approve our family session questions on education.

However, the short timeline for this consultation (6 months from start to finish), the fact that a few weeks of initial research and planning were needed, and the additional challenge of having 3 months of the project timeline span the summer months & school start-up in September[16] effectively cut our window for consultation to 2 crucial months.

In this short time frame, despite repeated efforts and multiple attempts to land on a day and time that worked for everyone, we were unable to find a date when all or even most of the organizations representing either HEALTH or COMMUNITY SERVICES could attend either a real-world or virtual meeting as a "working group."

Individual Interviews with Representatives of Agencies

Still wanting to share information and get input from as many stakeholder organizations as possible, we pivoted and began arranging private interviews with various agency representatives from both HEALTH and COMMUNITY SERVICES. This was a radically different dynamic than the one we had originally envisioned and a much more time-intensive way of gathering information.

RECRUIT FAMILIES

Luckily, out of all the agencies we canvassed, the school district agreed to forward our notices of consultation to all school principals, asking them to notify the families at their schools of the opportunity to participate.

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[16] Times, in Powell River at least, when most service organizations a are unwilling to undertake additional obligations

One of the reasons that we wanted to reach out to families through service agencies and organizations was that the families who came forward to participate would come into the process verified: they could only have heard about the consultation if they received services from one or more organization.

Somewhat later in the process, when we were really wanting to diversify[17] the group of parents who were engaging with the consultation, we also began posting notices about the consultation on our agency's social media

HOST FAMILY CONVERSATIONS

Again, we had a great initial plan to host three separate family conversations around each of the service areas, which only families and PRESS staff would attend. attending. We thought that defining a clear focus for each discussion would allow the conversation to go into richer detail, supported by the questions we to the table.

We did manage to host the family session on education just before school let out in June and collected an enormous amount of feedback from that group.

However, the fact that the next 3 months of the project timeline spanned the summer months & school start-up in September[18] effectively cut our window for consultation to 2 crucial months.

Individual Interviews with Families

Still wanting to share information and get input from as many families as possible, we pivoted and began arranging private interviews with families on both HEALTH and COMMUNITY SERVICES. This was a radically different dynamic than the one we had originally envisioned and a much more time-intensive way of gathering information.

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[17] See the *What We Heard section* below

[18] Times when families are unwilling - and basically unable - to undertake additional obligations.

What we heard – Family Conversations & Input

Our record of what families told us reflects our decision to approach the consultation across three defined service areas, and is arranged in 3 sections:

- Education
- Health
- Community Based Services

CHILDREN & YOUTH REPRESENTED

AGES REPRESENTED

- Pre-teens
- Young teens (13-14)
- Teens aged 15-17

GENDERS REPRESENTED

- Male[19]
- Female[1]

SPECIAL NEEDS REPRESENTED

- ADHD
- Anxiety disorder
- Autism/ autism spectrum disorder
- Complex behavioural issues
- Executive function challenges
- Global developmental delay
- Global distress disorder
- Global learning disorder
- Mental health challenges
- Oppositional defiant disorder
- Pathological demand avoidance
- Pervasive developmental disorder
- Severe learning disability
- Trichotillomania

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[19] Cisgender

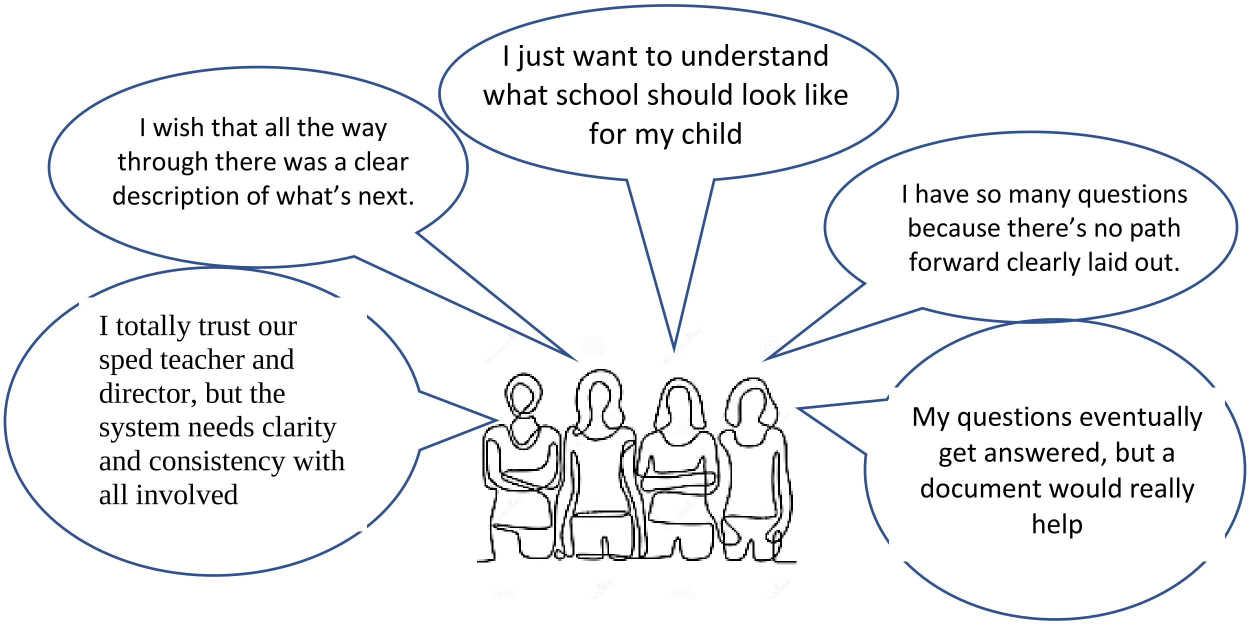
FAMILY SESSION ON EDUCATION

BLANKET WAIVER: The section contains parent verbatim quotes and opinions of individuals that have been shared confidentially. These are not verified facts.

COMMUNICATION WITHIN THE DISTRICT & SCHOOLS

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Want to be heard, and have their insights and concerns given proper consideration
- Report limited and inconsistent communication regarding the full scope of educational options, supports and resources available to their children
- Want timely and clear communication with SD staff, and to work in partnership with them
- Want to have a meaningful say in any proposed changes in support levels
- Have never been oriented to:
  - BC Min of Ed policies that guide assessment of children with a disability
  - The way these assessments drive district funding
- Have multiple unanswered questions about the district's use of funding tied to their child's assessed level of disability
- Feel schools would benefit from hosting late August / start of school year meetings:
  - Where teachers and EAs are collectively oriented to the different SN students who will be joining their school community[20]
  - Where SN students and their families are oriented to the school and given a sense of what the school year will look like for them
- Feel other students and their families would benefit from being briefed or oriented to the challenges facing the child/children with a disability in their school or class at each transition (pre-school to kindergarten and elementary to high school)



