Inclusion Langley

Community Engagement - What We Heard Report

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ROOTS & RIVERS
Enabling Transformative Change

Roots & Rivers respectfully acknowledges that our headquarters are situated on the unceded territories of the xʷməθkʷəy̓əm (Musqueam), Sḵwx̱wú7mesh (Squamish), and səl̓ilwətaʔɬ / sel̓íl̓witulh (Tsleil-Waututh) Nations.

Introduction

Inclusion Langley Society is one of the largest non-profit community organizations in Langley, providing a wide range of services and supports to children and youth with developmental disabilities and adults with intellectual disabilities.

In June 2024, Inclusion Langley Society partnered with Roots & Rivers Consulting to organize a series of community engagement sessions to hear from service providers and families with children (aged 0-19) who have intellectual disabilities, developmental disabilities and other support needs. These conversations were created in partnership with local community organizations to consider the specific circumstances of Langley, the young people, and families in need of support who live here. This engagement is a part of other engagement initiatives taking place across the province.

This engagement was designed to hear from families, caregivers, and service providers around what is working well, what's not working well, and what would an ideal network of services look like in Langley. This report is an interim report summarizing insights from the engagement phase. Upon completion of all phases of the engagement, a final report will be developed and shared with the Ministry of Children and Family Development with the expectation that it will be considered in the planning of future services for children and youth with support needs in British Columbia.

Approach

The engagement included an online anonymous survey and community engagement sessions. Across all methods, we engaged with 142 people.

Both the survey and sessions engagements focused on the below questions:

- What services and supports for children and youth with disabilities or support needs are working well in our community?
- What is not working in terms of services and support in our community?
- What would a better network of services and supports look like in Langley?

The survey was open to youth, service providers, and families/caregivers. The table below outlines the breakdown of participants we heard from.

Group	*Number of responses*
Parents & caregivers	36
Service providers	21
Youth	1
Total	*58*

Six community engagement sessions were held with service providers and families/caregivers. These sessions included a mix of in-person and virtual options on Zoom and sessions facilitated in Mandarin and Korean. Each session included facilitated dialogue, the support and presence of an Elder, a meal provided, and support for transportation and childcare.

The table below outlines the breakdown of participants we engaged with.

Session	*Date*	*Number of participants*
In-person parents & caregivers session (English)	June 5	15
In-person parents & caregivers session (English)	June 5	11
In-person service providers session (English)	June 10	30
Virtual parents & caregivers session (Korean)	June 11	7
Virtual service providers session (English)	June 12	12
Virtual parents & caregivers session (Mandarin)	June 13	9
Total		*84*

What we heard

Strengths

Family-Centered Services

Families and service providers describe specific services in Langley which are inclusive, family-centered, relationship-based, and ensure that children and families feel supported and heard. They specifically identify programs from Langley Community Services, StrongStart, and Inclusion Langley Society that excel in providing holistic and individualized support. For instance, Langley Community Services is known for its comprehensive family support, offering early intervention programs and parenting workshops. StrongStart provides early learning opportunities that engage both children and their parents, fostering an inclusive environment where families can learn and grow together. Inclusion Langley Society offers tailored support to children with disabilities, and aims to meet childrens' unique needs. Inclusive services in Langley are demonstrated when services prioritize building strong relationships with families, meeting families where they're at, and ensuring their voices are heard at every step of the way.

Collaboration and Resource Sharing

A key strength in Langley's network of support is strong collaboration between community partners, schools, and organizations. This collaborative approach allows for more efficient referrals, sharing resources and knowledge between service providers, and an approach to service delivery that ensures families receive comprehensive support. For example, the school district works closely with community services to identify and support children with disabilities, while daycares and nonprofits collaborate to provide additional resources and programs. Some describe Langley as having a "small community feel" which facilitates connection between families and partners. This networked approach helps ensure that families can receive support from multiple agencies and support families in navigating services in the community.

Accessibility and Flexibility

Participants identify key aspects of service delivery that support accessibility and meeting the varying needs of families. This includes offering virtual and in-person visits, flexible meeting times, and multiple referral pathways. It is important for families to be able to access services through self-referrals, professional referrals, or community recommendations, without the need for a formal diagnosis. Participants also highlighted the $10-a-day childcare initiative as a crucial step toward affordable childcare. Overall, a key strength of supportive services is an approach that reduces barriers to access and participation, and being continuously responsive to the needs of families.

