



Let's Talk CP & complex needs

Final report | January 31, 2019

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Executive summary

Cerebral palsy is a life-long neurological impairment that can affect people in various ways. The Children’s Health Foundation of Vancouver Island (CHFVI) received funding to explore different ways to better understand how it can play a role in supporting children and youth living with cerebral palsy across the island, as well as children/youth in the Capital Regional District (CRD) living with additional complex medical needs. By engaging families with lived experience, service providers and medical professionals who understand the system, its limits and its opportunities, CHFVI will establish stronger relationships with these important stakeholders.

As a result, CHFVI hired an external consultant to facilitate the community engagement process which included an online survey. An advisory committee was established to guide the process ensuring that suitable questions were asked, and the appropriate people participated in the process. The advisory committee included individuals living with cerebral palsy, parents or family members, medical and rehabilitation staff.

The community engagement process included **five focus groups** covering a significant portion of Vancouver Island; they were hosted in **Nanaimo, Comox Valley**, and three in the **Victoria** area – in the traditional territories of the **Snuneymuxw, K’òmoks, Songhees, Esquimalt** and **W̱SÁNEĆ** First Nations, respectively; the Foundation wishes to thank these Nations for the opportunity to visit their territories and engage in community dialogue. There was a total of **49 participants** that attended in person, representing family members, support networks, individuals with cerebral palsy, medical staff, and rehabilitation professionals. This was complemented by an online survey to ensure that the diversity of voices was captured from all across the island. A total **23 completed surveys** were returned. Both engagement processes explored similar questions. Participants were given an opportunity to highlight key themes and areas of opportunity for growth to strengthen the support for children and youth with cerebral palsy and complex needs. Each focus group was complemented by graphic facilitation; these visual recordings are included in their totality in this report. The discussions were focused on **5 domains**: medical services, health and well-being of the family, education and promotion, programs and services, and life transitions and independence.

It was evident that there are extra commitments when someone in the family lives with cerebral palsy and/or other complex needs. It is overwhelming to navigate through the variety of systems to find the “right” treatment, medical assistive device, funding, education supports, sport or recreation opportunities... the list goes on. Often, people feel alone in the process or unable to take on everything that needs to be done. An early diagnosis of cerebral palsy can influence rehabilitation and planning ahead for the various milestones of life. But the dynamics of having cerebral palsy change over time and ongoing and targeted supports are essential. Despite this, the Let’s Talk CP and Complex Needs conversations hosted across

Vancouver Island demonstrated that by coming together and focussing on the opportunities, there are many options for overcoming current hurdles and improving the experience and, subsequently, the lifelong outlook of children and youth living with cerebral palsy.

The discussions focussed on 5 domains and within each, several themes emerged. Based on the collated themes from all conversations and surveys, there are several opportunities identified to improve services and strengthen community relationships to better meet the needs of the cerebral palsy and complex needs community, with specific focus on children and youth. In some cases, regional differences are evident; for example, communities outside of Victoria were more likely to identify gaps in recreation opportunities, the challenges of traveling for appointments, and the limited number of families with similar lived experience to connect with. There are themes that surfaced connected to a particular domain (e.g. life skills training as a priority theme for life transitions and independence). Simultaneously, there are themes that emerged that transcend a particular domain. Key examples of these are:

- Navigation supports (medical and rehabilitation systems, funding streams, applicable and available programs and services, etc.);
- Centralization of information for the CP community (individuals, families, service providers and medical community); and
- Greater awareness of a Spectrum of Cerebral Palsy to equalize understanding of the complexity of CP and the ways that it does and does not impact a person's experience.

As a result of this process, this report provides a detailed overview of the findings for each domain. Subsequently, this report ends with seven Calls to Action based on the most frequently cited opportunities. At a glance, these are:

1. Awareness Campaign(s)
2. System Capacity Building
3. Partnerships
4. Childcare and School Capacity
5. Equipment and Specialized Supports
6. Support Group Options
7. Transition Programming and Services

The Foundation wishes to publicly thank everyone who helped contribute to this positive and powerful first undertaking at coming together: Parents who juggled work and family commitments, professionals who came outside of work hours, youth and young adults who confidently shared their stories and ideas, and the many people who traveled, sometimes long distances, to participate. Additionally, the Foundation wishes to acknowledge the additional contribution and effort of advisory committee members, all of whom were volunteers with a variety of life and work commitments, who made time for committee

discussions. CHFVI staff left each conversation feeling inspired by the resourcefulness, resilience and shared motivation to better support our kids. We hope you felt the same.

What is clear from this process is that the Let's Talk CP and Complex Needs conversations are a starting point. This report serves as an invitation for further exploration of the opportunities identified by participants and the co-creation of action plans to bring these ideas to life.

Background of the project

The origin of the Children's Health Foundation of Vancouver Island (CHFVI), formerly the Queen Alexandra Foundation, is deeply connected with the pediatric cerebral palsy and complex needs community. As the historic and ongoing partner of sites of expertise serving island children and youth, such as Queen Alexandra Centre for Children's Health (QACCH), CHFVI continues to play a role in enabling access to healthcare for Island children. However, over the course of time community care for children living with CP and complex needs has evolved. CHFVI received a generous donation through the Victoria Foundation to conduct a series of focus groups to better understand how it can play a role in supporting children and youth living with cerebral palsy across the Vancouver Island, as well as children/youth in the Capital Regional District (CRD) who live with a physical disability or serious medical condition, in the current landscape of community and public health.

By engaging families with lived experience, service providers and medical professionals who understand the system, its limits and its opportunities, CHFVI sought to establish stronger relationships with these important stakeholders.

The outcomes of this project were to:

1. Visualize or map the pathway of care that children/youth currently follow in community:
 - a. Identify and celebrate what's working
 - b. Understand where improvement and/or support is needed and, ideally, prioritize where attention should be focused
2. Develop relationships with stakeholders who can become CHF advisors, advocates and partners.

As a result, CHFVI hired an external consultant to facilitate focus groups across Vancouver Island. The consultant that was hired had experience working within the disability community, as well as living with cerebral palsy. To complement this, CHFVI hired a graphic facilitator from FuseLight Creative Inc. to visually transcribe the discussions.

- a. Timeline

The timeline for this project was as follows:

March – April 2018	Facilitator, Graphic Recorder & Stakeholder Advisor recruitment Focus group design (informed by Stakeholder Advisors)
April – May 2018	Participant recruitment and invitation
May 2018	Advisory Committee Conference Call
June - August 2018	Focus groups
August - September 2018	Online Survey distribution
September 2018	Advisory Committee Conference Call
Mid September 2018	Online Survey Results Completed
September 2018 – January 2019	Report writing
February 2019	Report finalized (shared with Victoria Foundation leadership and CHF CIC Committee/Board)

b. Advisory Committee

The CHFVI selected individuals, families, and organizations that had deep rooted experience in child/youth living with cerebral palsy and other complex needs. Those invited include CHFVI board of directors, service providers, families, community partners, and support networks:

Dianne Aikman	Physical Therapist, Comox Valley Child Development Association
Sarah Bower	Manager Child, Youth & Family Rehab Services, Vancouver Island Health Authority
Karena Crumpler	Parent
Feri Dehdar	Executive Director, Cerebral Palsy Association of BC
Michelle Kocourek	Resource Development Coordinator, Nanaimo Child Development Centre
Debi LaHaise	RDSP Navigator, BC Aboriginal and Disability Society
Melissa Lyon	Youth
Hanna Nagteggal	Senior Occupational Therapist, Dogwood Place Child & Youth Development Centre

Dr. Norgove Penny	Orthopedic surgeon and CHFVI board member
Erin Sloan	Acting Clinical Leader for Physiotherapy, Queen Alexandra Centre for Children's Health
Lyn Taylor-Scott	Director of Programs, Sundrops Centre for Child Development
Tracy Trousdell	Parent

The committee met several times via conference call over the course of this project, including individual calls with the contracted facilitator. They learned about the goal of the project and discussed the expected commitment as an advisory committee member. They played an instrumental role in the development of the focus groups and the designing of the questions asked for the focus groups. Following the focus groups, the committee met via teleconference to provide an opportunity for them to give feedback of the focus groups and for the CHFVI to outline the next steps of this project. The advisory committee was also invited to provide feedback and recommendations to the final report draft.

Overview of the collection from the community

a. Community Conversations

CHFVI hosted five focus groups covering all areas of the Vancouver Island. The purpose of these focus groups was to engage with families/individuals with lived experience, service providers, and medical professionals. As well, it provided an avenue to establish stronger relationships to understand the needs of the population living with cerebral palsy.

All focus groups were promoted to organizations, families, as well as medical, education, and rehabilitation professionals. Promotional posters were distributed through email and each contact was asked to spread it to their networks via word of mouth, email, printing & posting, and social media. The poster was also published on the CHFVI's website and social media (see Appendix G for samples).

All of the focus group participants who attended received an honorarium in appreciation for their time and input in the discussion, although not all accepted the gift. Along with this, they received a package that included information from the Cerebral Palsy Association of BC, a list of bursaries and scholarships managed by CHFVI, a Registered Disability Savings Plan (RDSP) brochure supplied by the BC Aboriginal and Disability Society, the agenda for the focus group, and contact information for CHFVI.

- Logistics and Attendance

Date	Location	#of Attendees
June 18, 2018	Nanaimo Nanaimo Child Development Centre Community Room 1135 Nelson Street, Nanaimo BC	9
July 11, 2018	Comox Valley North Island College, Comox Valley Campus Puntledge Building, Room 121 2300 Ryan Road, Courtenay BC	9
July 18, 2018	Victoria WestShore Child, Youth & Family Centre 345 Wale Road, Colwood BC	10
July 19, 2018	Victoria Camosun College - Interurban Campus Campus Centre building, room 121 4461 Interurban Road, Victoria BC	5

August 13, 2018	Victoria Queen Alexandra Centre for Children's Health 2400 Arbutus Road, Victoria BC	16
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All of the focus groups were hosted in an accessible space to ensure that all individuals could be included in the discussions. CHFVI provided food and refreshments for the participants, as the majority of conversations took place in the evening over the dinner hour. In an effort to reduce barriers to participation, CHFVI invited families and service professionals to discuss their exceptional needs related to child care and/or travel expenses in advance of the session they wanted to attend.

Promotional materials encouraged interested participants to RSVP, but it was not a requirement for participation. There were some drop-ins for each session. Each of the registered participants received an email confirmation a week prior, along with a handout outlining the themes that would be discussed. Due to low registration, the focus group scheduled for Campbell River was cancelled. Pre-registered attendees for the Campbell River session were invited to the Comox one and were offered compensation for unanticipated transportation costs. In addition, the focus groups were complemented with an online survey to enable diversity of voices and accessibility to participating.

Participants that attended the focus groups ranged from individuals living with cerebral palsy, support workers, parents of individuals with cerebral palsy, rehabilitation professionals, service providers, and medical professionals.

- Structure

The focus groups took place in the late afternoon/early evening (4:00 - 7:00 pm) apart from one focus group which was scheduled for the late morning/early afternoon (11:00 am - 2:00 pm). Each discussion was 3 hours long with a 30-minute break.

Depending on the number of attendants, the participants were split into two groups. The participants were divided according to whether they were individuals living with Cerebral Palsy and family members, or whether they were service providers, rehabilitation specialists or medical professionals. This allowed for more time for the participants to voice their comments and stories. In sessions with two groups, there was time allocated for both to report back to the larger group, as this approach promoted more sharing of ideas and connections between the groups. Please refer to Appendix H for the agenda for each focus group.

Each group was facilitated by a set of questions that were separated into five sections. The sections covered the following domains: medical services, health and well-being of the family, education and promotion, programs and services, and life transitions and independence. Everyone was given the opportunity to voice their feedback and comments as it relates to their own lived or professional experience. Following this, at the end of each section in all but the first focus group, each of the participants was asked to write on a post-it note:

1. What was one thing that stood out for you during the discussion?
2. If you had to dream, what is one idea you may have that will improve the current situation?

When the participants were asked the second question, they were asked to think big to focus in on solutions and alternatives to some of the barriers surfaced through discussion. Their responses to each of the questions were written on different colors of post-it notes so that it could be captured within the graphic illustrations and reported accurately.

In addition to writing the responses on flipchart, it was also captured visually. FuseLight illustrated the responses throughout the sessions. This process provided another outlet for their responses to be captured. As a closing for all of the focus groups, FuseLight did a “walk through” of the graphic to ensure that their voices were interpreted accurately. This gave an opportunity for the participants to give feedback to the graphic facilitation. See Appendix A for the complete illustrations.

Following each of the focus groups, a digital copy of the graphic recording from their session was sent, as was a follow-up survey to capture their thoughts about the facilitation of the focus group. CHFVI, FuseLight and the contracted facilitator also debriefed after each

session. As a result, facilitation of each focus group evolved based on feedback and trial and error.

b. Online Survey

Following the facilitation of the focus groups, an online survey was emailed out to the community at large to ensure that more voices could be heard. The survey was emailed out to the advisory committee and the focus group participants in which they were encouraged to spread it out to their networks. In addition, it was emailed to 146 contacts which included organizations, medical and rehabilitation professionals, and school districts all over the island. They were asked to distribute it to their networks and membership as well. It was distributed during the week of August 20th and the deadline for completion was September 14th, 2018.

There were 41 responses that were returned to CHFVI and 18 of those surveys were incomplete.

A copy of the online survey is in Appendix B.

Following the deadline, all the responses were reviewed, coded, and summarized within the findings section, along with the focus group responses. (See Appendix C for a sample of the online survey results.)

Findings

There were several findings that came through from the community engagement process. The findings are separated into the five domains: medical services, health and well-being of a family, education and promotion, programs and services, and life transitions or independence.

Medical Services



The majority of individuals with cerebral palsy live with many medical needs that require attention. These needs are met and/or managed by a variety of specialists that can include orthopedic, speech, physical therapists, occupational therapists, seating or gait analysis, and physicians. In almost every discussion participants talked about the broad spectrum of CP – the reality of how CP manifests in one person may be dramatically different in another person. Therefore, the medical treatments for someone living with CP are varied. As a result, it was agreed that appropriately addressing health needs requires a lot of energy from parents, young people as they mature and take more responsibility for their own healthcare, and allies to ensure that the individual achieves the best care as possible. Interestingly, the allies participating in the discussions observed that they are also constantly challenged to understand the opportunities, options and resources available for certain medical needs for the children and youth; this is particularly crucial to note given their passion and commitment to their clients. The main themes that emerged through this process and are further outlined are: The relationship with the rehabilitation team; navigating the system; funding issues; and specialized equipment.