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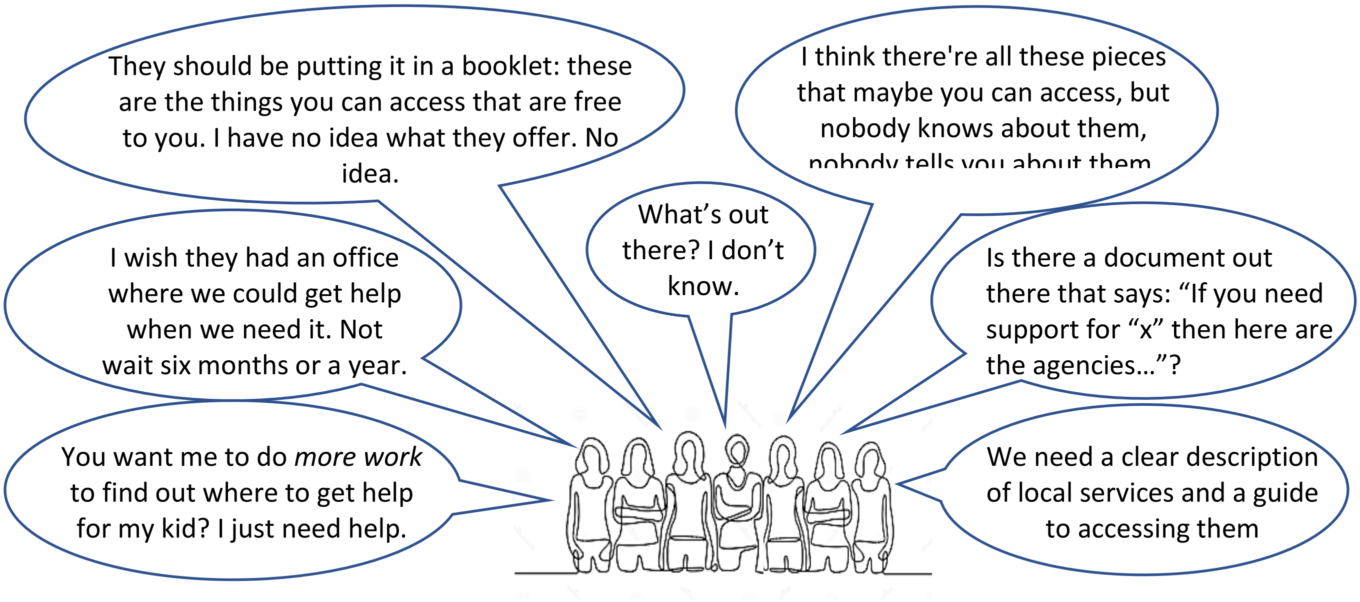
[20] IEP meetings are acknowledged, but all school personal involved do not attend.

NEED FOR A LOCAL COMPREHENSIVE GUIDE TO SERVICES

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Feel there needs to be more clarity on local services for children with a disability, both within the district and in the larger community[21]
- Want a better understanding of what supports are available in the local school district
- Think it's important to have an up-to-date guide to local services, or a physical location where they can get the information they need. or access to a system navigator
- Feel the school district is well-positioned to be the agency/organization providing this information
- Say their schools aren't connecting them to other services for their children, or helping them navigate the process for accessing those services
- Think the district should collaborate with agencies/VCH and provide a packet for parents of kids with a disability that explains how qathet district works for their kids



INDIVIDUAL EDUCATIONAL PLANS (IEP)

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Feel that the process for creating the IEP and the IEP document itself was too general
- Would like to see a functional analysis that really went into details, that could be used to drive the development of the IEP
- Haven't had a clear explanation of how their child's IEP establishes measures of progress or what measures of progress were used in their child's IEP
- Would like to see (because the IEP is so general) a form or process tied to the IEP that communicates important and relevant details of the IEP to the child's

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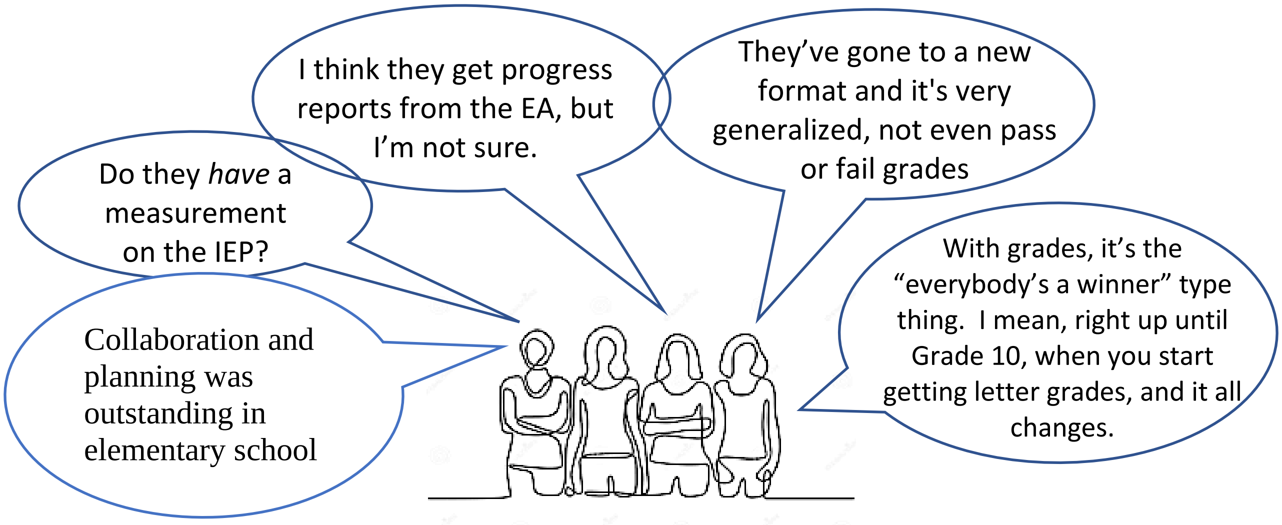
[21] SD47's website currently provides links to provincial resources, but no local guides See: https://mediasd47bcca/media/Default/medialib/prp-catalogue-of-servicesd0e6fc1265pdf

teacher(s). Report cards should go out for sped students in similar timing and fashion as all other students

INDIVIDUAL EDUCATIONAL PLANS (IEP)

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

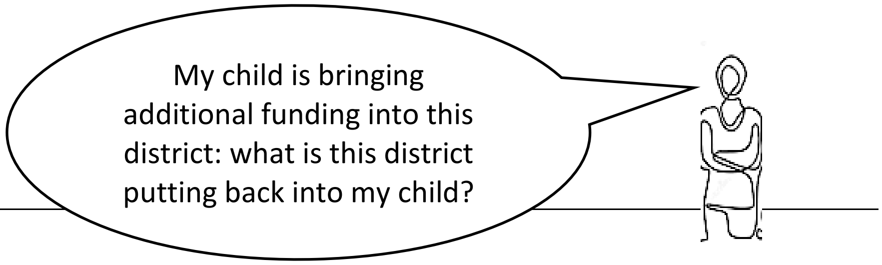
- Lacked details of:
    - How progress was tracked and measured for their children
    - Who specifically tracked and documented their children's progress
- Did not feel the progress reports they received really told them what they needed to know



FUNDING FOR SN STUDENTS

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

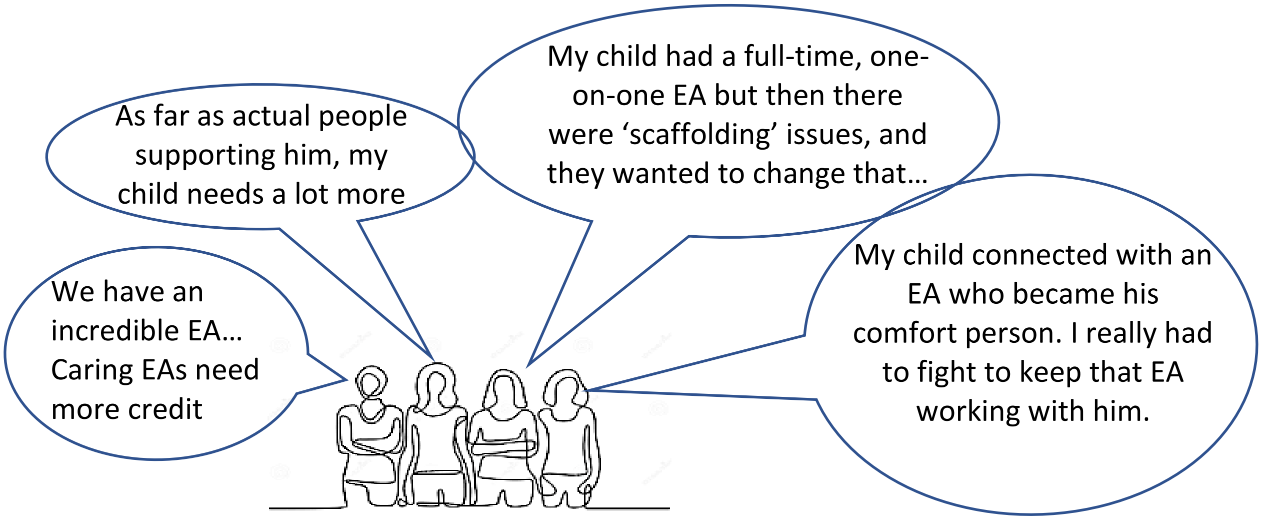
- Have questions and seek clarity about BC Ministry of Ed special needs funding models and district allocations of this funding
- Note that they themselves see many underserved kids – students who require more support but aren't receiving additional services
- Feel the district often "takes funding" from children identified and assessed for funding to help these other children
- Clearly feel bad for unidentified or unfunded children, but need to put their own children first
- Would like a real solution to this systemic problem of undiagnosed or underserved kids: one that did not result in a rationale for their own children getting less support
- Feel SN funding in school districts should be directly tied to the child whose assessment has triggered it (e.g., in the same way as autism funding from the BC Min of Health)



