

Findings from the Community-Led Conversations

Family Action Network (FAN), partnered with Diverse Family Roots Society (DFRS) in the fall of 2024 to host a series of community-led conversations designed to understand the gaps and challenges facing children and youth with diverse abilities in the Regional District of Kootenay Boundary (RDKB). FAN brought its network of partners to the table, including leaders in industry and business and service providers, all dedicated to making the RDKB an accepting, accessible and supported place to raise a family. Alongside DFRS, the only grassroots, parent/family-driven support network for families with children or family members with diverse abilities / disabilities in the West Kootenays, the two were able to engage families and service providers from across the RDKB including Trail, Rossland, Grand Forks, Montrose, Fruitvale, and Warfield.

We reached out to families to hear their lived experiences by placing posters within organizations that provide services to children and youth with diverse abilities as well as high-traffic public spaces often utilized by families. We promoted the sessions over social media using organic and paid content, as well as running a series of radio ads, and advertising at the Trail movie theatre, which offers a unique sensory friendly movie night for people living with autism. Participants were also offered the incentive of an honorarium to recognize their time commitment participating in the project, along with a meal and childcare support.

Conversations were held in a variety of formats including in-person, virtually, hybrid and through a survey that was promoted via social media, posters in community and word of mouth. This survey could be completed anonymously, and those who chose to include their address received a gift card to recognize their participation.

In-person conversations were held at accessible buildings including schools and Family Service Provider Centre's designed to meet families where they are at. Childcare was offered for all in-person sessions, although illness caused a cancellation in childcare services for the first session with families in Trail. A graphic artist was also used to capture the conversation, visually addressing the current gaps in the system and solutions that could be developed to overcome these challenges.

Service providers and families were encouraged to share in separate conversations. Trust emerged as an early theme between service providers and families, which reinforced the need for separate conversations. This model encouraged honest and open dialogue on obstacles and successes while fostering community and shared experience. Participants were also encouraged to share their feedback following the session and all participants

received a copy of the graphic developed during the conversation and were encouraged to provide comments and edits on this final report.

In total 15 families from Trail and Grand Forks participated along with 6 service provider organizations across the two locations including, Trail FAIR Society, Circle of Indigenous Nations Society, Family Support Institute, Boundary Family Services, Kootenay Society for Community Living, and Columbia Basin Alliance for Literacy. Service Provider meetings were held in a hybrid model, and a virtual session was offered for families. Ultimately, the virtual session did not move forward due to low registration from the region. It is important to note that the virtual session received more registrations overall than any other session; unfortunately, registrants did not live in the RDKB. This indicates a need for further engagement and conversation in regions across BC including Nelson and surrounding area and through the Lower Mainland.

About our Community:

The Regional District of Kootenay Boundary exists on the traditional and unceded territory of the Sinixt, Syilx, Ktunaxa and Secwepemc Peoples and services more than 33,000 residents. Stretching across 8,200 square kilometers from Champion Lakes in the east to Bridesville and Big White in the west and runs south along the Canada-U.S. border. The region is vast, and many municipalities are separated by large mountain passes and lakes, making travel between centres and outside the region difficult.

Eight municipalities call this region home including, Fruitvale, Montrose, Trail, Warfield, Rossland, Grand Forks, Greenwood and Midway and five electoral areas including, Area A, Area B/Lower Columbia-Old Glory, Area C/Christina Lake, Area D/Rural Grand Forks and Area E/West Boundary.

Based on the most recent census data, English is the most common language in the region followed by French, German and Italian. Approximately 2,100 people identify as Indigenous with 2,865 newcomers primarily from the U.S., U.K. and Germany. 1,340 people identify as a visible minority. Most families are two-parent households, and the median total income is \$38,400. Unemployment is typically higher across the Kootenay's and 2023 statistics placed the unemployment rate at 7.1%.

Currently the Ministry of Children and Family Development does not have statistics specific to the RDKB, but we know that in the West Kootenays and Okanagan there are 1,919 open cases for Children and Youth with Support Needs¹, with many undiagnosed

¹ CYSN. mcfcd.gov.bc.ca/reporting/services/children-and-youth-with-support-needs/case-data-and-trends.

individuals unaccounted for in this number. In a 2023 report from the McCreary Centre Society on Adolescent Health² it was reported that the percentage of youth with a learning disability had more than doubled in the past five years. The report also quoted a 17-year-old youth who said, “I struggle with many undiagnosed mental health conditions that I feel I cannot get diagnosed, because of a lack of healthcare and affordability.”