Relationship with Rehabilitation Team

What is a rehabilitation team? In the context of the conversations and online survey, this was interpreted a range of ways. For the purpose of this report, it includes acute care specialists (e.g. surgeons, pediatric specialists, physicians, etc.) as well as public and community health specialists (e.g. physiotherapists, occupational therapists, speech and language therapists, etc.). Because cerebral palsy is a lifelong diagnosis identified in infancy or early childhood,

families and children in their journey through the medical system early. Hospital care and interaction with specialists based in a hospital setting can begin immediately in a child's life and remain an intermittent but consistent part of a person's life. Similarly, community-based specialists are also an ongoing part of a person's care team. Depending on how CP affects a person, the team might include physiotherapists, speech language therapists and occupational therapists among others. These services are delivered in community health settings and sometimes in a client's home – the key difference is that these services are delivered as close to home as possible. Experiences with a person's rehabilitation team are therefore varied – particularly as a family is more and more removed from major urban centres where specialized hospital care is delivered (e.g. BC Children's Hospital in Vancouver and Victoria General Hospital) and complex care specialists based in community are harder to recruit and retain.

The need for relationships between individuals with cerebral palsy and their medical or rehabilitation team was commonly expressed. It can be a challenge in developing relationships with acute care specialists because of the infrequency of appointments, which doesn't lead to consistency of knowing each other. Hospital-based appointments can also be traumatic for a child and the family, particularly for more invasive surgical procedures. Additionally, hospital-based procedures almost always take the family out of their own community; the ripple affect of this is additional expenses for travel and accommodation, but also a greater isolation from their support networks at home. Families must be resilient through this marathon of ups and downs.

Another partner in an individual's rehabilitation team should be a family physician. A gap that surfaced through several discussions was the inability for GPs to fully meet the needs of individuals with complex needs; it can be challenging to stay on top of evolving therapies and also understand the specificity of how CP affects a particular individual because of how much it varies from one person to another. As a child physically grows, there are also changes that may be hard to follow and adequately support at the GP level – which often leads families to rely on their community care team and/or a pediatric specialist.

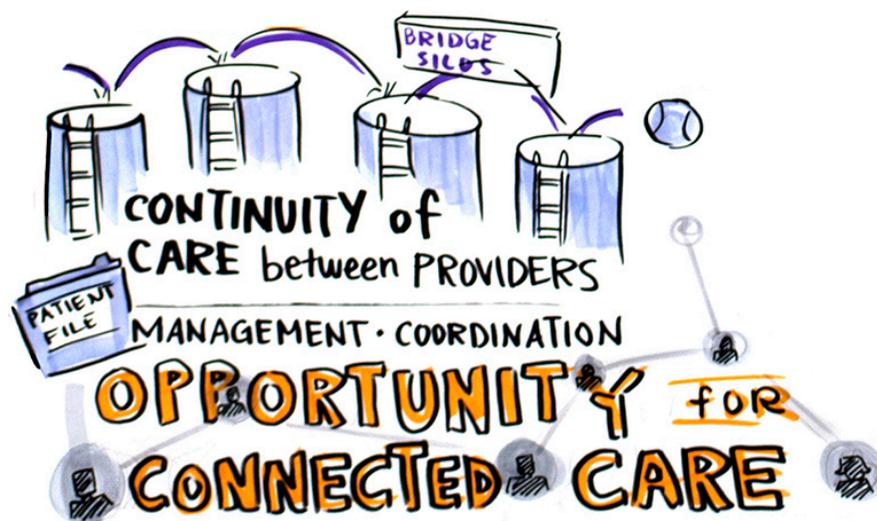
In both the hospital and GP scenario, participants articulated the challenge of how to holistically and consistently share information to best support a client. There may be many issues linked to cerebral palsy, and limited appointments may not allow for the medical team to get to know the full implications of living with cerebral palsy.

Strong relationships between a client and his/her/their community-based care providers were commonly celebrated. The consistency of these relationships was a key factor: client's regularly visit the same OT or PT, who consequently can observe slight changes, understand a client's barriers and strengths and create a customized plan, and also build rapport and trust. As evident from the individuals, cerebral palsy affects all aspects of life, so having the space to talk about it helps their growth and development. Having this relationship is about respecting the individuals and recognizing their voices. In addition,

their rehabilitation team has a greater sense of their life, not just in regard to a particular issue. When individuals gained a relationship with at least one person from their support networks, they viewed it as a lifesaver. Some people stated that “if it weren’t for her, then we wouldn’t have known all the resources available.” It is crucial to always be thinking ahead, asking questions and quite often, they were pointed in the right direction by a person on their rehabilitation team.

Navigating the System

One of the major themes that came through the Let’s Talk CP and Complex Needs discussions is how complex the systems of care are – this was true for families who spend a great deal of time researching and navigating themselves through community care; it was true for medical professionals who find continuity of information sharing between practitioners caring for the same clients lacking; and it was true for community-based specialists who are often multi-tasking between their specialization and unofficial role as navigator. Participants outlined the many treatments that exist: gait analysis; seating and positioning; hip surveillance; early intervention treatments (infant development consultant, speech therapist, social worker, occupational therapist, physiotherapist and the supported child development consultant); and alternative therapies (e.g. cranial sacral therapy). These treatments are in addition to surgical procedures that may be necessary and pediatric speciality appointments. Parents shared that navigating among all the service providers needed to appropriately support individuals with cerebral palsy can be “a full-time job”.



For caregivers, this work includes scheduling and travelling to appointments, obtaining the correct equipment, and figuring out what else is needed for their child. There is a lack of consistency between the medical and community-based care systems because parents feel like they have to put the pieces together themselves. For families, the inconsistency and lack of integration between care providers at various points created tensions in a few ways. The most commonly cited examples were:

- re-telling their story repeatedly;
- gaps in knowledge of the child's experience, capabilities, or special needs;
- responsibility for tracking and communicating health and treatment history;
- incongruence between travel time and actual appointment length (e.g. 3 hours to travel for 15-minute appointment); and
- lack of coordination of specialist appointments, particularly when traveling a great distance and multiple specialists are co-located and/or could be co-located.



One participant, a mother of a now adult son, noted that the efforts she made when he was a child were crucial for his long-term health outcomes. By spending a great deal of her own time learning how to support his physical therapy routines at home, she believes he was healthier than he would otherwise have been as he moved into adulthood. This relates to concerns raised about children turning 18 years old and no longer having the support or access to the therapies that had been more readily available in childhood. Many people still require care as issues may arise during development such as increased spasticity, bladder inconsistency, blood pressure, or decrease in mobility. Several participants suggested that an “aging plan” is needed for individuals living with cerebral palsy as new issues arise, as the “normal day-to-day functions” can add extra stress on the body. Additionally, the mother’s personal reflection on how her efforts positively impacted the long-term health outcomes for her son emphasize the importance of establishing robust routines in childhood and youth.

“[Given the chance to dream, a pathway would include] quality counselling & connection with others to help through crisis.” – Online Participant

Medical practitioners participating in the discussions also highlighted the challenges they face in navigating the systems and the barriers they face in providing optimal experiences

to their young patients. In all discussions the complexity of CP and the various medical conditions that may co-exist¹ was raised:

- What one child/youth may need could be completely different from the needs of another child; consequently, it's challenging for a GP to support the individual because appropriate care requires specialized knowledge;
- Information sharing between system providers is lacking – the ability to save information for a patient in a single place, regardless of service provider, doesn't currently exist;
- More professional development opportunities are needed to stay on top of trends in best practices or emerging treatments for children and youth with CP;
- There is no single centre of excellence on the island to adequately treat children and youth with complex medical needs, such as CP – as a result, it's hard to work collaboratively with a peer group to address a patient's health needs holistically.

Community-based specialists articulated similar challenges with navigating the system, with one key difference: they are often unofficial system navigators on behalf of their clients. There are social workers typically connected to a child with a CP diagnosis and these professionals play a crucial role in supporting the child and family; in that particular role, system navigation is part of the work. However, the other community-based specialists, occupational therapists and physiotherapists who meet regularly with children and youth find themselves often doing work to navigate the system to find information for their young clients – this work does not formally sit with them as an expectation of their role though. Examples include helping to identify funding for specialized equipment that can help with rehabilitation and therapy. If they recognize a barrier facing a family, for example, travel barriers, they often also go above and beyond to identify resources or supports that can reduce or eliminate those obstacles. Without a larger, holistic centre of excellence in place to centralize information its often left to individuals to do research and create documents for clients and their families.

Funding

All participants emphasized the challenges associated with accessing funding to support the health and well-being of a child living with CP. When caring for an individual with complex needs there are a range of services and expenses that arise for families. Equipment, unique treatments, travel and accommodation, household adaptations, and respite support all emerged as critical areas for funding support related to medical services. In some cases, funding is available, but availability and ease of access are very different. A key theme that also emerged through the Let's Talk CP and Complex Needs conversations was the inconsistency of available funding – because of the various coexisting conditions that may or may not accompany CP, funding may be available to one

¹ See Cerebral Palsy Guide, Coexisting Conditions explanation of “coexisting conditions”:
<https://www.cerebralpalsyguide.com/cerebral-palsy/coexisting-conditions/>

family and not to another. This alone makes navigating funding streams a challenge for families and the service providers supporting their clients. Once a child turns 18, the challenges of accessing funding are compounded as funding streams available in childhood are no longer available or require more research to understand what is available.

Availability of Funding vs. Ease of Access

Over the course of the Let's Talk CP and Complex Needs conversations, participants shared information about programs, services and funding streams. It became clear that funding may be available but unknown to a child's caregiving circle. Once known, the demands of completing paperwork to access the funding can be a challenge. In one discussion parents/guardians described the need to have a personal assistant who could help manage all the documentation to make a compelling application. The need exists but good and bad days cycle; some people advised that they present their child's "worst day" on applications so that their funding request is more likely to be approved.

Funding based on diagnosis vs. based on need

A common barrier for funding articulated by participants is that funding, particularly through government agencies, is based on diagnosis. In theory, this means that those most in need of funding support have priority access. In practice, however, funding isn't based on "complex medical needs" broadly; the most regularly cited example was children with an autism diagnosis. Children with CP do not all have the same coexisting conditions – if they have a specific coexisting condition they may be eligible for funding that isn't available to another child.

Significant discussion about the At Home Program (AHP)² managed by the province occurred. This program is intended to assist parents or guardians with some of the extraordinary costs of caring for a child with severe disabilities at home. This program is accessible to children and youths until the age of 18 years old. However, the experience of participants is that the eligibility criteria is limiting. When a child's diagnosis does not fit within the qualification framework there are limited funding options for a range of needs including equipment, therapy treatments, and respite for caregivers. Service providers noted that they often spend time away from therapeutic work rehabilitation services to support families in navigating funding resources to ensure the whole family has the care they require.

Another pertinent issue flagged by participants was how "need" is assessed, particularly in relation to household income thresholds. The cost of living on Vancouver Island is significant; according to the Canadian Rental Housing Index, rental housing costs account for a significant portion of a household's budget (in the capital region, 44% of households spend at least 30% of income on rent and utilities, that number increases in Nanaimo where 48% spend that much, and in Comox Valley 45% are spending that amount)³. On numerous

² Details about the At Home Program available online: https://www2.gov.bc.ca/assets/gov/family-and-social-supports/children-teens-with-special-needs/at_home_program_guide.pdf

³ Canadian Rental Housing Index data: http://www.rentalhousingindex.ca/en/#comp_cd

occasions the group noted that families may not qualify for funding support because the household income is higher than the threshold set by policy. The reality, however, is that the household income threshold policy does not necessarily reflect the family's financial ability to appropriately support a child with CP and complex needs while also taking care of basic standard financial responsibilities, such as housing expenses which are significant for islanders. Again, service providers noted that out of a feeling of responsibility to the families in their care they see parents/caregivers having to choose between what should be essentials or going without services that are not deemed by funders as "essential" or, more frequently, deemed affordable for 'fee for service' given a family's household income.

Specialized Equipment

Many people living with cerebral palsy and other complex needs require specialized equipment. The equipment may be permanently required (for example, a wheelchair) or may be temporarily needed for either therapeutic purposes or because of shorter-term physical changes. A key theme that emerged related to specialized equipment is both the process to properly be fitted for equipment, to trial it and ensure it's a good match for the individual's needs, as well as the reality of a child physically outgrowing equipment.

This topic surfaced in conversations across the island and is an example of a universal challenge faced by children, youth and their families. One practitioner noted that a child may need one piece of equipment and within 6 months they have outgrown it and require something bigger. Some stories were also shared about ordering equipment and then receiving something that didn't meet the individual's needs because they hadn't been able to trial the equipment before it was ordered; return policies were described as limiting. As a result, the discussions consistently advocated for creating systems to trial and/or share equipment. Several unique ideas were floated for consideration – everything from an expansion of some of the island's disparate equipment loan libraries to a Used Victoria concept for the community living with complex needs.



For families living outside a major urban centre like Victoria, there is often travel required to be properly fitted for equipment. There was discussion about the obstacles that proximity to specialized services can create for families living in more rural or remote communities. Some of the discussion covered the frustration that a family might experience when traveling for a singular purpose when ideally, they would have their entire care team engaging with the child/youth during a particular visit.

Repairing and replacing equipment was also a discussion point, particularly as individuals get older and are less likely to outgrow equipment and more likely to extensively use something to the point of needing repair. A few participants described the challenge of wait times for new equipment (for example, it can take up to 6 months to get specialized equipment). Repairs can be more complicated for individuals, as it's not straight forward to get 'lender' equipment and if the equipment is required for daily ongoing use this is particularly challenging. Additionally, for younger children who are growing quickly, a long wait time to receive new equipment can result in a poor fit once the equipment arrives.

Funding for equipment was also discussed as a challenge. There are some funding sources that families can turn to, including the Foundation's Bear Essentials program, and the At Home Program has funding for splints, orthotics, and other mobility aids. Support for families finding funding to attain appropriate equipment for their children is always needed and another reason an equipment lending program could be financially beneficial for families. In addition to specialized equipment needed for daily functioning, discussions also extended into therapeutic and quality of life equipment as well. Knowledge of what is available was inconsistent. For example, the Cerebral Palsy Association of BC's youth navigator spoke about a new form of equipment called the Alinker⁴, which they are helping

⁴ <https://www.bccerebralpalsy.com/join-the-movement-alinker/>

fund; it's a 3-wheeled walking bike designed to help people stay active without sacrificing comfort, style or safety. Greater coordination and information sharing will empower families to access equipment.