EDUCATIONAL ASSISTANTS (EAS)

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Feel strongly that their children's bonds of trust with certain EAs need to be recognized as critical factors in learning and EAs must be allowed to attend meetings and participate in IEP planning
- Genuinely struggle with the reality that the district's collective agreement means that children may be assigned someone at any time with little or no notice, and families have to start over at the beginning to build a trusting relationship
- Feel their children need more support
- Want to clearly understand reasoning for potential and actual changes in support levels (especially EA support) for their children



BEHAVIOUR SUPPORT SERVICES IN THE SCHOOLS[22]

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Feel that behaviour support practices are lacking in the school district
- Believe there is limited understanding, generally, of how sensory and cognitive challenges contribute to mental overload and can trigger behaviours
- Feel that children with behavioural challenges related to their disability were not always well served, and were often judged and blamed rather than properly supported
- Have had some positive experiences in trying to introduce behaviour support approaches into their child's school program
- Feel there needs to be a bridge built between behaviour consultants and teachers
- Feel their child's learning and social inclusion had sometimes been negatively impacted by the absence of a culture of behaviour support within the schools
- Feel there are district staff who don't understand or really accept their kids
- Feel there is not enough behaviour support knowledge and skills in schools
- More ABA training and support

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[22] PRESS has implemented Behaviour Support Plans in all of our adult programs and has seen first-hand how such practices, properly implemented, can radically transform outcomes for the individuals involved – especially for young adults for whom such practices were lacking within the school system.

BEHAVIOUR SUPPORT SERVICES (continued)

Our kids don't walk around with a label saying I can't handle this, or I don't like that

A kid will flip a desk… [but, if you ask] questions you can discover what…triggered them and can correct for next time

I feel like they are the first ones to get booted out of school - they're quick and easy to get out of the school system

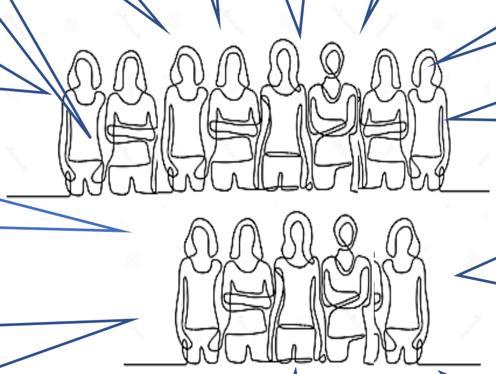
My kid needs lots of help being with 18 other kids in a closed room

In all honesty regular teachers are not educated on this stuff

I heard a teacher say, "Why is this child in school?" This is not okay.

You have to approach these kids with understanding: so often they're kids whose needs are invisible

I wish all staff read and followed the behavioural support plans



I find it very interesting that none of our kids are in regular school.

Our vice principle has gone above and beyond for my kiddo

We used our autism funding to get a behaviour consultant

Our consultant's creating "scripts" for our family and my child's support staff to use, so there's real consistency.

Our behavior consultant is working with the adults that are working with my child, trying to get a team approach going.

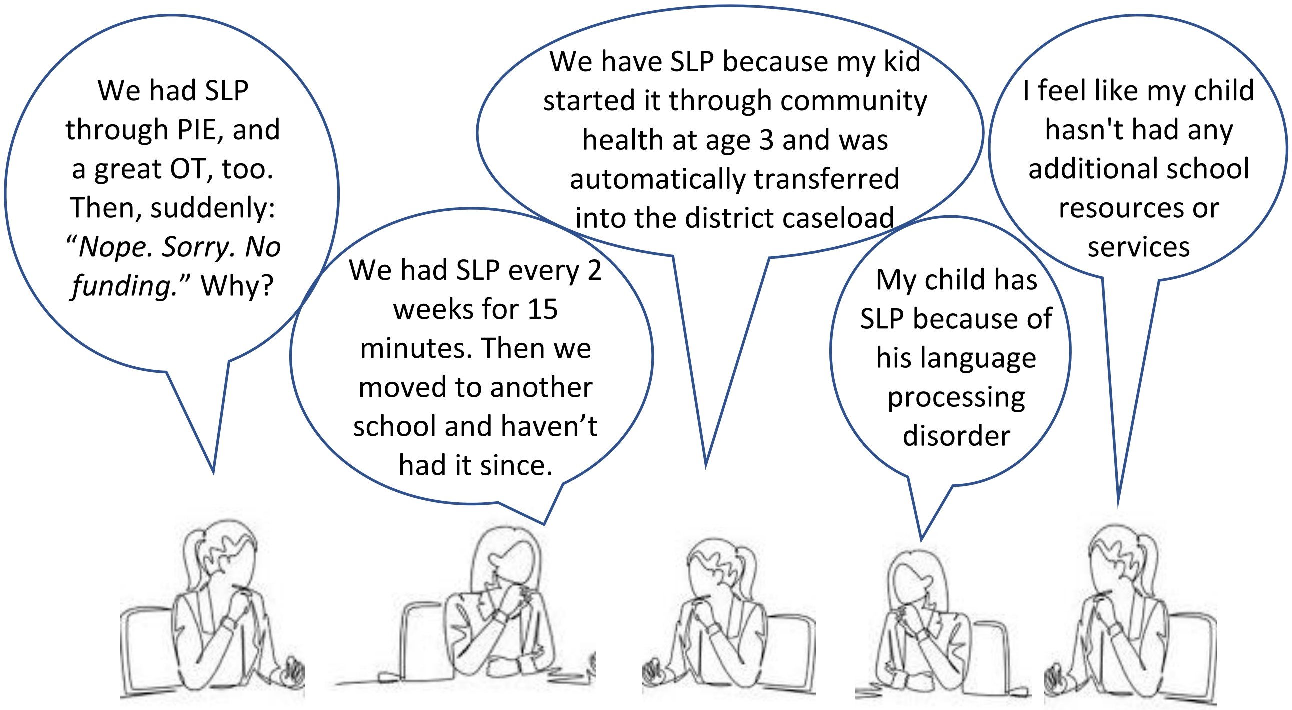
Our consultant's really helping us to understand how we need to approach things, and what skills to work on with my kid.