The report also cited that 66% of youth had not felt they needed mental health services. 13% were not able to access the services they need and 21% didn’t get the care they thought they needed. The number of youths not accessing care because of a waitlist also increased from 4% to 11% since 2018 and the number not receiving care because of lack of access in their community increased from 3% to 7%.

Using UBCs EDI data, 30.3% or 70 kindergarten children in SD51, (West side of the RDKB) were vulnerable on the one or more scales scale in Wave 8. While, 23.8% or 76 children on the south side of SD20, entering kindergarten, indicate one or more vulnerabilities. It should be noted that the Lower Columbia Region (south side of SD20) has a robust early years screening plan, that includes universal and frequent offers for checking young children’s development, catching little bumps in the road prior to entering school. It has been long thought that this system has decreased the number of vulnerabilities children have by the time they enter school, as they have been supported well before kindergarten.

What we Heard:

Families gathered in Trail on Sept 24, Grand Forks on Oct 7, and Service Providers met in a hybrid meeting on October 1. In addition to 30 online survey participants. Families were asked:

- 1) If we were able to create a perfect future where anyone who has additional support needs received the assistance they required – what would that future look like? How would this expand or change services?
- 2) What would these changes mean for you and your family?
- 3) What are some bold steps that we can take today that move us towards this perfect future?
- 4) Who needs to be around the table to turn these ideas into a reality?

Service Providers were asked similar questions, but tailored towards an organizational perspective rather than families.

² Anderson, Lucie, et al. *Kootenay Boundary: 2023 BC Adolescent Health Survey Results*. 2024, mcs.bc.ca/pdf/2023_bcchs_kootenay_boundary.pdf.

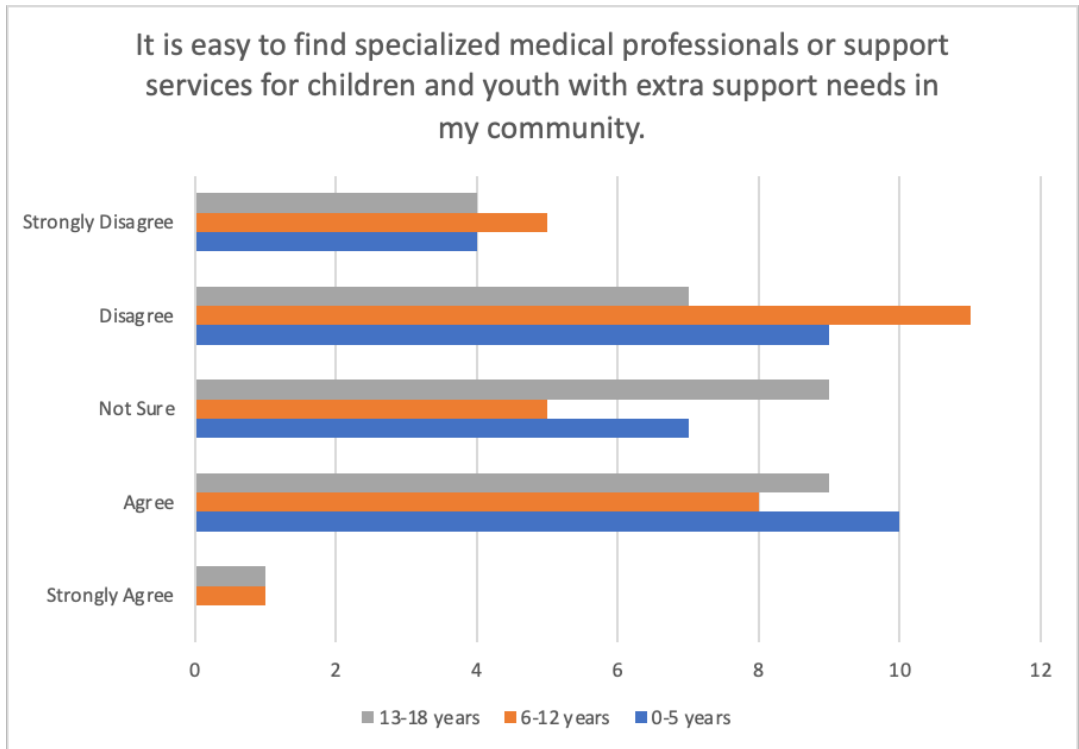
Trust and transparency emerged as key themes across the conversations with families and service providers, as well as a need for connection, belonging, consistency and continuity. Overall, families reported growing wait lists, difficulty navigating the system and frustration with funding levels.