Ongoing Training

Service providers describe their commitment to ongoing training and professional development as a key strength in their work. Many organizations prioritize ensuring that their staff are continuously updated on best practices to enhance the quality of support they can provide to families and children. This includes training for preschools, daycares, and information provided to parents that are updated as research continues to evolve. Specialized and ongoing training is elemental in ensuring staff feel well-equipped for their work and for providing high quality care and support.

Culturally-Safe and Specific Support

Families and service providers highlight various programs that are tailored to the needs of different cultural communities. For example, Aboriginal support systems provide tailored services to Indigenous families, and incorporate culturally-specific practices and values in their service delivery. Métis Nation British Columbia also has a Wellbeing Program, similar to Jordan’s Principle, that helps fund assessments, respite, and supportive equipment. Similarly, Métis chartered communities provide cultural camps that are inclusive for children and youth with diverse support needs. Language accessibility is also crucial to reduce barriers in accessing support services, especially for non-English speakers and newcomers. Some participants highlight Korean interpretation services as a key strength in Langley. It is also highly valuable for families when services are facilitated by members of their own cultural community, to support a sense of safety and connection.

Community Programs and Activities

There are a variety of community programs and activities in Langley for children with support needs. Participants describe programs like sports programming, playgroups, and special events that provide opportunities for social connection and inclusion. Sports programs that are tailored for children with disabilities are important to allow them to participate in an inclusive and safe environment, while fostering social connection. Families highlight playgroups and community events by StrongStart and Inclusion Langley Society offering safe and welcoming spaces for children to interact and for families to connect with each other.

Specialized Services and Funding

It is highly valued when families are able to access specialized services and funding in Langley that cater to the unique needs of their children. Programs like the Canucks Autism Network offer tailored activities and support for children with autism, while special needs childcare benefits provide financial assistance to families. Families also appreciate funding opportunities offered through different streams like Variety, JumpStart, and KidSport. Individualized autism funding is a crucial support, and allows families to access personalized support services, such as speech therapy and occupational therapy, which are essential for the wellbeing and support of their children. Families also appreciate that individualized autism funding offers some degree of flexibility, which enables families to choose their own services providers based on what works best for their child.

Gaps

Waitlists for Services and Support

The issue of waitlists for services and support was a significant concern. Families frequently reported long delays and wait times to access essential services such as speech therapy, occupational therapy, and assessments. Sometimes these extended wait times result in children aging out of eligibility before receiving necessary support, which creates further gaps in care. Many families describe waiting several months for services and additional barriers to connecting with available service providers. For example, there are multiple waitlists for childcare and daycare, especially for children needing 1-1 support. The family doctor shortage and lack of access to pediatricians is also a significant concern and delays the process of getting a diagnosis. Overall, families report rampant waitlists hindering timely support for their children and adding significant stress.

Lack of Access to Specialized Services

Participants consistently highlighted the significant gaps in access to specialized services in Langley, including speech therapy, occupational therapy, and behavioral therapy. Long wait times are a recurring issue, with some families waiting several months to a year for appointments. The lack of access to specialist services delays critical early intervention and exacerbates challenges faced by families in supporting their childrens' needs. Some families report needing to travel long distances to access services, which is an added barrier. Increased availability to accessible and tailored services is crucial to meeting critical windows of intervention and supporting children's development.

Lack of Access to Mental Health Support

Many families described deep concern about the lack of comprehensive mental health support for children and youth with disabilities. While there are some services available in Langley, they are often not tailored to the unique needs of children with intellectual and developmental disabilities. Families and caregivers highlight a lack of mental health professionals who have adequate training to be able to support children with disabilities, leading to inadequate care and support for their childrens' needs. They also describe how the mental health experiences of their children can often be overshadowed by other needs, such as physical or developmental needs, leading to a lack of care and attention.

Insufficient Support in School Settings

The education system in Langley was identified as having many gaps in supporting children with disabilities. Many participants report that schools lack the necessary resources, trained staff, and adaptive learning environments needed to effectively meet the needs of students with disabilities. This lack of support results in inadequate educational experiences for students with disabilities, and barriers to their learning, and academic and social experiences. In particular, families highlight an insufficient ability to support diverse learning needs and styles in the classroom, and a lack of effective implementation of individualized education plans. They highlight a need for better support services in school settings, including more support from classroom aides and specialized teaching resources.