I'm pursuing further education, because I want to be the person who bridges the gap between behavior consultants and schools

ACCESS TO ADDITIONAL SERVICES THROUGH DISTRICT

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Are aware of the Speech and Language Pathologist (SLP) services within the district[23]
- Have had radically differing levels of success in accessing these services
- Report difficulty in getting clear and consistent information on what, if any, additional services are available and funded through the district or free in the community
- Feel their children need support for the anxiety they experience in relation to school
- Feel their children needed better access to psychological or psycho-educational assessments to better support their success in school and in community
- Had often made repeated requests for such assessments within the district without success
- Are aware that there is only one psychologist working in a district with more than 3000 students, more than 600 of whom are students with special needs
- Report that some of them, using work benefits and paying out of pocket, have had their children assessed privately
- Report that some of their children have not been re-assessed in years
- No one present reported knowledge of / accessing support from **Powell River Youth and Family Services,** which offers **psychological support services to families with children aged 8 and younger,** including a neurodiverse playgroup (scroll down the page in the link to see "services to young children"), as well as **programs supporting youth mental health.**



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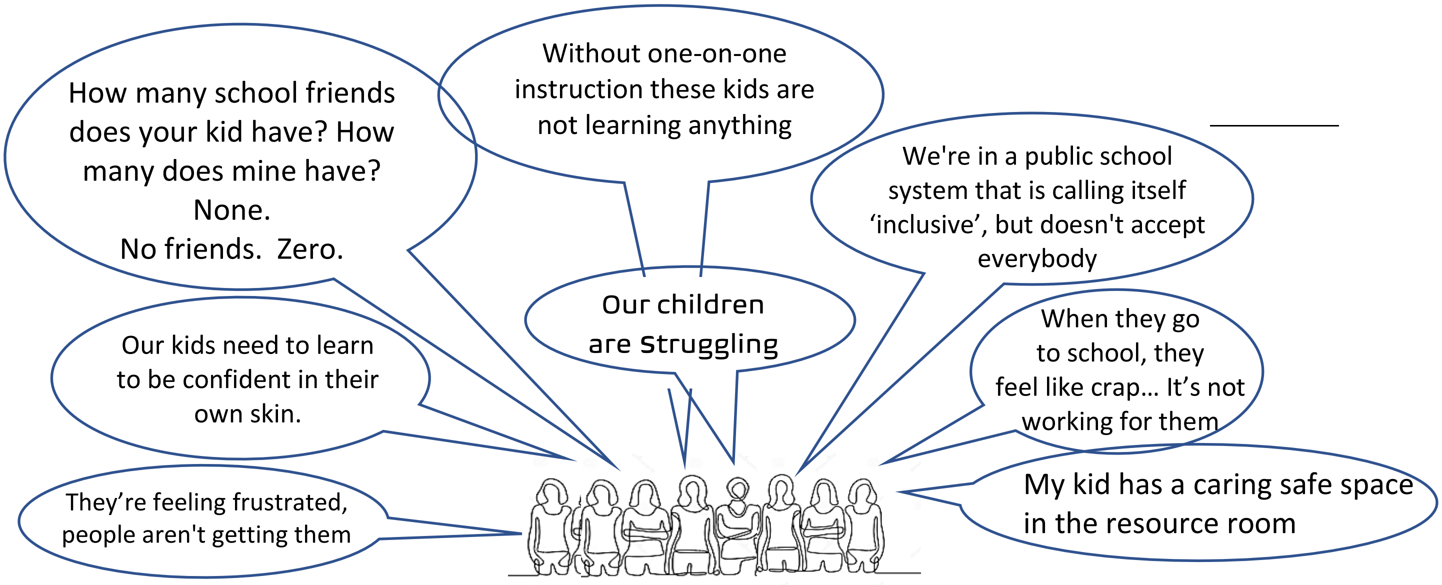
[23] Physiotherapy for children with a disability (like several other supports) is only accessible through a local community-based organization, Inclusion Powell River

SCHOOL EXPERIENCE OF STUDENTS WITH SPECIAL NEEDS



INCLUSION VS SEGREGATED SPECIALIZED INSTRUCTION

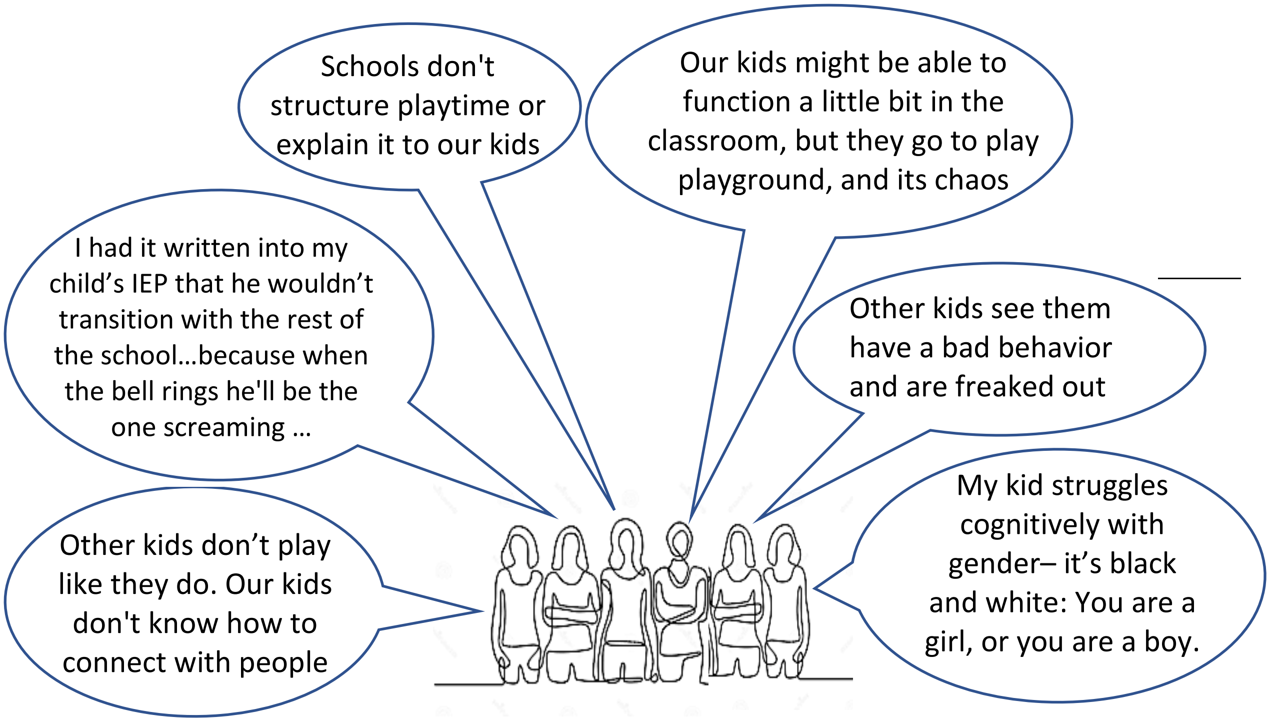
PARENTS PARTICIPATING IN THE FAMILY SESSION:

- Feel their children have the right to be in a traditional classroom and believe they could function with the right kinds of support. *“Pre-Covid my son had an amazing EA”*
- Are divided on the de facto segregation of their children after elementary school:
    - Some feel that this is the only way their kids can receive a genuine education
    - Others are left wondering what message this segregation sends to their children, to the education system and society as a whole
- See benefits and challenges in both inclusion and specialized instruction, but felt the inclusion model, on the whole, often failed their kids academically
- Often feel that their child:
    - Wasn’t learning anything in a regular classroom
    - Was often judged or blamed by other students, parents, and teachers in mainstream classes
    - Thrived in classes where teachers took time to review IEPs with parents
    - Is just there as a kid who is different, without there being real opportunities to help others understand what that child was dealing with, or teach social skills
    - Struggled to deal with the structure of regular classes in regular schools: the noise, the number of transitions
    - Wasn’t really “integrating” with non-disabled peers in mainstream classes
- Thought that perhaps being in a program dedicated to students with a disability might:
    - Put less pressure on their child
    - Make them feel less “different”
    - Decrease transitions and lessen impact of sensory issues
    - Give their children a genuine chance to learn what they needed to learn