Theme	What People Said
<p>Trust “It often feels like resources are only available on paper rather than in reality - Family Member</p> <p>“We need well trained professionals in classroom to increase trust” - Family Member</p>	<ul style="list-style-type: none"> ● Parents need to be believed when they say they are in crisis. This includes helping with support to prevent a crisis from occurring, and better early intervention strategies overall. ● Parents need the ability to tell their story once, and have it be believed, instead of repeating it over and over. ● Service Providers know that good communication fosters trust. Lack of time and increased caseloads are identified as one of the main reasons families feel they do not get enough information or communication from service providers.
<p>Connection and Belonging</p> <p>“[my kid] wants to be part of activities and friend groups. We attempt this as much as possible in supportive ways, but it's not the same as with my other kid who can navigate tricky situations or insensitive adults.” - Survey Response</p> <p>“Inclusivity, I feel like my child doesn't feel included into the community in terms or recreation even in school during play.” - Survey Response</p>	<ul style="list-style-type: none"> ● Connection between people with common experiences is essential for community building and combatting feelings of loneliness. ● Stigma in community around different diagnoses prevent support networks from forming. ● More work needs to be done to normalize conversations around disabilities ● More opportunities for community to form through accessible program times that work for families schedules including shift workers ● Improved transportation would allow for access to more activities ● An increase in the number of support and activity groups would improve the abilities of families to connect with each other.

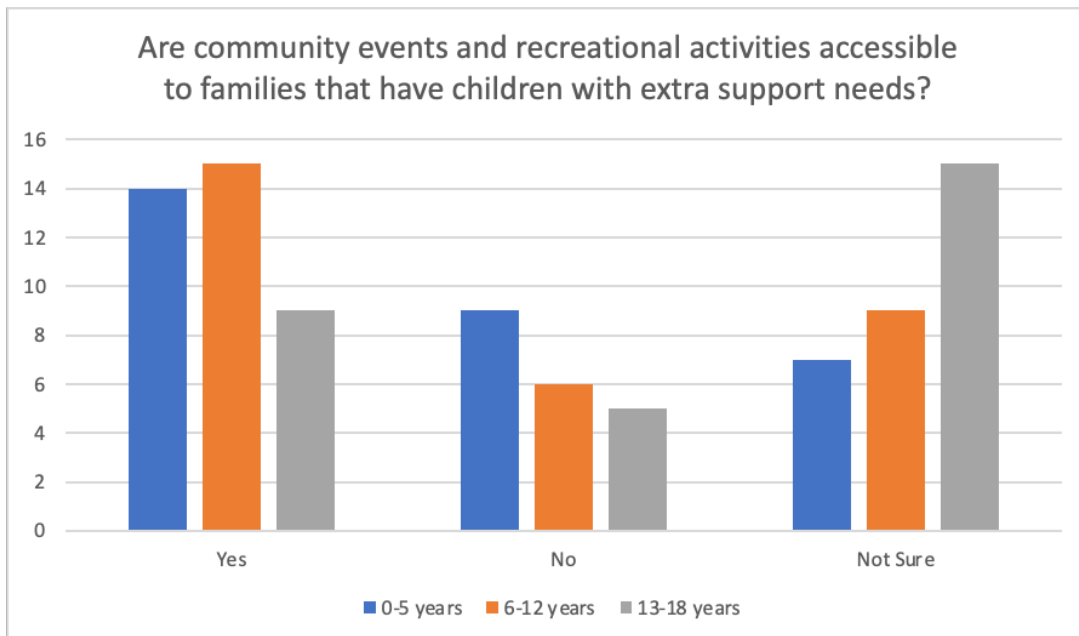
<p>Communication “Front-line worker voices need to be heard.” - Service Provider</p> <p>“It’s hard to know if medications are working because there is little communication between teacher and parent at the high school level, and instead communication is from teacher to child.” - Family Member</p>	<ul style="list-style-type: none"> • Time is needed to get to know the people who are receiving supports • Easy access to information that is digestible • Updated support directories are needed. FETCH is a good resource, but it’s only as good as the updates that are provided and more information is needed including if funding is available, and what is covered by insurance. • More follow-up is needed as kids grow to maintain continuity of care • Would like to have all information at the ready, either program and support options for service providers, or all the documentation provided to a family about their child or youth.
<p>Training “Keeping families in communities is even more important for rural communities.” - Family Member</p>	<ul style="list-style-type: none"> • More service providers are necessary, especially in rural and remote areas so that families can get the support they need without having to travel long distances. • Service providers need to better understand intersectional oppression. • Service gaps need to be eliminated between age groups.
<p>Advocacy “paperwork needs to be simplified and not based in deficits.” - Family member and Service Provider</p> <p>“It’s time to have hard and courageous conversations.” - Service Provider</p>	<ul style="list-style-type: none"> • The burden of advocacy needs to be shifted away from families • Funding needs to increase across organizations and to individual families to recognize training and staff shortages as well as increased barriers experienced by families including lost wages and respite costs. • More staffing and training in schools is necessary and must be flexible so that it makes sense within existing work schedules. • Supports need to exist for all kids, not just those with easily identifiable behavior needs or diagnoses.