Emerging Medical Practices



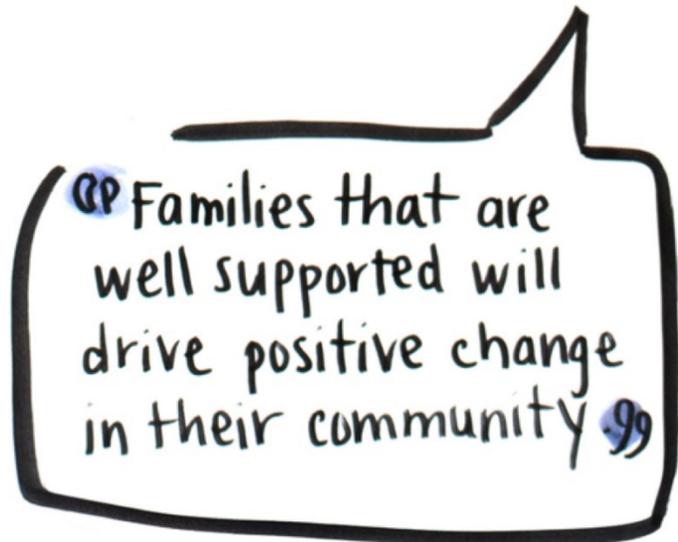
The medical and community-based care providers participating in these conversations noted the necessity to stay aware of emerging and best medical practices to support their patients with Cerebral Palsy and complex needs. Participants unanimously acknowledged how challenging it is for a general practitioner (GP) to confidently stay informed about practices to address their patient's unique needs. The medical practitioners who specialize in this area of child and youth care did express interest in finding ways to be better tune in with emerging medical practices. Examples of how this can be achieved with positive benefits for the long-term health outcomes of children and youth is taking place on a small scale in the South Island. Over the past two years staff from Queen Alexandra Centre for Children's Health (QACCH) and staff at Victoria General Hospital's Neonatal Intensive Care Unit (NICU) partnered to implement an early intervention practice to identify babies born with atypical movements that may be indicative of Cerebral Palsy. Specialized training in Prechtl's Assessment of General Movements (PAGM) was required to introduce this diagnostic tool on a small scale. However, there is still more to be done to partner with the physicians who receive referrals for diagnosis as well as for the families who require support to manage the implications of what this type of diagnosis means. Additionally, there is opportunity to expand this project beyond the South Island and ensure more staff are trained for this type of early intervention.



Cerebral palsy not only affects the individual but also the entire family and their support network. As evident from the participants, a range of support is needed including moral, emotional, and informational. Several themes were highlighted through the discussions across the region including connecting families, mental health supports for the whole family and respite.

Social Media and Support Groups

The desire to be connected and learn and support one another was evident in every discussion. Several community practitioners noted that they've observed a trend among families toward **social media channels** as a way to connect with other parents/caregivers. Several parents shared that they started or joined Facebook groups to seek out support, advice, or just to have conversations with others. These forums have popped up largely because families struggle to find information or are looking for connection with other people who can relate to and empathize with their experience. As one discussion group expressed it, "It's a trial and error process for all of us". Families are often struggling on their own, putting the pieces together, finding out what works and what doesn't work, and just figuring as they go along. It can be quite isolating, and it can add stress on the families and relationships because of the energy and time it takes to discover the right fit for the child. Social media can be used as a platform to bridge that gap, so that families feel supported. These channels are particularly helpful for families living in rural or remote communities where in-person support groups aren't practical, either because of the distance required to travel or the families in the community aren't numerous. Interestingly these groups are family-led and often do not include the community and public health experts who are working to support the child and family unit.



In communities where there are larger numbers of families with a shared experience and travel is less of an obstacle, **in-person support groups** were still desired. The opportunity to participate in the Let's Talk CP and Complex Needs was, for some families, the first time they had sat together with other families and had a chance to build a stronger sense of community. For many families, they can feel isolated and lonely. Participants identified the need for support groups increases during milestone moments and transition periods: early years, transition into public school, and preparation for adulthood. During these periods there is an influx of new information for everyone in the family and it can feel overwhelming. In several communities, in-person programming is hosted by navigators and other community-based practitioners who walk families through this unfamiliar information. Ideally more opportunities for this type of in-person support group would be welcomed by families. Parents and caregivers are looking for a range of supported discussions, including financial planning, mental health for themselves and their families, navigating the healthcare system, in addition to the comradery that comes from being with a peer group.



Support for siblings and youth was also commonly expressed as a gap in community. Just as parents/guardians are looking for a peer group with shared experiences to learn with and support, so are the children they're raising. Participants noted repeatedly that sibling programming has dropped off significantly in recent years, but that the need for it is still strong. Building relationships within a peer group sharing their experience can foster confidence, self-esteem and advocacy skills, all of which are protective factors particularly necessary during teenage years.

“I wish there was more of an opportunity for my son to meet kids with diagnoses similar to his so he didn’t feel like the only one.” – Online Participant

Groups and programming designed specifically for youth and siblings creates space to talk about the issues they face – what does it mean to be “different”; how to overcome bullying, discrimination, and assumptions about their experiences and/or abilities, etc. It’s also helpful to have the opportunity to just be themselves. It is vital for young people to have a place to share their journey, seek advice, mentor one another, and be among friends. The idea of **mentorship** was also popularly raised. Participants felt mentorship helps at transition points to hear what works for others and consider something that may work for them. Parents and others feel that there is “a lot of figuring it out on your own” and piecing it all together to best suit the needs of their child. CPABC already has an ambassador program to connect youth together. More opportunities to promote the program and engage youth to become ambassadors is ideal, as is inviting youth to connect with the program and find a mentor.

Mental Health Supports

In every discussion mental health was flagged as an area where more support is needed. The body is always at the forefront of care for many people living with CP and complex needs, and mental health is often de-prioritized. One discussion group stated that “mental health is as important as physical therapy”. In fact, support for the mental well-being of everyone in the family unit is of utmost importance. One family spoke about the trauma their child endured going through long surgeries and recovery times. Families spoke about the stress that can be felt by everyone in the family – including siblings and themselves. Additionally, children and youth may be going through their own struggles of acceptance or managing friendships.



Respite

“As a grandparent I looked at my role of supporting my grandchild/children. They carried a heavy load. Specialized child care was a huge issue when my daughter had to have surgery and their son needed to be cared for.” – Online Participant

In addition to mental health support, the need for more accessible and frequent respite care was a dominant theme in discussion. Of particular interest was seeing funding for respite care evolve. Respite care is available through the At Home Program⁵, but the amount of coverage depends on the level of disability and the family income, in addition to the waitlists. It is a positive service, but it is limited, so parents or their support networks feel that they can only use respite on a limited basis. Many families talked about relying on their own networks or families to help; however, not every family has someone they can comfortably or easily turn to. One discussion group also flagged the importance of supporting the well-being of those who offer respite care. Families are on a marathon and need to pace themselves – knowing that the challenges their children face will not go away quickly. As anyone who has flown on a plane knows, the advice is always to make sure you have your own oxygen mask on before you can take care of someone else.

Education/ Promotion



Let's Talk CP and Complex Needs conversations also tackled ideas around public education about Cerebral Palsy as well as the literal education experience for children and youth. Overwhelmingly, participants acknowledged that the lack of public understanding of what CP entails is a key obstacle. This gap in understanding CP impacts all aspects of an individual's experience. For the most impact, focussing efforts on developing a more robust understanding of CP within the school system was recommended, as was working with policy makers.

The Big Picture: CP as a spectrum

An obstacle facing families and service providers is how diverse CP is – the reality for families is that like autism, CP is on a spectrum as well. In fact, in almost every conversation participants spoke with admiration about how effective families advocating for their children with an autism diagnosis had been in affecting change – developing a consciousness of autism among the general public and by successfully engaging systemic

⁵ Details about respite care available online:

https://rcybc.ca/sites/default/files/documents/pdf/reports_publications/systems_of_services_for_special_needs.pdf

leaders in the provision of both funding and services. The parallels between the autism community and the CP community are strong; both diagnoses are complex, life-long, and with consistent support can enable individual well-being. In fact, several families participating in the Let's Talk series shared that their children have a diagnosis of both CP and autism. The groups talked through the range of support that begins to open up with an autism diagnosis, even though they acknowledge that the need for supporting the CP diagnosis are equally deserving.

Cerebral palsy often gets interpreted as being solely physical, but it can affect individuals mentally, emotionally, or behaviourally as well. Without a unifying message, individuals and their families often bare the burden of repeatedly educating others about how CP affects a particular individual. For practitioners, there is an additional level of responsibility for having insight into the various ways CP might present and the variety of concurrent conditions individuals may have. CP is by definition complex because of the myriad of diverse medical interventions that might be required. And to reinforce its complexity, the impact of CP can change, as several participants explained; every day is different. One young man shared how his teachers didn't understand how his abilities might vary – that on one day he could do X and the next day he couldn't. The need to educate and destigmatize CP was emphasized as profoundly needed.

In one meeting a participant also spoke about World CP Day that happens every October. She shared that there are materials available that can be distributed and used to help build awareness in the community. Other participants also highlighted the opportunity for CPABC to have a greater presence on the island to make presentations and share resources with communities.

Participants also brainstormed ideas to help reduce barriers, stigmas, and perceptions of the disability. Some suggestions of themes emerged; these ideas were further tested with online participants and the most popular message was: **Meet Kids Where They're At: Treat kids based on needs and abilities, not on diagnosis**

“[In the early years it would be great to have] Personal awareness of disability- books that represent kids with CP, support and kindness” – Online Participant

Several creative ideas also surfaced about how to engage in better public awareness and understanding of CP and complex needs for targeted audiences – these included (tele)conferences, webinars or even CP resource fairs. For school-age children and youth, participants also explored enhancing opportunities to educate peer groups. In one discussion a suggestion was to focus on similarities and build buddy programs.

Families and the School System

Families participating in discussions know that the school system is a big influencer on the long-term success of their children. As stated in one conversation, “We are experts in knowing our kids” – this places families in the role of advocate at every turn. Repeatedly parents noted their responsibility to educate a child’s teacher, educational assistant, and even the school administration to ensure appropriate supports are implemented. For parents who may not have the capacity to do this advocacy for their children, the reality is that these children are at a significant disadvantage. Rather than depending on individuals, the system needs to incorporate measures for equity and support that are not reliant on chance.

What does inclusive education look and feel like? Participants brainstormed different mechanisms that could be implemented to create equitable and supportive educational experiences:

- Create student advocate role & plan
- Inclusivity training for educators and administrators
- Strengthen after school programming
- Provide adaptability training (e.g. ensure gym programming is inclusive)
- Find matches for extracurriculars that meet the ability of the individual

Other modes of collaboration between schools and families need to be examined. On several occasions participants asked how we can ensure educational assistants are positioned to help our kids succeed. As with all things in life, you don’t know what you don’t know. Participants suggested educators could benefit from improved training. Professional development opportunities for educators and administrators focussing on adaptable and flexible activities and building curriculum that emphasizes a child’s strengths, not their deficits, sets the school providers up for success too. There was also discussion about the ideal of matching educational assistants with students based on fit and not administrative policies that may not have the child at the centre of decision-making. Parents want to partner with the schools to create positive outcomes for their children. In finding improvements for leveraging Individual Education Plans (IEP), teachers are also able to be informed, plan and execute.

Additionally, schools are central to destigmatizing disability and fostering a culture of inclusion and connection within peer groups. Ideas around how to support inclusive learning for students were also brainstormed. In one session a parent shared that when her child started school she put together a package to introduce her “whole” child, making it possible for teachers, parents and students to find points of similarity and understanding; she explained that some students even reciprocated. Educating a child’s peer group about cerebral palsy and complex needs helps reduce bullying and social exclusion. There needs to be more support for the educators and coaches to know how to include individuals with cerebral palsy and other complex needs.

How do we ensure the environmental design of school campuses is inclusive? Participants explored the idea of how the physical environment can facilitate exclusion and peer-to-peer isolation; children unable to engage in social activities or play because playgrounds, washrooms, or school activities are not accessible are at greater risk of poor mental health. Schools need funding to enhance the accessibility of playgrounds, classrooms and washrooms. The lack of accessibility of the schools may limit a child's ability to attend the school in their catchment, which creates added stress on the family responsible for transportation and childcare. School accessibility promotes more independence for the individual to participate in activities with their classmates and fosters opportunities for friendships to develop.

Schools and Rehabilitation Teams

Another theme that came through was the desire for an increase in collaboration of the rehabilitation and education system as more family want a further continuation of treatments within the school system. Some voiced that they want the occupational and physical therapy treatments to happen more during the school days as they would help with discovering strategies of inclusion during gym and school.

“Make therapies available before and after school hours so the child isn't missing learning and social opportunities at school as well as supply funding.” – Online Participant

As well, it was suggested that further partnerships will help with the sharing of ideas of how to best work with the individuals with cerebral palsy. Each of them needs flexibility to work with each other to determine the best support for schools and at the various life transitions so that the individual can be as successful as they can be. Together, it hopes to reframe their perspective and work together to focus on the progress and the strengths of the individual.

Programs & Services



As participants identified resources, services, and programs, a list was developed and is included in Appendix E; it is not exhaustive. Funding resources are included separately, in appendix D.

Across the board, participants engaged in the Let's Talk CP and Complex Needs process articulated the need for diverse, accessible programs and services for children and youth. Everyone wants the children and youth in their lives to have opportunities – programs and services can make a difference in the long-term health and well-being of a child. The most significant disparity surfacing through the process was how much need there is for programming for children and youth living outside of the Capital Regional District (CRD), particularly related to quality of life. Across the board, however, all children and youth on the island would benefit from a greater variety of the types of programs and services available to them. The hopes and dreams articulated among participants in talking about health & well-being and independence & life transitions is also closely tied to the gaps in available programs.

Rural and Remote Scarcity of Programming

The further north the conversation, the more apparent the need for any type of programming for children and youth living with complex needs. On multiple occasions participants flagged that often the programming that is offered is inappropriate for the child/youth in their care because of the individual's typical cognitive abilities; in other words, programs are built for individuals with intellectual challenges. Additionally, families living in rural or remote communities stressed the additional challenges they face in transportation. To find appropriate programs they are required to travel significant distances because there isn't a "volume" of other participants for programming.

Local service providers need to be supported in the process of building inclusive activities – the benefits of social inclusion and reduced transportation are helpful to everyone. Partnering with municipal parks and recreation leaders and connecting to post-secondary resources (researchers, students, etc.) could enable capacity in these communities. These communities need support to purchase and maintain adaptive equipment and appropriate space to operate programs as well. By taking the approach of layering inclusivity practices in the community's existing programs, local families are more likely to be able to participate and social connections can be developed.