SCHOOL SYSTEM PROCESSES, NORMS & ASSUMPTIONS

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Feel their kids are especially in need of support and mentoring during unstructured times at school
- Feel schools make assumptions about how comprehensible their patterns, routines and norms are, and that many informal settings and activities need to be made explicit for neurodiverse children
- Feel that, through lack of support, their kids are missing out on opportunities to interact successfully with their peers during unstructured times at school
- One parent commented that afterschool programs run by the district do not adequately support neurodivergent children
- One family commented that the decision to rotate vice-principals through elementary schools created a significant negative impact on their child (lack of consistency in support and leadership)



PARENT ENGAGEMENT WITH SCHOOL & DISTRICT PAC

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Reported that one of them had been a PAC member at an elementary school
    - This parent reported that "all they talked about was how they were going to spend the money that they got through fundraising, and it was always like: 'Let's get playground equipment or stuff.' Never about school."
- Know there is a Parents Advisory Council (PAC) at every school and a District PAC too
- Know that PIE also has a PAC, but hadn't looked into it or considered joining

TRANSITIONS WITHIN K-12

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Report a stark difference between their experience in elementary and high school
- This difference Included changes in:
  - The composition of the IEP team
  - The willingness of teachers to engage in implementing their child’s IEP
  - The process for reporting their child’s progress at school

I don't know how many times I emailed his teachers at high school about his IEP

My husband had it out with one of the high school teachers one time because the teacher hadn’t even looked at his IEP

In elementary school, you have the classroom teacher, SPED teacher, EA, principal, and other supports.
In high school, it’s me and the SPED teacher

Other kids don’t play like they do. Our kids don't know how to connect with people

In grade 10 you start getting letter grades, but up until then it's like false advertising

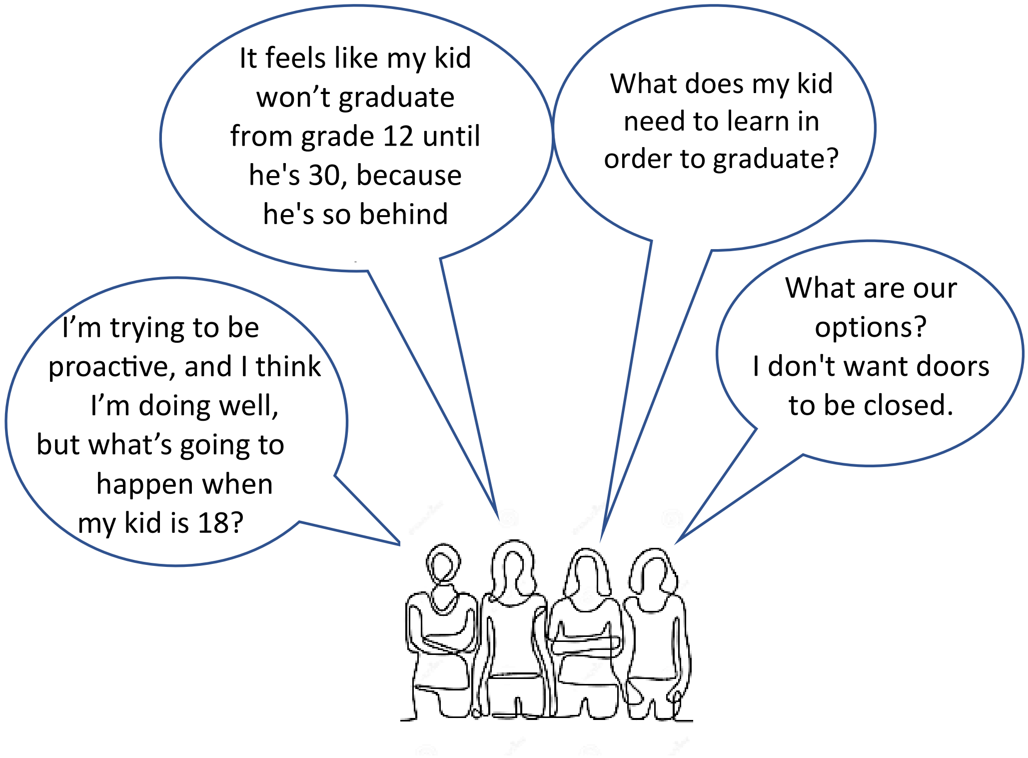
It’s like oh your kid is doing great, then you get to the point where it matters, you get to high school, and it can all change

Why are we documenting things that aren’t even acknowledged? He has an IEP, it's your responsibility as his high school teacher to know his IEP

TRANSITIONING TO ADULTHOOD (BEYOND SCHOOL)

PARENTS PARTICIPATING IN THE EDUCATION SESSION:

- Express a lot of anxiety about graduation and what will be available to and what will happen to their children beyond the K-12 school system



ACCESS TO SUMMER PROGRAMS

PARENTS PARTICIPATING IN THE FAMILY SESSION:

- Feel that the formerly offered summer program, where SD47 and the Salmon Society partnered[24], had helped their kids retain what had been learned during the school year in addition to hands-on, nature-based learning
- One family reported that the lack of district run summer programs has a "significantly de-stabilizing impact" on their family's home life
- Have not been consulted or briefed about the discontinuation of the summer program and so are left to speculate:
  - Is there no funding?
  - Is it because there is no staff available?
  - Is it because the district didn't think it was worthwhile?
- As with other aspects of district programs for children with a disability, parents felt they were completely in the dark about the reasons behind service decisions
- Parent would very much like to see this program re-instituted

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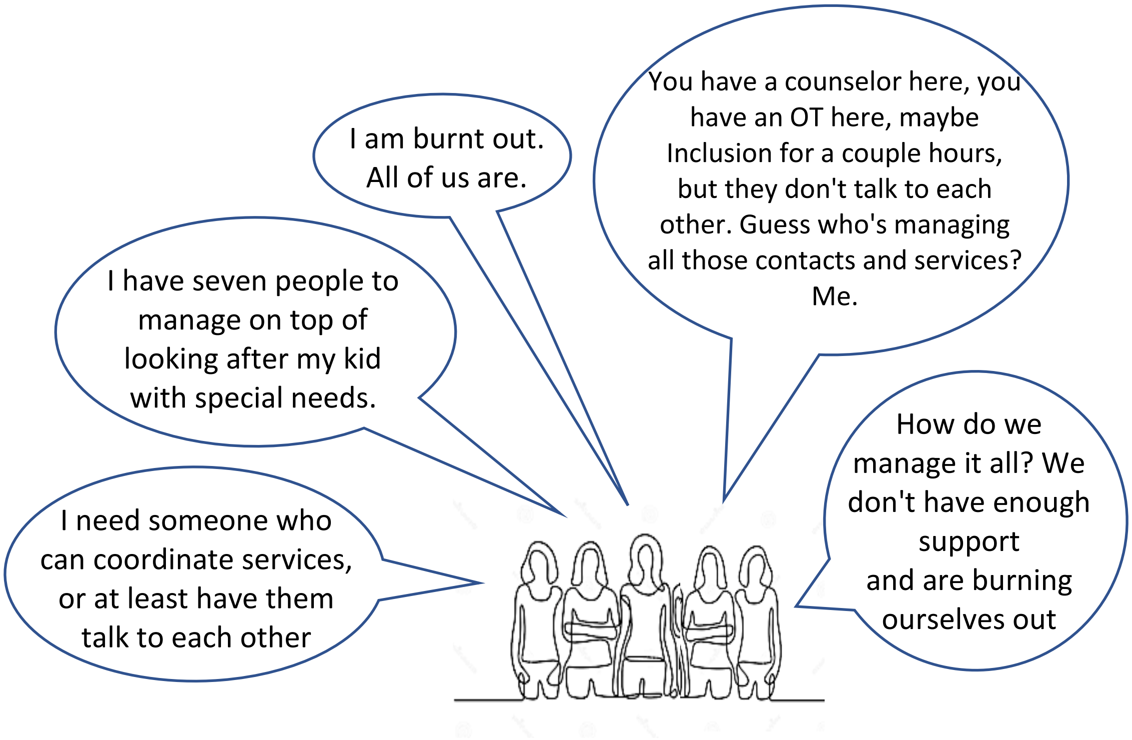
[24] Resources updated in 2023 with no evidence that programs were run in 2024. https://www.salmonpreservation.org/_files/ugd/ca63aa_053e5fd38f43486a9ebcf834fdae7611.pdf