<p>Collaboration and Coordination “Comprehensive supports are needed so that people aren’t stuck with piecemeal plans.” - Service Provider</p> <p>“Having a child with anxiety, it has been hard to figure out where to go and where to get support. The different organizations in town are hard to figure out, who does what and where to go.” - Survey Response</p>	<ul style="list-style-type: none"> • Power imbalances often exist in classrooms between teachers and educational assistants. EA’s need to be empowered to support their students • More interaction is needed with social workers to help improve continuity of information and care • Resources can be pooled across organizations and especially with schools to increase the reach and impact of opportunities like professional development days.
<p>Cultural Safety</p>	<ul style="list-style-type: none"> • Remove hierarchies, colonialism and racism from supports • Address the complexities around attaining status for access to Indigenous services. • Answer Truth and Reconciliation Calls to action to support children and youth.

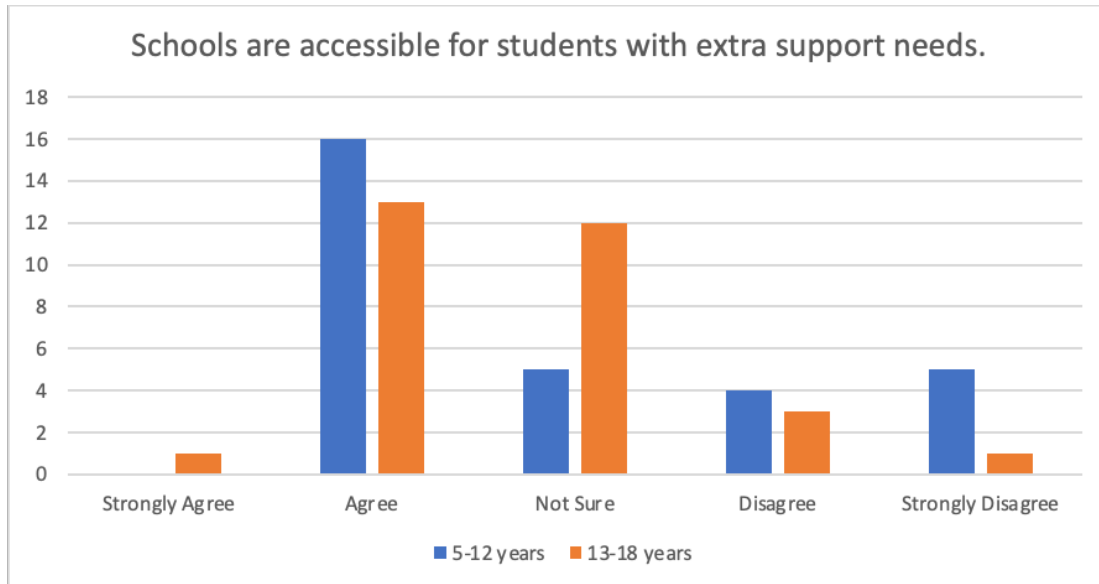
Survey results indicated some important trends as well.