Diversity of Programming

Participants across the island highlighted that many programs are offered for people with intellectual disabilities; children/youth with cerebral palsy often do not qualify as a result. For example, it was pointed out that Special Olympics has a large presence on the island, but a child/youth with a cerebral palsy diagnosis may not be fit for the programming because of the level of functioning. The gap points to the need for greater awareness of the many ways CP can impact a person's life.

The South Island was celebrated for a range of wonderful, supportive sport and recreation services that make quality of life possible: Recreation Integration Victoria; Power to Be; Pacific Institute for Sport Excellence, among others. The Cerebral Palsy Association of BC (CPABC) also offers a handful of inclusive programs in the CRD – Dance Without Limits and Adaptive Yoga. Sports can help physically, emotionally and mentally as it provides an “escape”. As well, it promotes a sense of “normalcy” as it provides a space for relationship building while simultaneously building on strength and movement. Central and North Island participants noted there are other great organizations providing services, including therapeutic riding programs. Conversations in these regions considered the potential for partnerships with South Island agencies to build capacity in communities outside the CRD and enable more opportunities for children/youth in their own communities. There were a handful of examples, including adult wheelchair basketball that one youth in the Central Island indicated had been made possible when he was still a teenager. Creating opportunities to fund specialized equipment for programs like wheelchair basketball, sledge hockey, adaptive cycling, or supported swimming are deeply wanted. One family noted that swimming lessons are a challenge because their child requires one-to-one lessons, which are expensive and the financial responsibility of the family. Almost every community has a pool and the possibility to support inclusive swimming programs could be beneficial.

While sports programming was often discussed, youth participating also voiced their desire for more diverse inclusive programming. More programs and services are needed to assist with the transition to adulthood such as cooking, financial literacy, or independent living –

these opportunities are explored in more depth in the “Independence and Life Transitions” portion of this report.

The desire for mentorship, support groups, sibling programs, and mental health supports for the whole family were also emphasized – these opportunities are explored in more depth in the “Health and Well-Being” portion of this report.

Inclusive Preschool, Before and After School Care

“[It would be helpful to have] inclusion in early years programs such as preschool.” – Online Participant

“After school care for CP disabled kids. Lack of availability of after school care, and care during school holidays means at least 1 parent cannot work.” – Online Participant

Families also articulated the challenges they face in finding appropriate preschool, before and after school programming. It’s widely known that there is a shortage of adequate childcare programming across the province; these challenges are exacerbated for families who are raising children with exceptionalities. As policies are developed broadly, consideration for how to support families with childcare demands attention.

Life Transitions/ Independence



INDEPEDENCE &
LIFE TRANSITION

“When you turn 18, they treat you like you don’t have cerebral palsy anymore.” – Let’s Talk CP and Complex Needs Participant

The challenges of transitioning from the child/youth system into the adult system are well known to young people, their families and service providers. Participants all explored how this transition could be better supported. Additionally, some discussion also occurred about other less emphasized transitions, including kindergarten and middle years changes. At each point families have new and evolving needs that require support. Cerebral Palsy and other complex needs are lifelong conditions and individuals and their support circles will benefit from early interventions and planning.

Early Years Transitions

“[In early childhood, the pathway would have] supports in place to help guide, give information to make informed decisions, specialized child care access, networking with others in similar situations so isolation, frustration and sadness are decreased.”
– Online Participant

Families and service providers noted that in the early years of a child’s life there are a handful of key transitions where support is helpful. Entry into kindergarten is a big milestone for all children, but parents/guardians of children with exceptionalities can experience greater apprehension and have greater demands to advocate for the needs of their child.

The ability in the South Island to conduct early identification of infants receiving a CP diagnosis also means that parents need support. Taking in the information about their child and preparing to support him/her can be overwhelming for a parent of a newborn. Service providers want to meet parents where they’re at and making sure they have what they need when they’re ready.

Middle Years Planning and Entering Adulthood



“[In the middle years, the ideal pathway would include] options presented before transition. Starting planning ahead of time.” – Online Participant

Several participants noted that the middle years are optimal for preparation for a young person’s transition into adulthood. Depending on the complexity of an individual’s medical

needs, families need time to think about financial planning, specialized equipment and infrastructure at home to enable a young person's growing independence. The need for life skill training, employment preparation, medical team preparation and navigating the adult system were all key areas highlighted by participants. The other big finding is how important it is to support individuals in becoming independent, while supporting parents transition away from their identity as "caregiver".

Life skill training and support

Independence was a popularly discussed topic among participants, particularly young adults who are in this stage. One participant gave the example of how cooking presents different challenges to people with complex needs. Similarly, financial literacy should be supported; youth are not getting support learning to budget, which is paramount to independent living. There are opportunities for community partners to step forward and build one-to-one and group-based programs for young people and their families.

For young people living on their own for the first time, they may also need assistance with house cleaning and personal care. For example, standard household materials may need to be adapted. One participant talked about the challenges of showering and brushing hair. At the very least, young people need to have support in building plans for how to manage these day-to-day activities.

Employment preparation

"... more inclusiveness in all aspects of the post-secondary system e.g. co-ops and practicums should be supported." – Online Participant

All people need meaningful work to feel like they are contributing, valued, and part of their community. An increase in employment support is needed for individuals to attain employment, specialized workplace equipment or other resources. At the same time, employers need more awareness and understanding of working with people with disabilities. Building an inclusive workplace is challenging, but it takes collaboration in working together to build a successful work environment for all. There was discussion about supporting young people begin to attain practical work experience. Programs like CanAssist's TeenWork is a leading example of youth employment training. Having a disability can be a hinderance in achieving paid employment so offering career counselling or employment training is needed to provide the extra support to assist people with disabilities to search for employment in their formative years.

For young adults, discussions also raised the opportunity to support employers prepare the work environment. Not all work spaces are accessible, and employers and employees need support to create inclusive work practices. This type of mindset can be fostered through

inclusive school design, so that as a cohort ages they are already equipped with an appreciation for how they can contribute to a healthy, inclusive work environment.

Medical team preparation

One of the big transitions flagged during the Let's Talk CP and Complex Needs series is the move away from the circle of caregivers a youth and his/her family has relied upon since childhood. As noted in the "Medical Services" portion of this report, family physicians are rarely visited due to the complexity of a child's medical needs. However, upon entering adulthood, the family GP is suddenly the most actively available medical resource for people. As a result, family physicians need support to more fully understand how they can support an individual. Ideally, a larger support team could help transition knowledge and information – including medical history, appropriate treatments or rehabilitation services. Mainstream physiotherapists and occupational therapists also do not have extensive knowledge about cerebral palsy or complex needs; having an opportunity to transition knowledge to this new practitioner team would benefit both the care provider and the individual.

Adult system navigation & handoff for funding, services, and support

As young people shared, in their experience rehabilitation services stop when they turned 18 years old. Participants acknowledged that major systems are beginning to work towards creating smoother handoffs from the youth to adult systems, but there is still opportunity to improve the experience for individuals and their circles of care. Families and individuals need support to understand the new range of services available, the nuance of accessing supports, and tools to make information accessible.

Individuals may be referred to Community Living of BC (CLBC), which is the provincial crown corporation that funds support and services to adults with developmental disabilities, as well as individuals who have a diagnosis of Autism Spectrum Disorder (ASD) or Fetal Alcohol Spectrum Disorder (FASD) and who also have significant difficulty doing things on their own. However, the criteria to receive support from CLBC may exclude individuals with CP, depending on their abilities. CLBC can assist individuals to achieve the "persons with disabilities" designation which includes financial or health support. To be eligible for this, the individual must:

- Show that they meet financial eligibility to receive assistance
- Have a severe physical or mental impairment that is expected to continue for more than two years
- Be significantly restricted in their ability to perform daily-living activities
- Require assistance with daily living activities from another person, an assistive device, or an assistance animal

There are some financial benefits available for people with disabilities, regardless of “persons with disabilities” designation, such as the Registered Disability Savings Plan or the Disability Tax Credit, BC Ferries Disability Card, the Handydart for Transit. However, older participants noted that there is a general lack of programs and services for adults. Participants voiced that there are several opportunities that can be available, but individuals have to find what works for them.

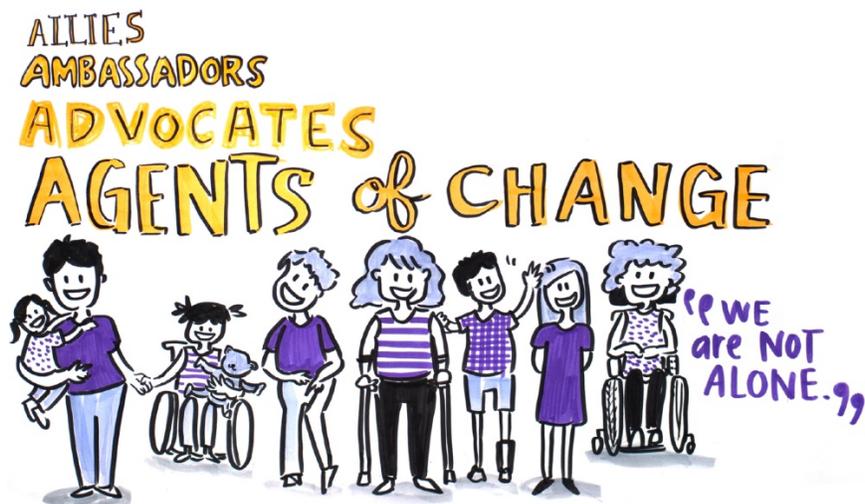
Independent Living

Similarly to all people, individuals with cerebral palsy have a desire to live on their own, but they may require more support. Long waitlists, lack of accessibility, and high cost of living makes it more challenging for people with cerebral palsy and other complex needs to move out, which is hard for both the individual and his/her parents/guardians. However, there are a range of housing options in various parts of the Island: independent living, supported housing, and co-housing. Independent Living BC (ILBC) is a subsidized, assisted-living program that provides housing with support services to seniors and people with disabilities. Independent Living BC is a partnership between BC Housing, provincial health authorities, the Canada Mortgage and Housing Corporation (CMHC), and non-profit and private-market housing providers. The program’s assisted living units provide a middle option between home care and residential care, so individuals can continue to live independently. Supportive housing provides a range of on-site, non-clinical supports, such as life-skills training, and connections to primary health care, mental health or substance use services. There are also 4 cohousing options across Vancouver Island; residents usually own their individual homes, which are clustered around a “common house” with shared amenities. These amenities may include a kitchen and dining room, children’s playroom, workshops, guest rooms, home office support, arts and crafts area, laundry and more. Conversation touched on the need to better engage in housing options, including co-located housing so young people and their parents can live more independently, while still being close by to support one another.

Emotional preparation for a new role

Empty nesting is a commonly known phenomenon. Watching your child blossom into an adult and begin to live their own life independently is hard for most parents. For parents/guardians who have dedicated their lives to being their child’s advocate, this transition may be particularly hard. Participants talked about the emotional toll of surrendering their advocacy hat when their child moves on. As noted in the “Programs and Services” and “Health and Well-Being” portions of this report, mental health and support group programming is essential to supporting families through these transition periods.

Calls to action



The Let's Talk CP and Complex Needs series is ultimately a call to action for system leaders, service providers, families, individuals with lived experience and the philanthropic community to heed the calls to action elicited through this process. There are so many wonderful people committed to ensuring quality of life and access to care for the many children and youth on the island(s) living with CP and other complex needs. Many creative ideas surfaced through this process – too many to individually list here but they are captured in the visual recordings from the conversations. Instead, this report seeks to highlight seven calls to action. These are areas of opportunity highlighted through the process where real change in the lives of children and youth could be created with focus, collaborative action and additional research.

1. Awareness campaign(s)

Based on the collective conversations, one of the biggest opportunities is to build awareness about Cerebral Palsy and complex needs among educators, policy makers, medical practitioners, and child and youth peer groups. There are opportunities to leverage lessons from other jurisdictions and advocacy groups, including World CP Day and autism awareness advocates in Canada. Small, strategic steps can be taken to engage the community in a better understanding of what cerebral palsy and complex needs can involve. With a champion organization, possibly the Cerebral Palsy Association of BC (CPABC), there are people eager to step forward and support awareness building.

2. System capacity building

A strong system fosters positive outcomes. There are opportunities to build scaffolding to strengthen the already good foundational pieces supporting children, youth and their

families in community. Ideas include engaging with policy makers in conversation about how to transform access to better meet the needs of children/youth, informed by those on the ground. Additionally, opportunity exists for building infrastructure within the system to enable better support for children, youth and families. Ideas surfaced through this series that demand deeper exploration: integrated information management among acute, public and community health providers; a complex care clinic to provide coordinated healthcare; professional development for physicians, educators, community planners, and so on.

3. Partnerships

The complexity of cerebral palsy and complex medical needs demands that system leaders and service providers work together in partnership with families. There are opportunities to do more outreach and partnership building. Other partners that more traditional healthcare providers and families should prioritize relationship building with include municipal leaders, post-secondary institutions, and community agencies with deep expertise in specific areas of service delivery. Working with municipalities responsible for leisure and recreation programming, construction of accessible public spaces for all bodies, etc. can ensure greater equity of access, particularly for families living in rural and remote communities. Engaging with post-secondary researchers and students also poses another huge opportunity; research projects and practicums establish leadership and integrative thinking among the future workforce, while also addressing current challenges and building a runway for progressive research. Post-secondary education programs also have capacity to adapt their own programming to ensure children and youth living with complex needs are also positioned to be future leaders. Additionally, there are community agencies steeped in experience with great programming that is scalable into other communities (e.g. Power to Be; Recreation Integration Victoria; CPABC; etc.) – in many cases the first step is to invite these agencies into the community to dream about what is possible.

4. Childcare and school capacity

All parents across the Island are experiencing challenges finding reliable, affordable and safe childcare for their children. For families raising children with CP and other complex needs, the obstacles for childcare increase. This extends into before and after school programming, and beyond into the public education experience. There is an opportunity for system leaders to support professional development for early childhood educators, educational assistants, before and after school service providers and teachers. By equipping educators with skills and knowledge for how to support children with CP and complex needs, educators will gain greater confidence in creating safe and inclusive learning environments. In turn, (all) the children in their care will gain opportunities for meaningful inclusion, connection, and confidence-building.

5. Equipment and specialized supports

Access to specialized equipment and supports is an island-wide need. There is opportunity for systems leaders and service providers to facilitate coordinated access to equipment – for trial purposes or short-term basis. Equipment loan libraries exist on the island, but are not equally accessible to children and youth living in rural and remote regions. Additionally, there is room to enhance and promote programs that support access to specialized equipment and supports; this includes expanding the reach of resources such as the Foundation’s own Bear Essentials program. Furthermore, there is room to support networking among professional navigators (these specialists include social works, navigators, outreach workers, etc.) to enable better awareness of access to equipment and specialized supports.