PARENTS AND FAMILIES OVERWHELMED

PARENTS PARTICIPATING IN THE FAMILY SESSION:

- Clearly expressed that they are feeling burnt out and overwhelmed
- Have a genuine need for support for them as they support their children



FURTHER BACKGROUND – Education Session

- All represented students are engaged in learning in PIE-administered programs and had been in PIE from a few months to several years.
- In PIE, students are receiving three, 45-minute sessions of 1-on-1 instruction per week
  - Focused on an academic area of importance to the child/family
  - Can be online, in person or combination of both
  - May come from a teacher, an EA or a combination of both
- Some students have access to individual speech therapy, art therapy, or music therapy sessions
- All students have access to PIE's *Support Zone*, a daily drop-in study hall open mornings and afternoons, but not exclusively for students with a disability
- Majority of families in consultation are not using Support Zone, or using it on a very limited basis (e.g., 2 mornings a week)

SUCCESSES

- Successes reported by parents
    - *My child is much more emotionally regulated at PIE*
    - *The reading support provided through PIE has been a huge success for us*
    - *I can choose what times my child goes in to get supports, and this helps my child avoid conflict.*
    - *My child has quadrupled the amount of work s/he did at Brooks.*
    - *PIE understands that it can be hard to keep a child motivated to work online at home and met with me to look at my child going to the alternate school.*
    - *Now, with PIE, my child's probably getting the most out of learning*
    - *PIE is changing. Before it was homeschooling with a bit of support. Now with the new principal, he's really trying make it more inclusive and better structured.*

CHALLENGES

- Mainly at home learning. which means:
    - Children have limited opportunities for interaction with peers
    - Parents have the responsibility of helping at home (keeping them on task, managing gaps in schedules, etc.) for more than 60% of their 'school time'
    - Nothing beyond academic programs offered or coordinated through PIE: no music classes, no gym, no clubs
- Parents report that there is limited:
    - 1-on-1 direct instruction time (usually 2.5 hrs per week)
    - In-person schooling
    - Flexibility in the duration and circumstances of being "at school"
    - Behaviour support planning for child or training for staff
    - Recognition that their children's bonds of trust with certain EAs, teachers and other support professionals are critical factors in their learning
    - Information on additional educational /developmental resources and opportunities available to their children

PARENT REFLECTIONS AND RECOMMENDATIONS

- Provide families with more and clearer information on educational resources
- Provide school-based activities that go beyond simply academic type courses: music classes, gym classes, sports teams, clubs: *Kids in other schools get music, why don't we?*
- Help parents coordinate /schedule the non-PIE services that support their children
- Offer more hours of direct instruction / time in school
- *The system has lots of well-intentioned caring people, but everyone wants them*
- Make it easier to structure hybrid/blended models that work for their kids
- Do more to link kids to useful community-based supports
- Structure twice a year "check point" meetings with PIE principle, so families can really dig into how their kids are doing
- *Sped teachers and the Director go above and beyond trying to help*

FAMILY INPUT ON HEALTH SERVICES

BLANKET WAIVER: The section contains parent verbatim quotes and opinions of individuals that have been shared confidentially. These are not verified facts.

COMMUNICATION WITHIN THE HEALTH SETTING

PARENTS PROVIDING INPUT ON HEALTH SERVICES DISCUSSED:

LACK OF AWARENESS / COMMUNICATION ABOUT AVAILABLE RESOURCES

Families often do not know what services are available, partly due to limited transparency on service websites and other resources. The lack of clear information leads to uncertainty about which programs are offered and for whom. This affects families' ability to access necessary care promptly

THE NEED FOR OUTREACH TO FAMILIES

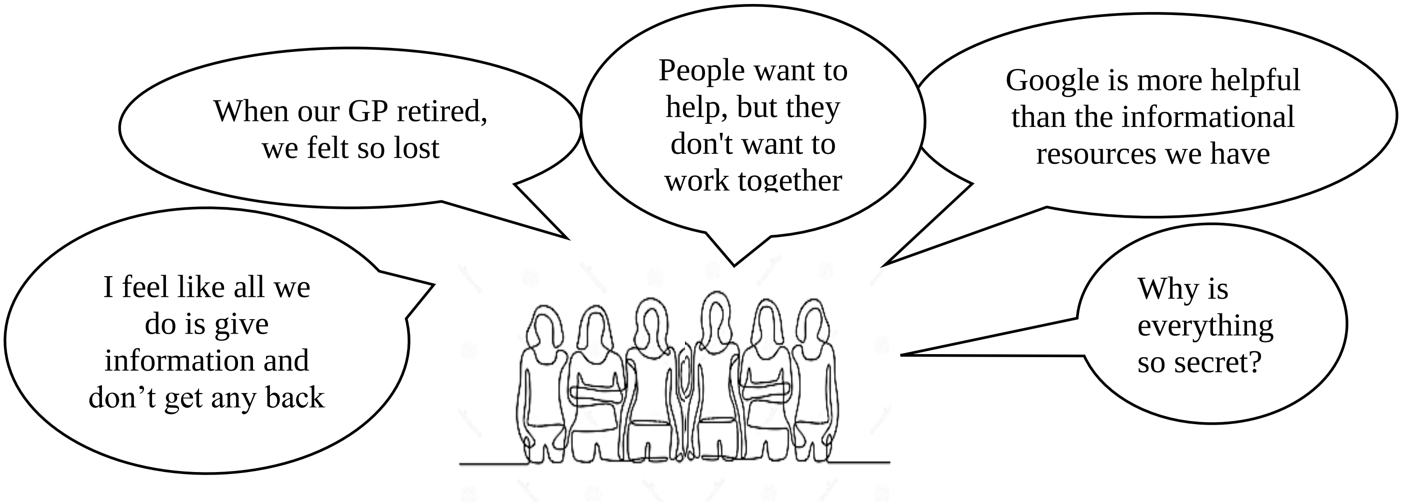
There's a significant need for proactive communication with families to inform them about available resources. For instance, parents would like regular updates and accessible materials that would ensure their families are better informed.

THE NEED FOR COORDINATION BETWEEN SERVICE PROVIDERS

The lack of seamless coordination among healthcare providers, schools, and community resources, results in fragmented care. Families report that there's often a disconnect where General Practitioners (GPs) and families are unclear about what programs are available or in use, which affects patient referrals and comprehensive care

THE NEED FOR TRANSPARENCY AND INFORMATION-SHARING

Miscommunication between GPs, specialists, and allied health professionals can lead to fragmented or delayed care, and sometimes unnecessary duplicate tests. It was noted that while some patients may already be connected to organizations like Inclusion, GPs see few new assessments or referrals, which may suggest a gap in information-sharing or coordination efforts.



NEED FOR A LOCAL COMPREHENSIVE GUIDE TO SERVICES

PARENTS PROVIDING INPUT ON HEALTH SERVICES DISCUSSED

PROACTIVE AND ACCESSIBLE RESOURCE DISTRIBUTION

Parents expressed interest in having both digital and physical formats of a guide, ensuring accessibility for families without reliable internet access. A printed guide available in clinics, schools, and community centers would serve as a readily available resource, supporting fair access to information.

LIMITED AWARENESS OF SERVICE AVAILABILITY

Families often lack a clear understanding of what health services and supports are available in qathet. Because some services are infrequently publicized or only partially listed on various websites, families may be unaware of key resources, such as specific therapies or respite options. A local guide could compile all service options, making it easier for families to quickly learn about available supports.