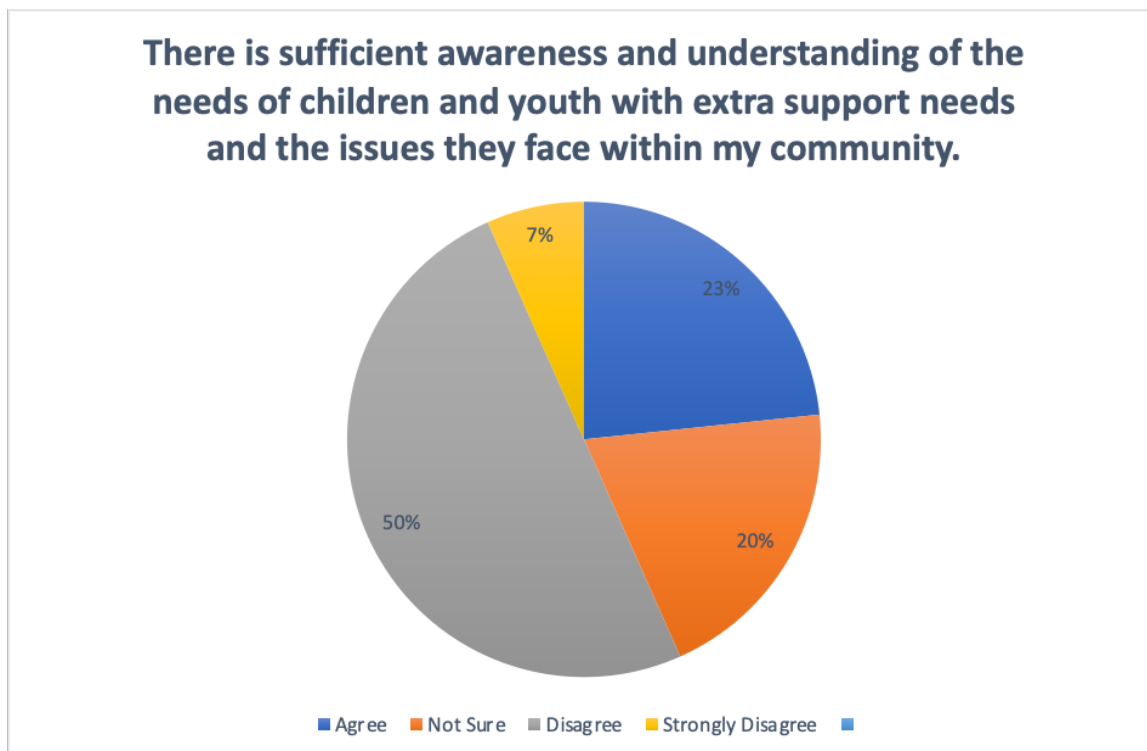
“The support services are targeted at children, very young children, and they are not able to work with youth or teens in any capacity. Nothing stops your child from accessing services, and refusing further support, than being treated like a toddler when they are 12 years old.” - Survey Response



“I think some adaptive sports programs, wheelchair-accessible facilities, and sign language interpreters will do the most.” - Survey Response



“More aid in helping to use their accommodations (in the high school they are mostly meant to ask for themselves ... such as quiet space for tests or readings, the ability to get up and go walk the halls for a moment etc. Often mine have been too afraid/ ashamed/ overwhelmed to ask and I wish it just would have been somethings that happened no matter what.)” - Survey Response



“It needs to be talked about more, community members and business could have more information somehow. It is difficult for those in the community to know how to accommodate and/or understand if they have 0 information.” - Survey Response

4. Solutions

As part of the families and service provider conversations, a PATH was developed. PATH stands for Planning Alternative Tomorrows with Hope and centers around the idea of creating a graphic representation of a perfect future with the steps needed to achieve that goal including what needs to change and who needs to be around the table to change it.