6. Support group options

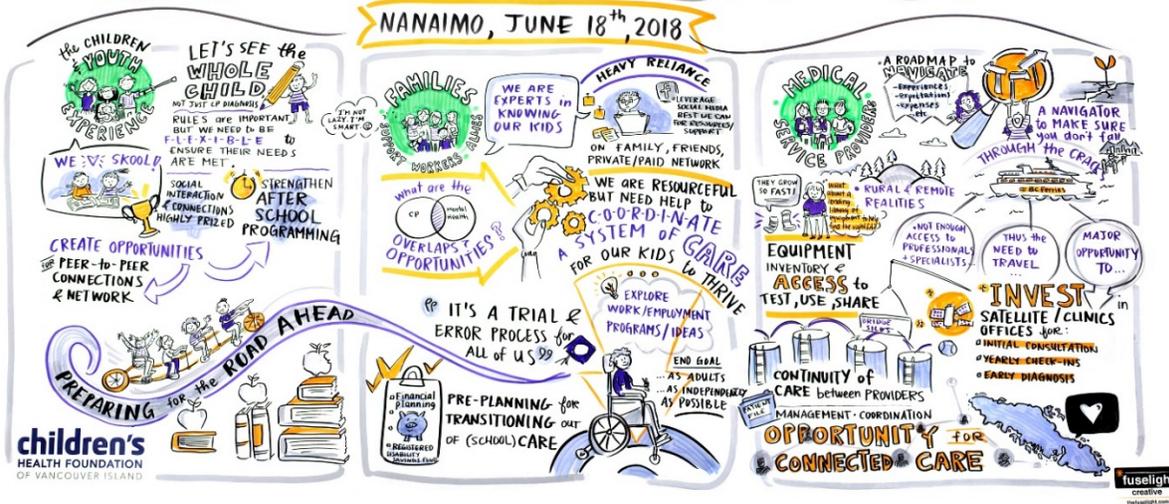
Connection is an essential ingredient for human well-being. Revisiting support group models aimed at supporting parents/caregivers, siblings, and children and youth living with complex needs is timely. Families are turning to informal social networks, but are missing the intimacy and expertise that formal in-person gatherings offer. Families need a variety of options to enable connectivity, mentoring, learning, and relationship building. Isolation caused by factors including remote living, transportation barriers, and time constraints are essential to consider in planning programming; however, consulting with families directly, the network has the ability to develop creative solutions.

7. Transition programming and services

Raising a child equipped for transitioning into adulthood is essential. Service providers have the opportunity to build a network of experts who can support life skill development for youth and families. There are best practices already in place that can be leveraged to enable future independence – CanAssist’s TeenWork program for employment; numerous financial institutions offer financial literacy and RDSP expertise; and post-secondary schools offer co-op and intern programs that with support can prepare both youth and employers for inclusive work experiences. Additionally, conversations about the transition into adulthood needs to be supported earlier in a young person’s life.

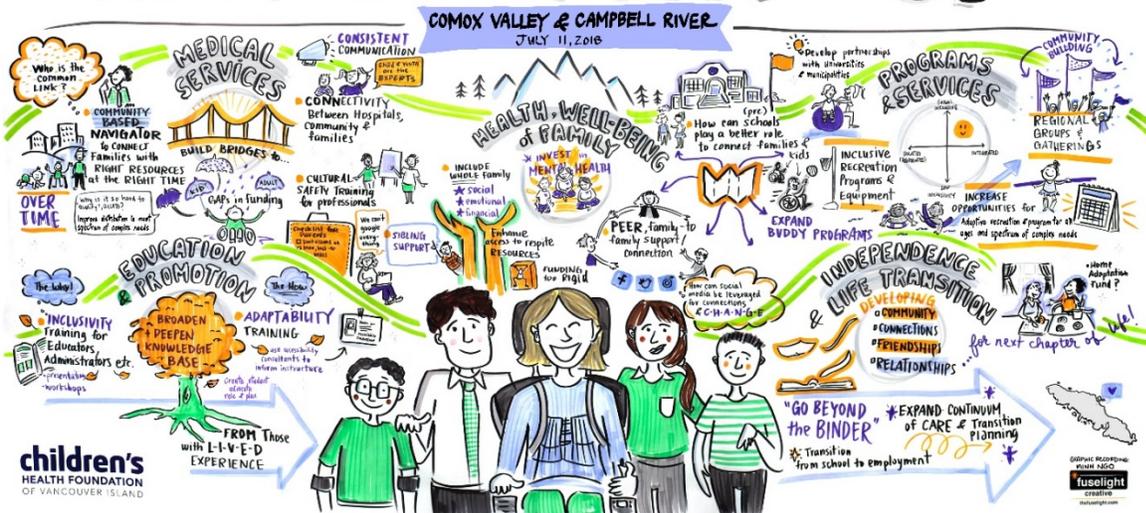
Appendix A: Graphic recordings

LET'S TALK CP



Nanaimo focus group, June 18, 2018

LET'S TALK CP



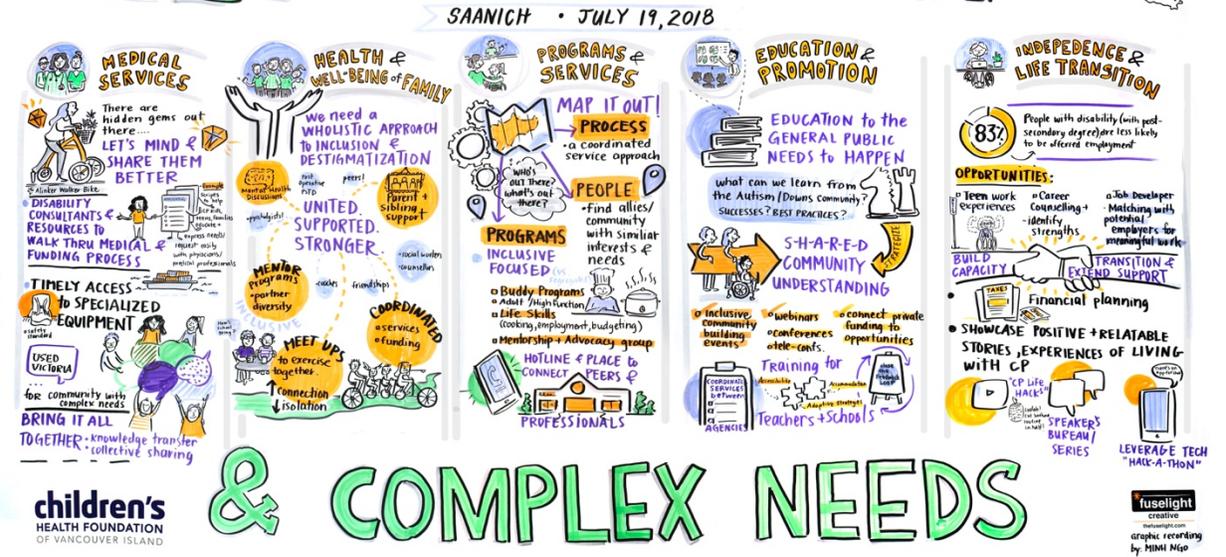
Comox Valley focus group, July 11, 2018

LET'S TALK CP



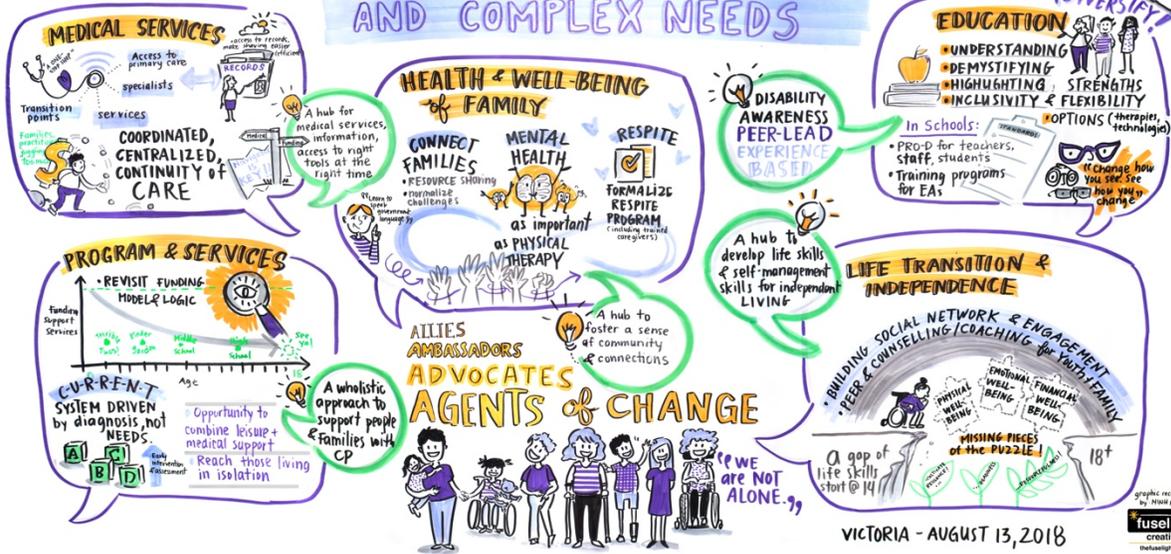
West Shore, Victoria focus group, July 18, 2018

LET'S TALK CP



Saanich, Victoria focus group, July 19, 2018

LET'S TALK CP



Victoria focus group, August 13, 2018

Appendix B: Questions for the online survey

CP (& Complex Needs) focus group Island-wide survey

Let's Talk CP and complex needs

In collaboration with donors interested in supporting youth and families with Cerebral Palsy and other complex health needs, Children's Health Foundation of Vancouver Island hosted a series of conversations across Vancouver Island between June and August 2018. The goal is to better understand how we can support children and youth living with CP as well as children/youth in the CRD living with a physical disability or serious medical condition. The Let's Talk CP project is intended to celebrate what's working well, where there are opportunities to improve, and dream about new ways of serving island kids. It is also a forum to strengthen relationships and foster community among individuals with lived and professional experience.

The discussions to date have helped identify current trends in the health system, gaps in care, and opportunities for how to better collaborate. This survey provides the opportunity to gather more voices amidst busy summer schedules and overcome possible barriers to attending one of our conversations in person.

Please take the time to complete this survey to the best of your knowledge by September 14th, 2018.

We'll ask you for your input on 5 different categories. This survey should take no more than 20 minutes.

What region do you reside in?

- Capital Regional District (Victoria, Esquimalt, Oak Bay, Saanich, Central Saanich, North Saanich, Sidney, View Royal, Colwood, Langford, Metchosin, Highlands, Sooke, Port Renfrew)
- Southern Gulf Islands (Valdes Island, Salt Spring Island, Galiano Island, Mayne Island, Pender Island, Sidney Island, Saturna Island)
- Cowichan Valley (Ladysmith, Chemainus, Thetis Island, Penelakut Island, Crofton, Duncan, Lake Cowichan, Youbou, Honeymoon Bay, Cowichan Bay, Cobble Hill, Mill Bay, North Cowichan, Shawnigan Lake, Westholme, Mesachie Lake)
- Greater Nanaimo (Lantzville, Nanaimo, Gabriola Island, Cedar)
- Campbell River & District (Campbell River, Sayward, Quadra Island, Cortes Island, Oyster River)
- Oceanside (Deep Bay, Bowser, Qualicum Bay, Qualicum Beach, Coombs, Errington, Parksville, Nanoose)
- Port Alberni/West Coast (Port Alberni, Ucluelet, Tofino, Bamfield, Ahousaht)

- Comox Valley (Black Creek, Merville, Courtenay, Cumberland, Comox, Lazo, Union Bay, Buckley Bay, Royston, Fanny Bay, Denman Island, Hornby Island)
- North Island (Port Hardy, Port Alice, Port McNeill, Coal Harbour, Quatsino, Alert Bay, Telegraph Cove, Kingcome, Zeballos, Gold River, Tahsis)

What is your relationship with Cerebral Palsy or other complex health needs? I am a

...

- Individual living with CP and/or another physical disability or serious medical condition
- Parent of an individual living with CP and/or another physical disability or serious medical condition
- Sibling of an individual living with CP and/or another physical disability or serious medical condition
- Service provider for individuals living with CP and/or another physical disability or serious medical condition

If healthcare provider, please specify your role:

- Other (please specify):

Which of the following services do you or your family member use on a regular basis (I.e. within the last 3 months)? Check all that apply.

- Primary care (I.e. family doctor)
- Occupational therapist
- Physiotherapist
- Speech therapist
- Counselling or other professional mental health support
- Peer support groups
- N/A – I am a healthcare provider
- None of the above
- Other (please indicate)

How would you rank the accessibility of services in the following categories (I.e. with regards to waitlist or availability of services in community)? (not at all, somewhat, very, completely, N/A)

- Primary care (I.e. family doctor)
- Occupational therapist
- Physiotherapist
- Speech therapist
- Counselling or other professional mental health support
- Peer support groups
- Other (please indicate)

Where do children/youth receive services? (check all that apply)

- Queen Alexandra Centre for Children
- BC Children’s Hospital
- Sunny Hill
- Local physicians/specialists in home community
- Local child development centre
- Other (please indicate)

Are children/youth able to access mobility aids that they require?

- Yes
- No
- Sometimes

Please explain:

What types of supports are needed by families? Rank in order of most to least needed.

- Emotional/moral support
- Physical support (I.e. equipment)
- Intellectual support (I.e. access to knowledge about health condition and applicable services)
- Quality of life support (i.e. recreation programs, life skills, etc.)
- Financial support
- Other (please indicate)

Where do you/your family/your clients go for moral support? (advice, mentor, respite, etc.) Check all that apply.

- Service Provider (I.e. Counsellor)
- Formal support program (i.e. group)
- Mentor
- Peer(s) with similar experience
- Social media (I.e. Facebook group)
- Friends & Family
- N/A
- Other (please indicate)

Do you think your experience would have been different if you/your child or client was diagnosed as a baby?

- Yes
- No
- Unsure

On a scale of 0-10 (0 being not at all, and 10 being well supported), how supported does the family unit (individual, parents, siblings, etc.) feel?

On a scale of 0-10 (0 being not at all, and 10 being fully met), are mental health needs being met with current services in the community?

If they are not being well met, where are the gaps and what would you like to see?

Which are the programs/services you use in your community? Check all that apply.

- primary healthcare (i.e. family doctor)
- specialized care (i.e. physiotherapists, occupational therapists, speech therapists)
- knowledge (i.e. help navigating the system)
- recreation & quality of life (i.e. inclusive recreation; life skills; etc.)
- funding (i.e. program fee coverage, equipment funding, etc.)
- support groups (i.e. peer or family)
- Other (please indicate):

What resources would you like to see (more of) in your community? Rank from most to least important.