DISPARITIES IN SERVICE ACCESSIBILITY

As noted, some families bypass local health services, opting instead for private clinics or general practitioners who can provide immediate support. A comprehensive local guide would help bridge this gap by listing not only publicly funded services but also private options, where applicable. It would detail eligibility, service locations, costs, and relevant contact information, helping families make more informed decisions about care.

COORDINATION AND TRANSPARENCY ACROSS PROVIDERS

With fragmented communication between providers, a guide that includes all providers' offerings, approximate waiting times, and requirements could help reduce this disconnect. For instance, families and providers would have a shared resource listing all local and regional supports, including detailed descriptions of each service and its availability. This guide would also aid in reducing unnecessary referrals and duplications by clarifying service pathways.

SUPPORT FOR LONG-TERM PLANNING AND CONTINUITY OF CARE

A comprehensive service guide could also support families in planning for long-term needs, from early interventions to adult services. This is especially important given the different age-based eligibility cutoffs that currently complicate transitions for individuals with a disability. Such a guide would outline age-related services, clarify transition processes, and specify how families can access supports as children move to adulthood.

INCREASED COMMUNITY AWARENESS AND INTEGRATION

Besides aiding families, a well-organized guide could help healthcare providers and community organizations remain informed about local resources. This would promote a more integrated approach to care across different providers and increase community-wide awareness.

PARENT REFLECTIONS AND RECOMMENDATIONS

- *The lack of trained professionals, such as occupational therapists and behavior interventionists, within qathet is a significant challenge for our family.*
- *I feel that it would be good to have an online resource, but also for families that can't access the internet, a pamphlet for resources as well would be amazing.*
- *Health services that were previously available in the community, such as the Snoezelen room and private speech therapy should be restored.*
- *The age cut-off for pediatric services should be reconsidered, as the needs of individuals with disabilities shouldn’t be based on their biological age.*

FAMILY INPUT ON COMMUNITY SERVICES

BLANKET WAIVER: The section contains parent verbatim quotes and opinions of individuals that have been shared confidentially. These are not verified facts.

- Parents expressed frustration about the decline in available services and resources for children with a disability.
- Parents expressed that they would like organizations to work together to make a website that shows all services and programs offered in qathet.
- Parents highlighted that community organizations and support groups should be informed about specialized services, such as visiting pediatricians, to share these resources with families.
- There is a significant gap in fully integrating children with a disability into accessible, inclusive community programs in qathet.
- There is an expressed desire for programs, especially where children can participate alongside abled peers
- Some families are accessing community-based services like occupational therapy through providers such as VK Wellness. However, challenges have been noted in accessing consistent support.
- *It seems like COVID wiped out a lot of services*
- *Different organizations say different things and I just don't know who's right or wrong.*
- *My older child was integrated into community-based programs when he was younger, and it helped with his social skills so much. I don't think there's options for that anymore, or if there are, we don't know about them*
- *We registered in a community program which is supposed to be inclusive, and my child loved it but it's not actually inclusive and we've really struggled*
- *If we [families with a child with a disability] are oblivious to community programs being offered for our children, how accessible can they really be?*
- *There's a lack of community within the community. People want to help, but they don't want to work together to help*
- *It all comes down to community communication, and qathet doesn't have it.*

What we heard – Agency Conversations & Input

CHALLENGES IN EDUCATION SYSTEM

STAFFING CHALLENGES

Worker Shortages
SD47 has struggled to recruit and retain specialized staff, such as educational assistants, occupational therapists, speech-language pathologists, and psychologists. These roles are critical for supporting individualized education plans (IEPs) and providing one-on-one attention for students with a disability.

Increased Staff Burnout
With limited staff to meet high needs, existing workers often face increased workloads, leading to burnout and higher turnover rates. This creates a cycle where students may face interruptions in their support, impacting consistency in their learning and development.

FUNDING CHALLENGES

Inadequate Perception of Funding Needs
There is often a misconception that existing funding covers all needs for students with a disability. However, many disability-related resources and supports are costly, and funding does not always align with the demand.

Strain on Resources
With funding challenges, SD47 must prioritize essential services, which can limit the range of support for students who could benefit from more comprehensive or additional services, like sensory rooms, technology tools, and extracurricular programming.

VIRTUAL LEARNING CHALLENGES

Access and Engagement
Virtual learning can be difficult for students with a disability who rely on hands-on support and structured, in-person routines. Many students require adaptive technology or specific modifications, and virtual formats often lack the tailored interactions they need.

Social and Emotional Impact
Social isolation can be more pronounced for students with a disability in virtual settings, as peer interactions and in-person guidance are limited, impacting social skills development and overall emotional well-being.

CHALLENGES IN HEALTH SYSTEM

REFERRAL AND COMMUNICATION GAPS

General Practitioners (GPs) express concerns that they rarely receive updates or new assessments by the time patients reach them from community programs, suggesting a communication disconnect. Miscommunication between family physicians, specialists, and allied health providers can lead to fragmented care for patients. If key information—like patient history, care plans, or medication updates—is not effectively shared, patients can experience delays in treatment, duplicated tests, or medication errors. Additionally, this makes it challenging for GPs to fully understand the current needs or services already in place for their patients.

LACK OF TRANSPARENCY IN SERVICES

The reference to Inclusion as a “black box” underscores the difficulty in understanding what specific services are available or being provided in qathet. Although the websites may list available services like Physical Therapy (PT) and Occupational Therapy (OT), families and healthcare providers find it hard to grasp which programs are actively running or what specific support is accessible. This lack of clarity can make it challenging for families and professionals to navigate the system or advocate effectively for needed services.

FUNDING AND RESOURCE CONSTRAINTS

Funding limitations impact the availability and expansion of programs. While organizations with Division of Family Practice works collaboratively with other health organizations, it relies on funding allocations and grants, which restrict program reach and scalability.

ACCESS TO TELEHEALTH OPTIONS

The mention of telehealth options points to the need for flexible service delivery methods, especially for specialist assessments and updates. Parents are encouraged to ask about virtual options to avoid the inconvenience of repeated in-person visits. That being said, not all assessments and updates are available via telehealth, forcing families to travel for appointments.

PHYSICIAN AND PRACTITIONER SHORTAGES

qathet faces a shortage of primary care providers. This shortage has resulted in longer wait times for appointments (over a year post-covid), limited availability of new patient attachments, and increased reliance on emergency services for non-urgent health needs. Increased Demand for Specialized Services: The demand for specialized health services continues to increase. Meeting this demand requires additional resources, specialized staff, and infrastructure, which is not always readily available

Key solutions

INCREASE COMMUNITY-WIDE AWARENESS AND CONVERSATION ABOUT THE ISSUES

- Share this report with all identified stakeholders, whether they ultimately had capacity to participate in the consultation or not
- Publicize this report through local media and other means
- Invite and facilitate feedback and discussion

COORDINATE SERVICE ACCESS

- Facilitate creation and ongoing work of a standing committee on local services to children with a disability

IMPROVE COMMUNICATION WITH FAMILIES ABOUT AVAILABLE SERVICES

- Seek local community partners and identify funding sources for the creation of a *guide to local services / information hub* for families
- identify the service organization(s) who are the most appropriate “owners” or “hosts” of the guide / hub

SUPPORT FAMILY ACCESS TO & COORDINATION OF SERVICES

- Seek local community partners and identify funding sources for the creation of a navigator position to support families in accessing and coordinating services

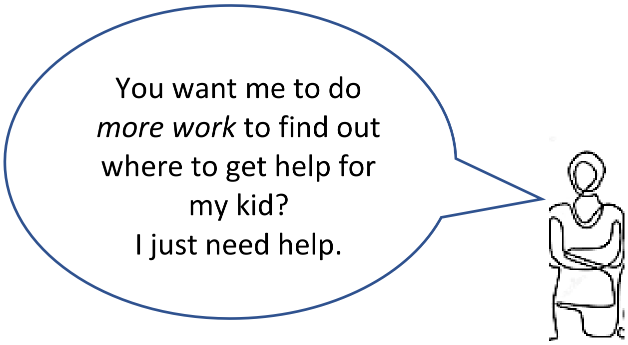
AFTERWORD: Ableism

Communities and governments often focus on accessibility issues in their most blatant form: physical and structural barriers to the participation and inclusion of people with a disability.