The graphic representation from each conversation is included following the solutions table in this report.

Solutions Table

What is the opportunity for change and/or challenge facing your community?	Description of the opportunity for change/challenge.	What is the solution that will address this opportunity or challenge?	Who will deliver this solution?
Families lack a feeling of community and belonging.	Kids struggle with wanting to be a part of activities and friend groups. Parents work to bridge that gap, but it's not the same for children and youth who are better equipped to navigate tricky situations or insensitive adults.	<p>Better connections between families is essential so that common experiences can be shared.</p> <p>Increase drop-in / stay-and-play groups for children and youth.</p> <p>Build community through diversity including establishing support and activity groups</p>	Parents and family members, service providers, and non-profits focused on advocacy around diverse support needs
Information from service providers can be inconsistent.	It is difficult to navigate service providers and organizations as it is unclear who does what and where to go for different supports. There is also a lack of information on what is covered by insurance or what supports may have grants attached to them.	<p>A team coordinator could be utilized to get the right people in the room to support a child or youth with diverse support needs.</p> <p>Make information easily accessible and digestible with details on available funding.</p>	Service Providers including front-line staff to better understand each others programs and increased funding to organizations helping families navigate the system.

<p>There is a lack of access to counselling and support.</p>	<p>This gap seems to increase when children and youth progress into their primary and teen years. Supports also seem to be geared towards children and youth with the most urgent needs rather than all children and youth that require support.</p>	<p>Invest in more specialized counselling supports within community to eliminate wait lists and heavy caseloads. Increase the number of specialized counselling supports and options available so that the right care plan can be developed for the child or youth in question.</p> <p>Increase availability of services rather than decline through the life of a child or youth.</p> <p>Allow for direct service to be provided by assistant under supervision.</p> <p>Improve early detection and service delivery.</p>	<p>Government to explore loan forgiveness for those pursuing education as counsellors or support providers</p> <p>Provide incentives to counsellors and support workers in rural communities</p> <p>Post-secondary institutions to expand support services training opportunities</p>
<p>Stigma and discrimination are commonplace.</p>	<p>Families often experience stigma around diagnoses and are often discouraged from asking for help as a result of discrimination.</p>	<p>Improve information and awareness around diverse support needs including advertising, marketing and anti-discrimination campaigns</p> <p>Normalize the discussion around disabilities and support needs</p> <p>Organize workshops and training sessions for providers and families</p>	<p>Government has the opportunity to launch provincial ad campaigns and information sessions in community. Local advocacy organizations can work with businesses to improve information sharing on support needs within communities and service providers can ensure that language and events represent inclusion and acceptance across all the unique</p>

		Use inclusive language and host inclusive events	needs of children and youth.
Inclusivity and accessibility at school remain a concern.	Parents have reported that they feel their child doesn't feel included in the community in terms of recreation or at school during play.	Invest in quality professional development to improve knowledge across service providers and educators on children and youth with diverse support needs	Bring together municipalities, school boards, service providers and parents to improve accessibility to recreational services, ensure inclusion in classrooms and utilize parents lived experiences to better understand accessibility and inclusion needs.
Cultural supports are often lacking for Indigenous children and youth as well as newcomers.	Negative attitudes are difficult to overcome including stereotypes and exclusion	Flexible funding supports for Aboriginal child development Support a knowledgeable advocate in culturally safe settings. Remove hierarchies centered around racism and colonialism from supports Answer Truth and Reconciliation commitments in regard to supporting children and youth.	Work with friendship centers and organizations supporting newcomer populations to develop better support networks for Indigenous people and newcomers. Increase funding for cultural supports via the provincial and federal government
Lack of trust between parents, teachers and service providers	Parents often feel that there is a lack of transparency around information sharing, including from teachers to child / parent. Service providers also feel	Improve communication between teachers and parents - not only relying on communication from teacher to child and child to parent.	Service Providers, school boards, teachers, education assistants, parents, and funding providers all need to come to the table to demonstrate a