- primary healthcare (i.e. family doctor)
- specialized care (i.e. physiotherapists, occupational therapists, speech therapists)
- knowledge (i.e. help navigating the system)
- recreation & quality of life (i.e. inclusive recreation; life skills; etc.)
- funding (i.e. program fee coverage, equipment funding, etc.)
- support groups (i.e. peer or family)
- Other (please indicate):

What resources do you lean on and love?

In order to increase public education and awareness, rank from most to least which channels should be prioritized.

- Buddy/peer education and awareness programs (inclusive)
- Presentations to elementary and high school students
- Professional development for education system staff (i.e. administrators, teachers, EAs, etc.)
- Public campaigns
- Professional development for service providers (i.e. therapists, counsellors)
- Professional development for family physicians
- Other (please indicate)

If you could choose, which public campaign do you think is the most important?

- CP Spectrum: Like Autism, people with CP have a range of experiences
- Meet Kids Where They're At: Treat kids based on needs and abilities, not on diagnosis
- We're more alike than different: Let's normalize the way we view exceptionalities
- Equity of access to funding: Financial support should be based on need not diagnosis

How do you feel about the following statements with regards to your/your child's/client's education: (agree/disagree/neutral/NA)

- The school is/was prepared for accessibility needs
- The teachers/education team was prepared/receptive to adapt to my (child/client) learning needs
- The teachers/education team was prepared/receptive to facilitating inclusive practices into class wide activities
- Classmates were supported with inclusive learning and social interactions

What supports are necessary for you to make important life transitions (elementary - high school, high school - independence, post-secondary)?

- Moral & emotional support
- System knowledge (i.e. preparation beginning several years before transition)
- Continuity of funding (i.e. between 18 and 19 years)
- Increased flexibility within school system (i.e. the option to begin/end school at transition points determined with the family)

What would help you to become more independent and have the necessary supports in place?

- Inclusive community housing (i.e. independent housing for people with and without exceptionalities)
- Supported housing (i.e. communal housing with specialized support including cooking, etc.)
- Life skills training (i.e. to teach adapted cooking, cleaning, budgeting, etc.)
- Mentorship program
- Employment programs (including inclusive employer support)
- Other (please indicate)

What would help you in navigating resources in the best way possible?

- A centralized location with information about all resources (i.e. website or app)
- Increased access to equipment (i.e. mobility aids, vehicle with accessibility, etc.)
- Navigator (i.e. a dedicated person to go to for support)
- Other (please indicate)

Given the chance to dream, what would the pathway look like?

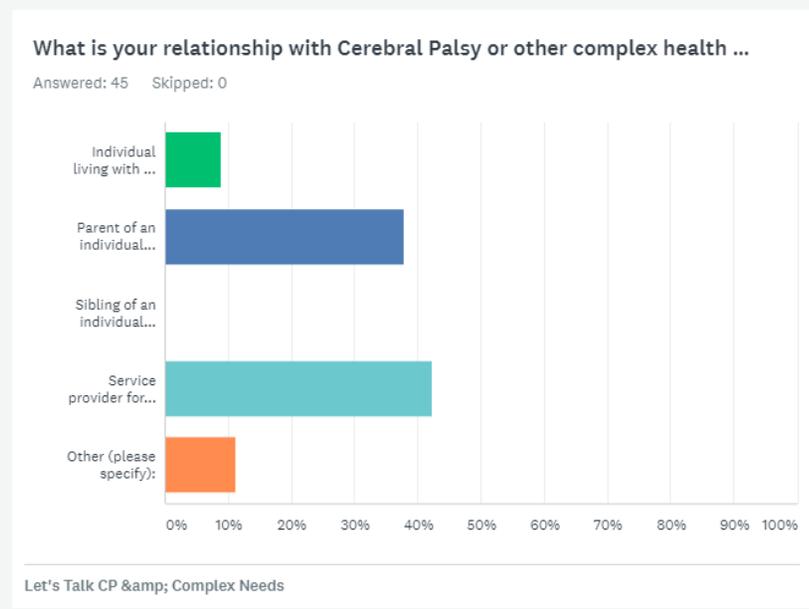
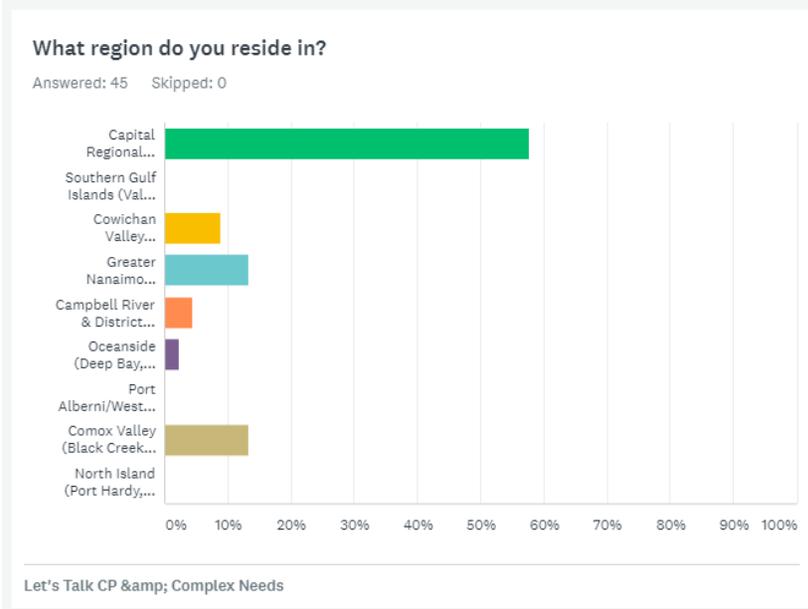
In early years?
in middle years?
in transition years?
in times of crisis?

Please share any additional thoughts.

FINAL MESSAGE

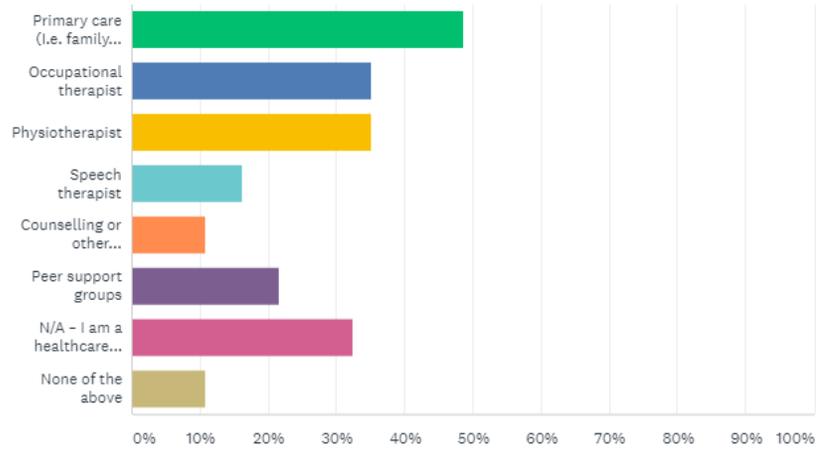
We hope that this project and the resulting knowledge will guide the Foundation in the coming years as we work with funded partners, community and families to create change. For more information, please contact community@islandkidsfirst.com or 250-940-4950. Thank you!

Appendix C: Online survey results



Which of the following services do you or your family member use on ...

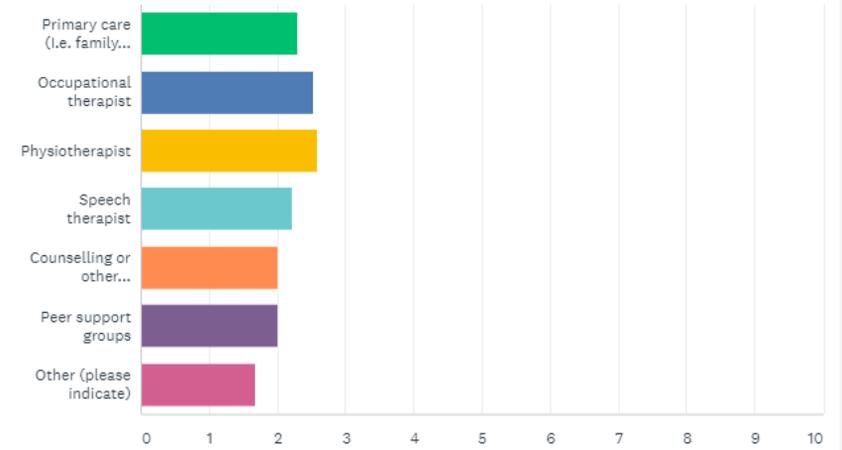
Answered: 37 Skipped: 8



Let's Talk CP & Complex Needs

How would you rank the accessibility of services in the following cate...

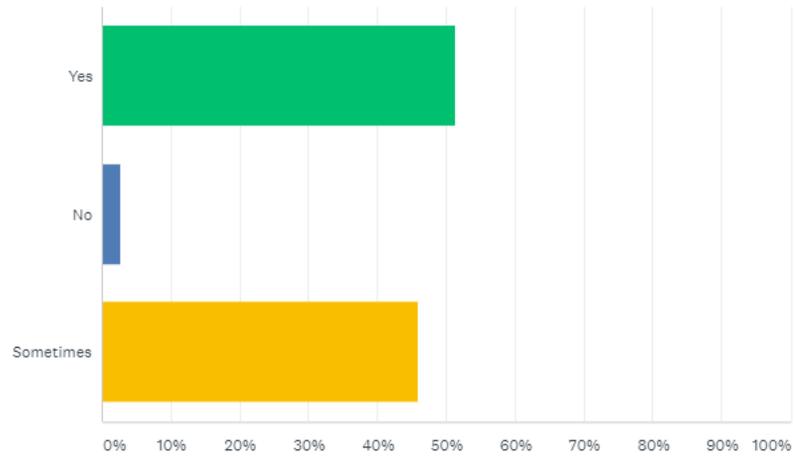
Answered: 37 Skipped: 8



Let's Talk CP & Complex Needs

Are children/youth able to access mobility aids that they require?

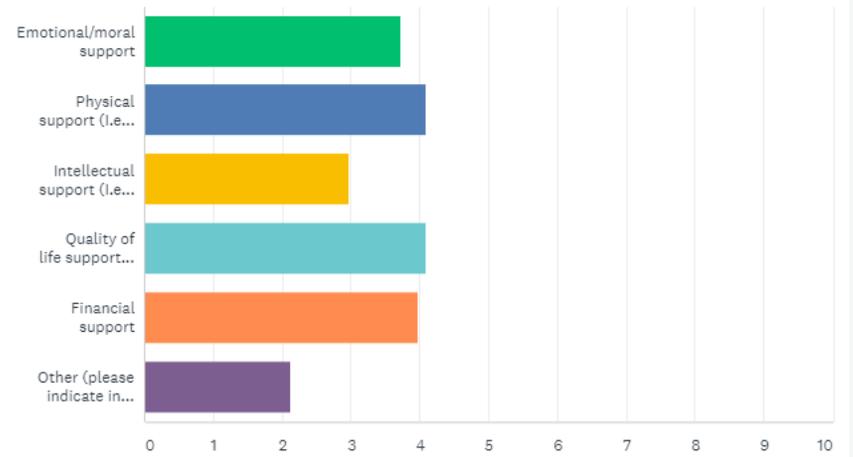
Answered: 37 Skipped: 8



Let's Talk CP & Complex Needs

What types of supports are needed by families? Rank in order of most...

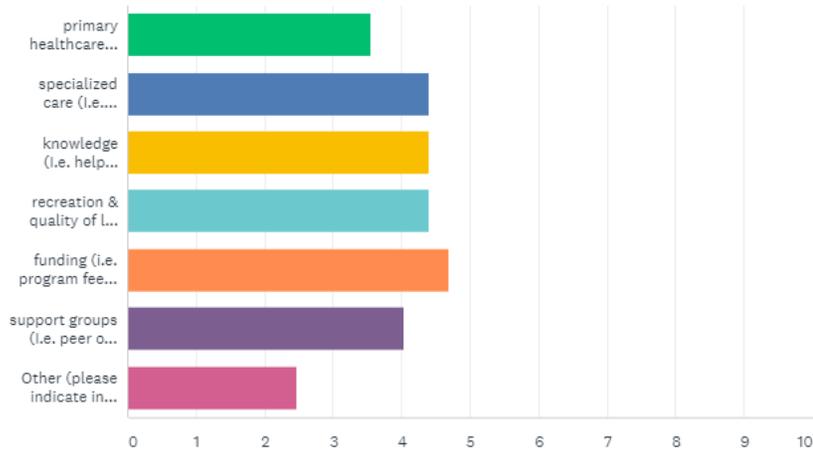
Answered: 30 Skipped: 15



Let's Talk CP & Complex Needs

What resources would you like to see (more of) in your community? R...

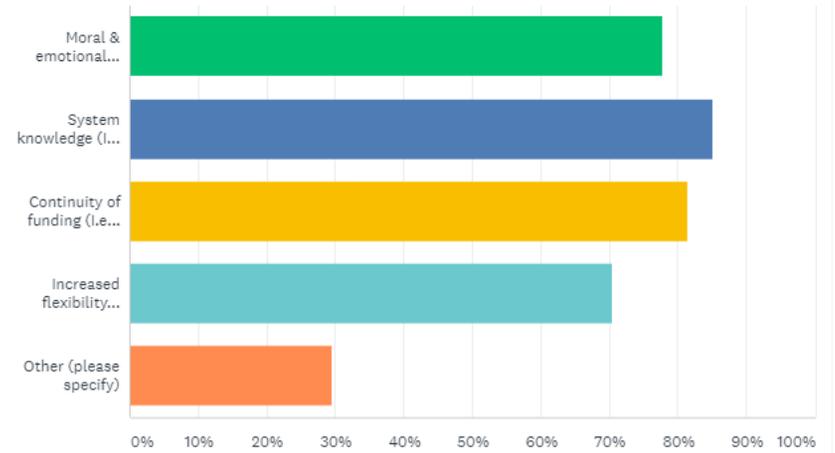
Answered: 29 Skipped: 16



Let's Talk CP & Complex Needs

What supports are necessary for you to make important life transition...