Inadequate Respite and Support for Families/Caregivers

The need for more robust respite care and family support services is a critical gap. Families describe deep emotional and physical strain they face in navigating systems that are not set up to best support the needs of their children, and that the current options for respite are insufficient to provide support for them. Many parents reported a lack of temporary relief services, which are essential to enable caregivers to support their own wellbeing and rest. Families also highlight a lack of support and counselling groups tailored to those providing support for children with disabilities. To address this isolation and overwhelm, there is a desire for more opportunities for families and caregivers to connect with each other and have their own support system.

Fragmented Services

Many families and caregivers describe the current network of support services as fragmented and disjointed. This can create a complex and confusing experience of accessing support and difficulty in understanding the range of available services. Participants express the feeling that service coordination among different providers is lacking and disjointed, and highlight a need for a more integrated approach, where service providers collaborate to offer a seamless continuum of care. For example, families would like to see case management services to help them understand, access, and coordinate support and care for their child. Overall, without a centralized point of service navigation, or support for service coordination, families feel like they are left to piece together services on their own, and feel that they miss out on opportunities to access comprehensive care.

Limited Recreational and Social Opportunities

Many families identified the lack of inclusive recreational and social opportunities as a significant gap. Families report that many community programs are not designed to meet the needs of children with disabilities, resulting in their exclusion from sports, social activities, and other recreational programs. Participants emphasized the importance of adaptive sports programs and inclusive community events that allow children with disabilities to participate with their peers. The increase of these opportunities is integral for children with disabilities to build social connections, engage in physical activity, and promote overall wellbeing.

Financial Barriers to Accessing Support

Financial barriers are a major constraint for families accessing necessary services and supports. Families identify key needs including specialized therapies, adaptive equipment, and private services as challenging to access, especially for those without comprehensive insurance coverage. For those with funding support, such as through autism funding, families want more flexibility to use the funds for their self-identified needs (e.g. for support around the home). Out of pocket expenses can be substantial, leading to financial stress for many families. Participants desire more funding and subsidies available to reduce financial barriers, and want to see accessible support where families can access services regardless of their financial situation.

Insufficient Early Intervention

Families identify a lack of sufficient early intervention services in Langley, which poses a key gap as these services are crucial to support children with disabilities in a timely way. This contributes to delays in diagnosis and delayed initiation of accessing support services. Families report that this leads to missed opportunities for supportive development. Participants highlighted the need for more robust and accessible early intervention programs that provide timely assessments and interventions for young children. These programs are essential for identifying developmental delays and implementing strategies to address them early on, improving long-term outcomes for children with disabilities.

Insufficient Transition Services

Transitioning from child to adult services is a challenging period for youth with disabilities and their families. Participants identified significant gaps in support during this transition, including a lack of planning and coordination between child and adult service providers. Families reported difficulties in accessing adult services, which often have different eligibility criteria and processes. Families want to see more comprehensive transition planning services to help them navigate this complex transition, ensure continuity of care, and support their children through different life stages.

Lack of Awareness and Information Sharing

Participants highlighted a general lack of awareness and information dissemination about available services and supports. Many families are not aware of the full range of services they can access, leading to underutilization of available resources. This barrier is exacerbated for newcomer and non-English speaking families navigating the system. There is a need for better communication and outreach efforts to inform families about the services and supports available to them. Participants suggested creating centralized information hubs and utilizing community outreach programs to raise awareness and provide families with the necessary information to access the support they need.

Ideal Network of Services

Comprehensive and Accessible Support Services

Families emphasize the need for a comprehensive network of services encompassing medical care, therapeutic interventions, educational support, and social services. Access to multidisciplinary teams, including doctors, therapists, educators, and social workers, was seen as crucial for providing comprehensive care. They highlight the importance of these services being easily accessible to families, with minimal wait times and within reasonable proximity to their homes. It is also crucial for services to have more streamlined processes and reduced bureaucratic hurdles to access. The concept of a centralized resource hub was frequently mentioned as a way to consolidate information and services, and make it easier for families to navigate the system. Families suggest the idea of a one stop shop - where integrated services are under one roof, for better coordination among service providers and reducing the burden on families to travel to multiple locations.