	<p>untrusted by parents, and parents lack trust in the system overall due to long wait lists, inadequate and piecemeal supports along with the pressure to become an expert in order to advocate for their child or youth.</p>	<p>Parents need to be believed when they are in crisis and provided with necessary supports before they reach that stage.</p> <p>Improve communication with service providers to build trust with families</p>	<p>commitment to building trust and accountability across care planning for children and youth with diverse support needs.</p>
<p>Lack of qualified respite people.</p>	<p>Lack of trained respite people, and networks through which to access them is a major reason for family burnout and results in decreased mental health and family connection.</p>	<p>Local advocacy organizations are building networks to connect respite workers with families, but more awareness is needed around these programs along with increased funding.</p>	<p>Local advocacy organizations, provincial government and post-secondary institutions need to come to the table to develop better networks and train quality respite workers, including extending loan forgiveness for training programs.</p>
<p>Lack of qualified staff at both the service provider level and in classrooms</p>	<p>There are not enough Education Assistants in classroom or enough resources in service provider organizations to provide the level of support required for children and youth with diverse support needs in community.</p>	<p>Ensure one Education Assistant per classroom at a minimum</p> <p>Increase training resources and funding to hire qualified support workers in service organizations.</p> <p>Expand provincial programs to provide funding to people</p>	<p>Explore establishing CYSN as its own ministry to better support training and service delivery through direct funding to community organizations and post-secondary institutions</p> <p>Bring schools, service provider organizations and post-secondary</p>

		wanting to train as service providers	to the table to discuss funding needs and alternative solutions.
Limited/ inflexible hours of services	Parents find it difficult to navigate the hours-of-service providers, and programs are often offered at times that are more convenient for early years participants rather than primary age and teens	Explore lost wages support for parents who need to take time off for appointments and to assist with other support needs. Improve service availabilities so that it works for parents and their schedules including offering services in the evening and on weekends.	Service Providers, community organizations and families can come together at collective impact tables to better define and implement programs that better support families.
More support for advocacy, including moving this responsibility away from parents	Families are often overwhelmed trying to become experts so they can advocate for their child or youth to service providers and teachers	Create a permanent support advocate to work with families to create the care plan they need and help to put it in place. Reduce the need for families to tell their stories over and over again, and instead be able to share their story once to their advocate to help create their support plan	Service organizations and schools to consider creating this position to better support families with funding support from the provincial government
Access to quality transportation on schedules that work for children, youth and their families.	Accessible and inclusive transportation options would help families, children, and youth with extra support needs to access education,	Adjust service schedules so that they run 7 days a week in all municipalities with a service schedule that ensures workers can	Bring municipalities, the Ministry of transportation to the table, along with parents, and local business to improve service schedules and

	employment opportunities and recreational activities.	access job sites during working hours. Conduct an accessibility audit to determine if new supports can be included for transportation including easier payment systems and easier to understand schedules	implement new accessibility protocols
Improve communication between families, schools, service providers and everyone else involved in a child or youth's support network.	Strong communication builds trust and continuity of care. Current communication systems are engendering a lack of trust and hindering the development of care plans while increasing family burnout.	Streamline paperwork so that it focuses on a child or youths strengths versus deficits Ensure that information across service providers is consistent and up to date	Bring schools, parents, service providers and cultural support leaders to the table to discuss improved communication strategies.
Conduct accessibility audits across government buildings, schools and public infrastructure including sidewalks and recreation facilities	Recreation facilities, schools and service provider organizations may not have the physical infrastructure needed to accommodate diverse support needs and disabilities.	Examine recreational facilities to make them wheelchair accessible. Improve public infrastructure like sidewalks to ensure they can be navigated by people with diverse support needs. Increase accessibility at schools including elevator access and	Ensure adequate funding for municipalities to maintain public infrastructure and add adaptive technologies where necessary. Provincial government support to schools in order to make the improvements needed to be more accessible.

		<p>other supports for mobility issues</p> <p>Increase quiet rooms and other support spaces for sensory needs</p>	<p>Support service organizations and providers with grants to improve accessibility at all work sites.</p>
--	--	------------------------------------------------------------------------------------------------------------------	------------------------------------------------------------------------------------------------------------