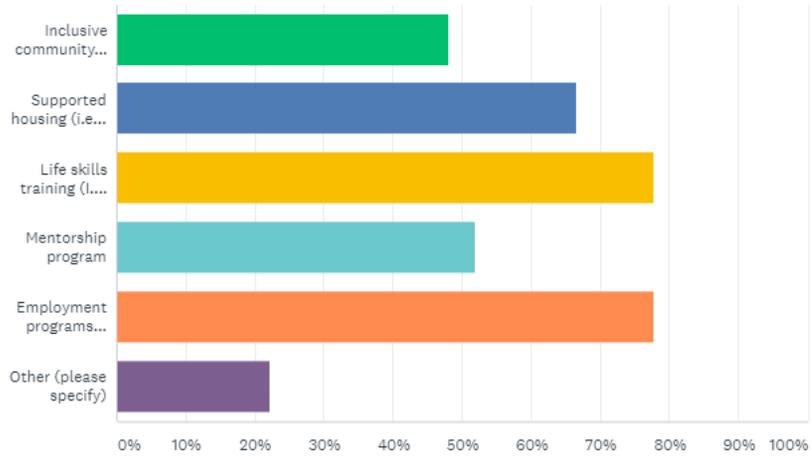
Answered: 27 Skipped: 18



Let's Talk CP & Complex Needs

What would help you to become more independent and have the nece...

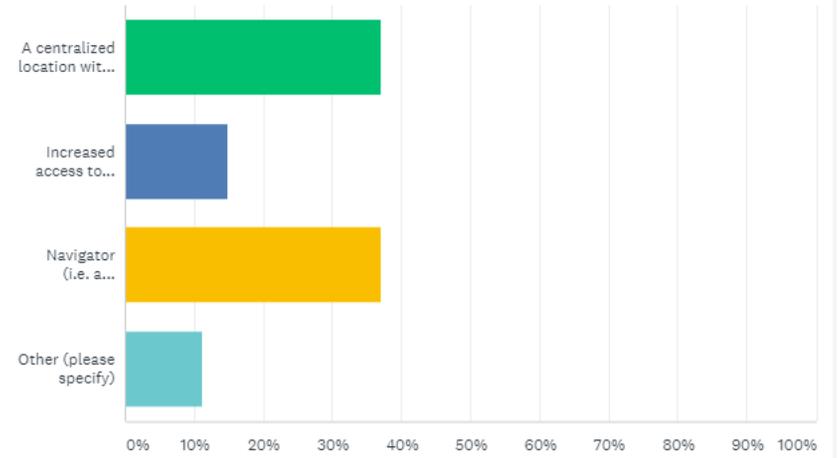
Answered: 27 Skipped: 18



Let's Talk CP & Complex Needs

What would help you in navigating resources in the best way possible?

Answered: 27 Skipped: 18



Let's Talk CP & Complex Needs

Appendix D: Funding resource list

This list of resources is by no means exhaustive, nor is it an endorsement of the services. This list instead represents the information shared by participants, and in particular service providers, at various Let's Talk CP and Complex Needs conversations. It is strongly recommended that anyone looking to this list do further research and speak to other trusted experts on their care team.

Organization/ Initiative	Details	Website/ Contact Information
Access 2 Card	The Access 2 card program helps ensure entertainment, cultural and recreational opportunities are more available to all.	http://access2card.ca/
Assistive Technology - British Columbia	Assistive Technology BC (ATBC) provides assistive technology resources to make learning and working environments usable for people with disabilities throughout British Columbia. In collaboration with persons with disabilities, post-secondary institutions, employers, community organizations, and funding partners, ATBC offers a wide range of individualized, centrally coordinated technology services including assessments, assistive equipment, training, and consultation to enable persons with disabilities to achieve their educational and employment goals.	https://www.at-bc.ca/ 108 - 1750 West 75th Avenue Vancouver B.C. V6P 6G2 Phone: 604 264-8295 Fax: 604 263-2267
At-Home Program - Province of BC	The At Home Program is designed to support children and teens with a severe disability or complex health care needs.	https://www2.gov.bc.ca/gov/content/health/managing-your-health/healthy-women-children/child-behaviour-development/special-needs/complex-health-needs/at-home-program
Autoplan Discount	If you have been approved for the fuel tax rebate under the BC government's Fuel Tax Refund Program for Persons with	http://www.icbc.com/autoplan/costs/Pages/Discounts-and-savings.aspx

	Disabilities, you could also qualify for a 25% discount on your autoplan insurance, even if you don't personally drive the vehicle you insure.	
BC Ferries	BC Ferries provides a variety of services for persons with disabilities to ensure a safe and comfortable journey for passengers. Discount fares are available for residents of British Columbia who have a permanent disability.	https://www.bcferrries.com/travel_planning/disabilities.html
BC Housing	The Rental Assistance Program provides eligible low-income working families with cash assistance to help with their monthly rent payments.	https://www.bchousing.org/housing-assistance/rental-assistance-financial-aid-for-home-modifications/rental-assistance-program
BC Parks	Camping Fees for Persons with Disabilities The purpose of this program is to provide support for persons with disabilities who are also receiving income assistance from the authorities identified.	http://www.env.gov.bc.ca/bcparks/fees/disability.html
Bear Essentials Program	Bear Essentials support is available to help cover: -Travel costs associated with receiving health care that is unavailable in a child/youth's home community (e.g. transportation, parking, food, accommodation) -Medical or therapeutic equipment to address special needs (e.g. Orthotics, insulin pump, specialized seating) -Therapeutic resources to support a child/youth (e.g. Specialized formula, non-insured medications, therapies not publicly offered) Referrals to the Bear Essentials program are accepted from health care professionals.	https://www.helpfilladream.com/bear-essentials/
Cerebral Palsy Association of BC (CPABC)	CPABC is independent charitable organization that provides support, education, and information throughout BC. Their mission is to raise awareness of cerebral palsy in the community; to assist those living with cerebral palsy to reach their maximum potential;	https://www.bccerebralpalsy.com/programs/ Suite 330 – 409 Granville Street Vancouver, British Columbia V6C 1T2

	<p>and to work to see those living with cerebral palsy realize their place as equals in a diverse society.</p> <p>One of their objectives at CPABC is to financially support those with CP. They offer camperships, Jason & Rand Fund, and Educational Bursaries</p>	<p>Phone: 604-408-9484 1-800-663-0004 (toll-free) info@bccerebralpalsy.com</p>
Consumer Discount Card	<p>The Action Committee for People with Disabilities offers a consumer discount card for 4\$ entitling people with disabilities retail service discounts including the following:</p> <p>Cargo Games-Coffee & Tea, Bay Center Food Fair- 10% off coffee, tea, and related items</p> <p>Cordova Hair Boutique Ltd-discount on all products</p> <p>Cook Street Market Place- 10% off all products</p> <p>Orange Julius (Tillicum & Hillside locations)- 10% off food and beverages</p> <p>Esquimalt Optical- 15% off regular prices.</p>	<p>Website: Leisure Assistant's Pass Info Phone: 250-477-6314</p>
Disability Assistance - Province of BC	<p>Disability assistance can help you if you need financial or health support. You must be designated as a Person with Disabilities (PWD) to receive this type of assistance.</p>	<p>https://www2.gov.bc.ca/gov/content/family-social-supports/services-for-people-with-disabilities/disability-assistance</p>
Excise gasoline tax refund	<p>If you have a permanent mobility impairment and cannot safely use public transportation, you can ask for a refund of part of the federal excise tax on the gasoline you buy. A qualified medical practitioner must certify the impairment.</p> <p>For more information, see Form XE8, Application for Refund of Federal Excise Gasoline Tax on Gasoline.</p>	<p>https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/excise-gasoline-tax-refund.html</p>
Gas Tax Rebates	<p>Purchasing fuel in BC means you are paying fuel tax as well. The Ministry of Finance offers a fuel tax rebate for persons with disabilities. The amount of a rebate you can receive depends on the type of fuel your vehicle uses – see the tax rates here.</p> <p>18 cents returned per litre</p>	<p>Information on how to apply for the rebate here. General information on BC's fuel taxes here.</p>

	you must keep receipts to receive the rebate. but the first year doesn't require this average person gets \$200 a year	There is also a federal rebate, but it's not worth the time investment as it only returns 1.5 cents per litre. See here for details.
Government of BC Bus Pass Program	Low-income seniors and Persons with Disabilities (PWDs) have access to the BC Bus Pass Program. A BC Bus Pass is a Compass Card pass that can be used on both BC Transit and TransLink systems throughout the province.	https://www2.gov.bc.ca/gov/content/transportation/passenger-travel/buses-taxis-limos/bus-pass
Government of Canada Disability Tax Credit	The disability tax credit (DTC) is a non-refundable tax credit that helps persons with disabilities or their supporting persons reduce the amount of income tax they may have to pay. An individual may claim the disability amount once they are eligible for the DTC.	https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html
Help Fill A Dream	Help Fill A Dream Foundation often comes into the life of a family when things are at their worst. When a child is diagnosed with a life-threatening condition a family's focus becomes their child, their medical appointments and treatment; there's no time for anything else. Since 1982 Help Fill a Dream Foundation has been supporting those families from Vancouver Island and the Gulf Islands whose lives have suddenly changed due to their child's diagnosis with a medical condition or severe health challenge.	https://www.helpfilladream.com/
Leisure Assistant's Pass	Recreation Integration Victoria (R.I.V) offers a Leisure Assistant's Pass that provides free and discounted rates for a leisure assistant at various locations.	http://www.rivonline.org/LA%20Pass%20Cover%20Sheet.pdf
Medical Travel Assistance Travel Assistance Program (TAP)	TAP is available to eligible B.C. residents who are required to travel outside their home community to obtain non-emergency, physician-referred specialist medical care. For more information and to find out if you are eligible, see: Travel Assistance Program	https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/transportation/medical-travel-assistance

Registered Disability Savings Plan	A registered disability savings plan (RDSP) is a savings plan that is intended to help parents and others save for the long-term financial security of a person who is eligible for the disability tax credit (DTC).	https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/registered-disability-savings-plan-rdsp.html
Specially Equipped Motor Vehicle Rebate	Complete this form to claim a specially equipped motor vehicle rebate if you paid GST/HST on the purchase of a qualifying motor vehicle, a modification service performed on your motor vehicle, the importation of a qualifying motor vehicle, or the bringing of a qualifying motor vehicle into a participating province from a non-participating province.	Website: GST/HST Specially Equipped Motor Vehicle Rebate Application
Student Aid BC	This program helps students with permanent disabilities pay for exceptional education-related services and adaptive equipment. Depending on your need, grants of up to \$10,000 (\$12,000 if an attendant is required at school) are available to students attending public and private post-secondary schools in B.C.	https://studentaidbc.ca/explore/grants-scholarships/assistance-program-students-permanent-disabilities
Student Aid BC	B.C. supplemental bursary for students with a permanent disability \$800 bursary is available if you: qualify for Canada student grant for persons with permanent disabilities are studying at a course load of 40% or greater. \$400 bursary is available if you: qualify for Canada student grant for persons with permanent disabilities are studying at a course load of 20% to 39% .	https://studentaidbc.ca/explore/grants-scholarships/bc-supplemental-bursary-students-permanent-disability
TaxiSavers	This program allows you to buy TaxiSaver coupons by mail or through the TransLink FareDealer office to save 50 per cent on the cost of taxi fares.	

Translink	HandyCard customers can now use an orange Concession Compass Card to pay for travel on bus, SkyTrain, SeaBus, and West Coast Express.	https://www.translink.ca/Rider-Guide/Accessible-Transit/HandyCard.aspx
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Appendix E: Crowdsourced programs and services resource list

Similarly to the funding resource list, this list of resources is by no means exhaustive, nor is it an endorsement of the services. It represents information shared by participants, at various Let's Talk CP and Complex Needs conversations and via the online collection of information. It is strongly recommended that anyone looking to this list do further research and speak to other trusted experts on their care team.

Organization/ Initiative	Details	Website/ Contact Information
Access RDSP	The Registered Disability Savings Plan is a Canada-wide registered matched savings plan specifically for people living with disabilities.	http://www.rdsp.com/2017/02/06/access-rdsp-partnership/
Angel Accessibility (HandiCare)	Handicare has passion for solving mobility issues. Founded in 1986 by three men who met in a rehabilitation center, Handicare was born out of a drive for innovation and finding a better way. today. With mobility solutions for the hospital and the home, they have a complete line of ceiling and floor lifts, slings, manual transfer and bathroom safety aids.	https://www.handicare.ca/
Bear Essentials program	The Bear Essentials Program helps families cover unexpected or extraordinary expenses related to their child's health and special needs, especially families whose needs fall between the cracks of other available programs and/or are of an urgent need.	https://nanaimocdc.com/files/8314/3015/6618/bear_essentials_form_2014.pdf
BC Family Hearing Resource Society	BC Family Hearing Resource Society is the largest not-for-profit organization in British Columbia serving children who are deaf and hard-of-hearing, aged birth to school-entry. For 35 years, we have been providing intervention, support, education, sign language instruction and peer-to-peer mentoring to families throughout the province.	http://www.bcfamilyhearing.com/

BC Family Residence Program	The BC Family Residence Program provides accommodation assistance to enable families to stay together when their child requires medical care at BC Children's Hospital or Sunny Hill Health Centre for Children, including premature babies and newborns with other health concerns. Enhanced travel assistance is also provided through air transportation for patients of all ages.	https://www2.gov.bc.ca/gov/content/health/accessing-health-care/tap-bc/bc-family-residence-program
BCAA Child Passenger Car Seat Safety	BCAA Community Child Car Seat Program provides child car seats to eligible non-profit agencies and community groups throughout BC.	https://www.bcaa.com/community/child-car-seat-safety
Be my eyes for visually impaired	Be My Eyes is a free app that connects blind and low vision people with sighted volunteers and company representatives for visual assistance through a live video call.	https://www.bemyeyes.com/
Canadian Associate Schools of Karate-Do	CASK runs beginner, intermediate, and black belt programs year-round, with students receiving a chance to compete nationally and abroad. The style of Karate taught is Wado, which is one of the four largest styles of karate in the world.	https://www.caskkarate.ca/
CECIL - Independent Living	Choice in Supports for Independent Living (CSIL) is a self-directed option for eligible home support clients. CSIL clients receive funds directly from their local health authority to purchase their own home support services. Clients become employers who manage all aspects of their home support, from hiring and supervising staff to overseeing how CSIL funds are spent.	https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/choice-in-supports-for-independent-living
Cerebral Palsy Alliance	Cerebral Palsy Alliance help babies, children, teenagers and adults living with cerebral palsy and other neurological and physical disabilities lead the most comfortable, independent and inclusive lives possible.	https://www.cerebralpalsy.org.au/
Cerebral Palsy Association of BC	The Cerebral Palsy Association of British Columbia (CPABC) was started in 1954 by a group of parents who wanted to assist their children living with cerebral palsy to reach their maximum potential	https://www.bccerebralpalsy.com/