Culturally Safe, Holistic, and Family-Centered Approach

Families want to see a holistic, family-centered approach that addresses the needs of the entire family. This would include providing support for siblings, offering mental health resources for parents, and creating opportunities for families to connect with one another for mutual support and information sharing. Families also stress the importance of respite support for parents to prevent burnout. Cultural safety is a key lens for services, and a holistic approach to care must meet the linguistic needs of families and be delivered in a culturally appropriate way. Peer support groups and family mentorship programs were suggested as valuable resources to help families build connection and relationships with each other.

Professional and Compassionate Support

A recurring theme was the need for qualified, professional, and compassionate services and care. Families stress the importance of having service providers who are knowledgeable about different disabilities and who can provide personalized care and support. They also stressed the value of continuous professional development to ensure that service providers remain up-to-date with the latest best practices and interventions. Building trust between service providers and families is also crucial, and helps families feel like they can access empathetic, compassionate support.

Inclusive and Adaptive Education

Educational settings that are inclusive and adaptive to the individual needs of children with disabilities are crucial. Participants expressed a desire for more inclusive classrooms, specialized educational programs, and individualized education plans (IEPs) that cater to the unique learning styles and needs of each child. Collaboration between educators, parents, and service providers was highlighted as essential for the success of these educational initiatives. Families called for better training for educators on disability inclusion and the implementation of universal design for learning principles in schools. Families also want to see improved transition planning to support their childrens' transitions from early childhood services, to elementary and secondary school, and to the workforce.

Community and Social Inclusion

Participants highlight the importance of recreational programs, social groups, and inclusive community events that are designed to support the needs and participation of children with disabilities. In particular, families name inclusive playgrounds, sports programs, and extracurricular school activities as essential spaces for their children to build connection and friendships. In addition to accessible programming, participants highlighted a desire to see broad community education initiatives aimed at reducing stigma around disability, promoting the understanding of disability justice issues, and promoting inclusion in their communities.

Advocacy and Financial Support

Families call for increased financial support from government programs and greater insurance coverage for a wider range of services. There is also a need for improved communication about financial support available, and support in navigating application processes. Some families suggest having financial planning support for families to manage costs associated with their care needs. In addition, advocacy efforts at a policy level was identified as a key way to push for system changes that will ensure families receive the support they need. Families

Technology and Innovation

Participants describe the future roles of technology in supporting children with disabilities. Assistive technologies, telehealth services, and innovative therapeutic tools can be leveraged to improve the accessibility and effectiveness of care. Families also mention continuing to use specific technologies such as communication devices, sensory tools, and adaptive equipment to support their child’s needs. They would like to see more research and development in the field of assistive technology to create tailored support for their children. Service providers emphasize staying up to date with technological advancements and incorporating them into their service delivery.

Coordination and Collaboration Among Service Providers

In an ideal network of support, there is strong coordination and collaboration among various service providers. This collaboration would address the current fragmentation of services, and improve communication between different agencies and professionals who are involved in childrens’ care. Participants would like to see the development of integrated care plans that bring together medical, educational, and social services in a cohesive manner. Regular case conferences and inter-agency meetings were suggested as ways to ensure that all providers are aligned and working towards common goals. Families also highlighted the importance of having a single point of contact or case manager who can help coordinate services and provide ongoing support.

Early Intervention and Support

The importance of early intervention and prevention services was emphasized by many participants. Families want to see increased availability of early childhood programs that focus on developmental milestones and provide support to parents in the early years. There is a desire for more measures like public health campaigns and education on the needs of children with disabilities to help families identify needs in their children and identify how they can support their children earlier on.

Legal and Policy Support

There is a continued need for strong legal and policy support to protect the rights of children with disabilities and their families. Families and service providers want to see the enforcement of existing disability rights laws and the creation of new policies that address gaps in the current system. Advocacy for policy changes at the local, provincial, and national levels is crucial for ensuring that children with disabilities receive equitable access to services and support. There also needs to be accessible legal assistance for families to navigate barriers and issues around education, health care, and social services.

Next Steps

In fall 2024, Inclusion Langley Society will host a share back session to share what we heard from the community engagement phase, and hold a solutions table session for service providers to identify actions toward building a better network of support. Following these sessions, a final report will be developed and shared back with participants of the engagement.