But subtle ableist assumptions continue to be embedded in many services, institutions, and spaces within our community, region, and province. For example, many service systems seem to – quite blithely – place extra burdens on families who already face the challenge of raising a child with a disability: requiring them to search for information, complete applications, submit documentation, show up for meetings and continually advocate for the needs of their child.

While our consultation has found genuine 'material' service delivery challenges, there are 3 critical service gaps, locally, that come down to just these types of organizational assumptions or 'ways of doing business'

- Communication with families about available services
- Centralization and coordination of services
- Genuine practices of inclusion of neurodiverse children



Comment from a parent in the education session

Learnings from the process:
FINAL INTERVIEW QUESTIONS

What surprised us most about this process?

Seeing the profound, long-term impacts of the pandemic on services to children with a disability.

PARENT AND SERVICE PROVIDER BURNOUT
Overburdened families are doing the best they can for their children in these unparalleled post-pandemic circumstances, while service providers don't have the scope to really reflect on how the new reality has affected their deepest values, because they are deal with its impacts (workforce issues, operational challenges, etc.) every day.

EDUCATION
During the height of the pandemic, all students had to make the move to online learning. However, in June 2024, a year after the WHO declared the pandemic officially over, 45% of all the district's special needs students were still online learners. Key service positions (speech & language pathologist, hearing specialist) are currently vacant in the district, and there is an ongoing challenge to fill educational assistant positions (the school workers who provide front line support to children with special needs).

HEALTH SERVICES
Across the province and in our own community, health-care workers at all levels continue to feel overworked, undervalued and pushed toward burnout. While there has been a provincial response –
– many health service challenges remain

- Increased provincial investment in nurse recruitment and retention, and expanded funding for healthcare assistant training program
- Shifts in provincial health service delivery standards like the minimum nurse-to-patient ratios

COMMUNITY BASED SERVICES

In the first quarter of 2022, the number of vacant positions in Canada's health and social assistance sector rose 90.9%. Community based service organizations who support local children with a disability continue to face vacancies in key positions (Rehabilitation Assistant, Early Intervention Workers, FAS Key Worker, etc.) with related impacts on service delivery and capacity.

REVISITING THE "LEFT OUT" REPORT

The BC Representative for Children and Youth's December 2020 Report, Left Out: Children and youth with special needs in the pandemic, outlined a disturbing set of circumstances facing BC children with special needs and their families during COVID. These circumstances urgently need to be revisited, as many persist, post-pandemic:

- The realities of the post pandemic world amplify and continue to negatively impact the challenges of already fraught service systems
- Support for children and youth with special needs and their families often does not meet international standards reflected in the UN Conventions on the Rights of the Child and the Rights of Persons with Disabilities
- A transparent and consistent communications plan for providing relevant and useful information to families is critically important for all organizations providing services to children with special needs.
- Supporting children with special needs and their families continues to require flexible strategies that fit their unique needs and situations.

What worked well in the engagement process?

- *Defining three key service areas and structuring the consultation process to examine each one in turn.*

- *Doing preliminary research*

- *Identifying key local stakeholder organizations in each service area*.

- *Creating a draft plan for the consultation process.*

- *Sharing the draft plan with all stakeholder organizations and requesting their feedback as a way of supporting their engagement and moving the process forward.*

- *Recruiting local parents of young adults with a disability, who've had experience of all three local service areas, to draft questions to guide family session discussions of services in each domain.*

- *Choosing child-and-family-friendly environments for the parent sessions.*

- *Being prepared to pivot and alter our approaches to engaging with families and organizations.*

- *Recognizing that families and organizations are all struggling, post pandemic, and remaining positive in the face of unfulfilled commitments to participate or to support the process.*

What did we do that resulted in the greatest participation?

- *Reach out to families through service providers*

- *Create a participation survey for parents, that would help us to understand and practically address barriers to their participation*

What needs / gaps did we discover?

- *Families who already face the challenges of parenting a child with special needs have the added burden of having to navigate and coordinate multiple systems & services for their children, from early development years to school leaving.*

- *Post pandemic realities continue to negatively impact already stressed service systems.*

- *Support for children and youth with special needs and their families does always not meet international standards reflected in the UN Conventions on the Rights of the Child and the Rights of Persons with Disabilities.*

- *A transparent and consistent communications plan for providing relevant and useful information to families is often lacking in organizations providing services to children with special needs.*

- *At the very least, there is a need for an accessible, comprehensive, and integrated guide to all local services for children with special needs. Ideally there would be a dedicated person – a system navigator, for example – who could actively help families to connect to and coordinate the services their child needs.*

What could have been done differently to engage with families & service providers?

Increase the funding and extend the timeframe of the consultation to at least a year and provide clear and immediate benefits to all participants.

Every family and every service provider who spoke to us is struggling with burnout: feeling overburdened and under-supported in fulfilling their roles. Much more time is needed to provide real scope for participation, and to create genuine trust in the process, rather than have the consultation seem to be yet another demand – a demand without clear immediate reward for them.

What new partnerships were developed?
What partnerships should be nurtured and sustained on an ongoing basis?

Possible stakeholders in a future coordinated effort to enhance local services to children with a disability are all aware of the consultation process, and their contact information is in hand.

Because we all operate within a small, isolated community, it has historically been common practice for service agencies serving the same population to meet quarterly or bi-annually to identify opportunities for coordinated, collective action.

However, while inter-agency case management teams (centred on a single individual) are not unusual, there has never been, to our knowledge, an integrated working committee on local services for adults or children with a disability. It will take ongoing work to develop such a committee and sustain it over time.

Were the funds made available through the grant enough for this project?

NO, not at all.
Neither the time frame nor the funding for this project was sufficient for the consultation to be conducted to the extent and to the depth that was needed. Seeing that we could easily end up with a very superficial survey of the situation in our community, PRESS invested weeks of unfunded work in this project because we believe the outcomes associated with it are genuinely important to local children with special needs and their families. We're committed to identifying practical actions that can have real, positive impact, and continue to work well beyond the project scope. timeline and funding envelope to ensure that these key actions are undertaken and completed.

What kind of community engagement did the money allow us to do that we couldn't do before?

Receiving funding for this project gave us space to begin to really look at the local situation for children with special needs and their families.
Some conversations were started, and some initial insights were gained. However, it's still unclear how already stressed organizations and agencies can extend to collective action on improving the experience of children with special needs and their families in our community.

What are the key solutions that we would like to focus on?

INCREASE COMMUNITY-WIDE AWARENESS AND CONVERSATION ABOUT THE ISSUES

- Share this report with all identified stakeholders, whether they ultimately had capacity to participate in the consultation or not
- Publicize this report through local media and other means
- Invite and facilitate feedback and discussion

COORDINATE SERVICE ACCESS

- Facilitate creation and ongoing work of a standing committee on local services to children with a disability

IMPROVE COMMUNICATION WITH FAMILIES ABOUT AVAILABLE SERVICES

- Seek local community partners and identify funding sources for the creation of a *guide to local services / information hub* for families
- identify the service organization(s) who are the most appropriate "owners" or "hosts" of the guide / hub

SUPPORT FAMILY ACCESS TO & COORDINATION OF SERVICES

- Seek local community partners and identify funding sources for the creation of a navigator position to support families in accessing and coordinating services