	<p>within society. They provide support, education, and information throughout BC.</p> <p>One of their programs is <i>Movement Without Limits</i> gets people with disabilities active and highlights their ability through the Alinker. The Alinker is a 3-wheeled walking bike that is designed to help people stay active without sacrificing comfort, style or safety.</p>	
Community living Victoria	<p>Community Living Victoria supports people with intellectual disabilities together with their families, support networks and community by promoting their full citizenship.</p> <p>One of their programs is Victoria Opportunities for Community Youth Leaderships (VOCYL). VOCYL's philosophy is that everyone has a right to belong – no matter their race, gender, size, age, sexual orientation or ability. VOCYL members come from diverse backgrounds and abilities, and include those with and without developmental disabilities. Yet they have a common desire to share their knowledge and advocate for change in their local high schools and communities. They meet bi-weekly and have many opportunities to get to know new people and participate in worthwhile events.</p>	http://www.communitylivingvictoria.ca/
Community Options for Children and Families	<p>They provide quality support services and information to people with disabilities and their families within their communities.</p>	http://communityoptions.bc.ca/
Disabled Sailing Association of BC: Victoria Branch	<p>The Disabled Sailing Association of BC, Victoria Branch was incorporated as a Branch of the Disabled Sailing Association of BC in 1994. DSABC Victoria provides people with disabilities liberating experiences of recreational and instructional sailing opportunities to people with disabilities.</p>	http://rivonline.org/about#dsavic

Facebook Support Group	This private group chat on Facebook provides a platform for peer-to-peer online information sharing. Contact the group's facilitators via email to join.	BCComplexkids@gmail.com
Family Support Institute of BC	Family Support Institute of BC is to strengthen, connect and build communities and resources with families of people with disabilities in BC. They believe that families are the best resource available to support one another. Directed by families, the Family Support Institute provides information, training, and province-wide networking to assist families and their communities to build upon and share their strengths.	https://familysupportbc.com/
Familysmart.ca	FamilySmart™ was founded as a provincial organization to provide families with an opportunity to speak with other families who understand and can offer support and/or information on services they know about and/or have accessed. They developed tools and resources to assist both families and professionals supporting and assisting children and youth experiencing mental health challenges.	http://www.familysmart.ca/
Hope Air	Hope Air helps make Canada's universal healthcare accessible by bridging the distance between home and hospital, patient and physician.	https://hopeair.ca/
HUGR - web app for mental health	Hugr is built from our collective experience with anxiety, depression, and bipolar along with our research and is not a replacement for professional medical care.	https://hugr.ca/
Independent Living Housing Society	The Independent Living Society of Greater Victoria is a non-profit society that has been offering inclusive housing options for over forty years. ILHS supports adults with diverse abilities to live independently in a variety of accessible settings throughout greater Victoria, promoting the belief that "good living starts with home."	http://ilhs.ca/

Jordan's Principal	Jordan's Principle makes sure all First Nations children can access the products, services and supports they need, when they need them. It can help with a wide range of health, social and educational needs.	https://www.canada.ca/en/indigeno-us-services-canada/services/jordans-principle.html
LAVA app	Born out of the Recreation Integration Victoria, the LAVA website was conceived in order to increase availability of information pertaining to the access of recreation facilities in the Victoria area. It will highlight information on accessibility features by including pictures, videos and descriptions about the facilities in the hopes of increasing the physical activity of individuals with disabilities in Victoria. The LAVA website is available to use by anyone who has an interest in attending a local Recreation or Community Centre in the Capital Regional District.	http://rivlava.ca/
Medical ID iPhone app	Your Medical ID provides medical information about you that may be important in an emergency, like allergies and medical conditions as well as who to contact in case of an emergency. You can create your Medical ID in the Health app that can be accessed without unlocking your iPhone.	https://support.apple.com/en-ca/HT207021
Meetups.com	Getting together with real people in real life makes powerful things happen. Meetup brings people together to create thriving communities.	https://www.meetup.com/
Neurological Wellness Association (NWA)	Neurological Wellness Association (NWA) is an organization in British Columbia and Alberta to help as many people as possible by providing funding for health services that are not paid for by our government.	https://www.wellnessassociation.org/
Ontracbc.ca	This resource helps with the transition to adult care is to support youth with special health care needs and their families or caregivers to gain the confidence, skills and knowledge to be ready to enter the adult health care system.	http://www.bcchildrens.ca/our-services/support-services/transition-to-adult-care

Pacific Institute Sport Excellence (PISE)	PISE is a non-profit supporting your health and wellness through state-of-the-art facilities, programs, education and services – accessible to all of our community members and all of their abilities.	http://www.pise.ca/
PLAN Institute for Caring Citizenship	Their mission is to improve the lives of people with disabilities and their families so that they can lead a good life now and in the future.	http://planinstitute.ca/
Power to Be Adventure Therapy Society	<i>Power To Be</i> began with a simple idea: help youth and families living with a barrier or disability access nature. Led by an inspiring team whose diverse backgrounds make our award-winning programs possible, they have enriched the lives of more than 10,000 people.	https://powertobe.ca/
Recreation Integration Victoria	Recreation Integration Victoria is a service that has a vision for all people with disabilities to have equal opportunities to participate in in community	http://rivonline.org/
Regional Resources for Adults with Disabilities	A program that promotes the abilities and independence of adults with complex neurological or multi system disabilities by providing a range of specialized interventions and services that are: client directed, coordinated, time-limited, and integrated. Services are provided to clients living in the South Vancouver Island Health Authority catchment areas; consultation is provided to Central and North Island.	https://sci-bc-database.ca/wp-content/uploads/2012/12/Regional-Resource-for-Adults-with-Disabilities-Victoria.pdf
Rick Hansen Foundation	The Rick Hansen Foundation provides programs and initiatives work to create an accessible and inclusive world where people with disabilities can live to their full potential. One of their programs is Let's Play, which encourages children with disabilities to be active.	https://www.rickhansen.com/
Rick Hansen Institute	The Rick Hansen Institute is a Canadian-based not-for-profit organization that drives innovation in spinal cord injury research and care. They strive to improve the lives of people living with SCI in Canada and around the world.	http://rickhanseninstitute.org/
Self Management BC	These programs give people the knowledge, skills and confidence needed to successfully manage chronic health conditions	http://www.selfmanagementbc.ca/

SLACK business program	Slack brings all your communication together within a single place for messaging, tools, and files, helping everyone save time and collaborate.	https://slack.com/
South Island Child	South Island Child is the online home of the Victoria, Peninsula, and Sooke and Westshore Early Years Centres. This website aims to connect parents, caregivers and service providers on Southern Vancouver Island with tools and resources to help children get the best possible start in life.	https://southislandchild.ca/
Sunnyhill Positioning Mobility	The team sees children with disabilities who require special equipment to sit, stand or move.	http://www.bcchildrens.ca/our-services/sunny-hill-health-centre/our-services/positioning-mobility
SUP4ALL	SUP4ALL is a social-impact project that provides a service to empower people living with disabilities to embrace and explore the outdoors. They specialize in paddling adventures for people of all abilities. They believe that adaptive outdoor recreation improves quality of life by bringing communities together and connecting individuals with nature.	https://sup4all.ca/
Teen Works	TeenWork is an innovative youth employment program from CanAssist at the University of Victoria. The program is designed to help youth with disabilities and mental health challenges find and retain meaningful, part-time paid employment while attending high school. TeenWork was developed with the aim of filling a gap in the employment field for youth with disabilities as they near the transition to adulthood.	https://www.canassist.ca/EN/main/teenwork.html
The LifeSkills Centre	The LifeSkills Centre Inc. has been providing person-centred services that facilitate people living with disabilities to develop the necessary skills that will open the door to new life possibilities. These possibilities include personal independence in their homes,	http://lifeskillscentre.ca/

	possible employment and volunteer opportunities, and most importantly a positive self-image.	
Travel Assistance Program	The Travel Assistance Program (TAP) helps alleviate some of the transportation costs for eligible B.C. residents who must travel within the province for non-emergency medical specialist services not available in their own community.	https://www2.gov.bc.ca/gov/content/health/accessing-health-care/tap-bc/travel-assistance-program-tap-bc
Tyee Aquatics Para Swimming	Tyee Aquatic Club boasts Vancouver Island's only dedicated Para Swimming Program, with the goal of providing both competitive and recreational opportunities for individuals with physical and intellectual disabilities.	https://tyeeaquaticclub.com/para/
Victoria Disability Resource Centre	Victoria Disability Resource Centre (VDRC) is a cross-disability, grassroots, not-for-profit organization run by and for persons with disabilities. They work closely with people who have a disability and with community organizations to find and remove barriers that prevent full participation in life.	http://drcvictoria.com/
World CP Day	World Cerebral Palsy Day is a movement of people with cerebral palsy and their families, and the organizations that support them, in more than 65 countries. Their vision is to ensure that children and adults with cerebral palsy (CP) have the same rights, access and opportunities as anyone else in our society. It is only together, that we can make that happen.	https://worldcpday.org/

Appendix F: Discussion questions

Note, these questions would evolve based on the conversations. Exact questions may not have been asked and/or probing questions may have followed that are not noted below. However, this gives a sense of the questions asked.

Nanaimo Focus Group: 18 June 2018

Medical/Supports

1. Where do children/youth receive medical attention?
2. Are children/youth able to access mobility aids they require?
3. What are barriers and/or system limits?
4. What types of supports are needed by families in period immediately after diagnosis?
5. What mental health support gaps exist? What would you like to see?
6. Do you think your experience would have been different if your child had been diagnosed as a baby?

Health Well-being of a Family

1. How does the family unit get support? What's missing?
2. Where do parents/guardians go for support? (Advice, morale, respite, financial aid, system navigation, etc.)
3. What resources do you lean on and love?

Programs & Services

1. What services/supports are children/youth accessing in their communities?
2. What are pinch points in the pathway?
3. Are there adequate services/programs in your community to serve your specific needs?

Disability Supports

1. As a youth living with a disability, where do you go for moral support? (Advice, mentor, respite, etc.)
2. Given the chance to dream, what would the pathway look like? In early years? In middle years? In transition years? In times of crisis?
3. What resources would you like to see in your community as a youth?

Public Awareness/ Education

1. What are some of the public education and awareness opportunities? What needs to happen to heighten awareness?

Independence/Life Transitions

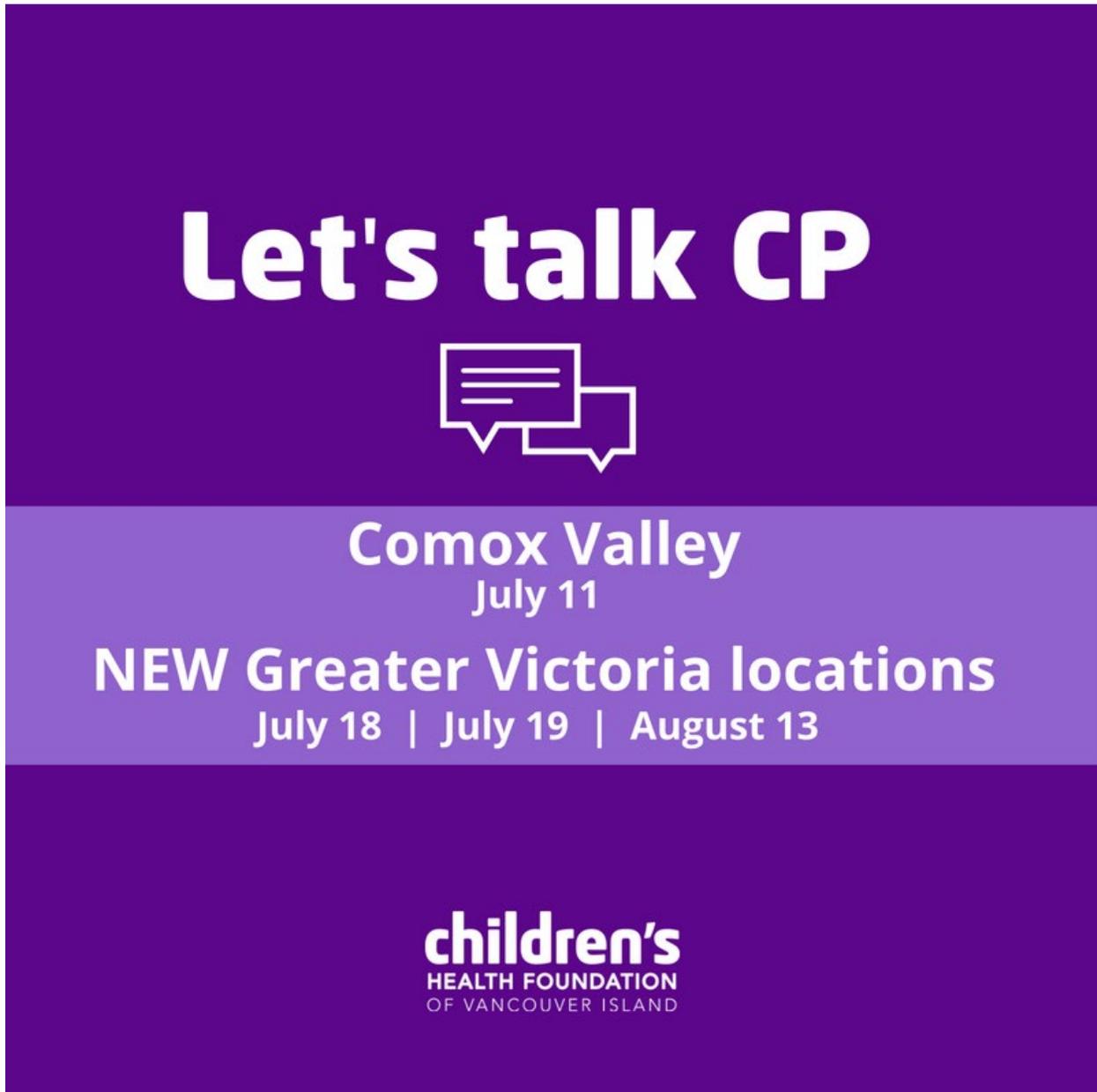
1. What supports are necessary for you to make important life transitions (elementary-high school, high school – independence, post-secondary)?
2. What would help you to become more independent and have the necessary supports in place?
3. What would help you in navigating your community in the best way possible?
4. What's working really well in the community for their care and quality of life?

Some of the proposed questions that may be used for the children/youth only focus group are as follows:

1. What are some strategies you have used through your life to live with your disability?
2. Where do you get your support (moral, emotional, etc.)?
3. Do you have a mentor? If so, who?
4. How do you present yourself among your peers (with or without an identified disability)?
5. How do you explain your disability to others?
6. What service/ support is missing that would help support you in living with a disability?

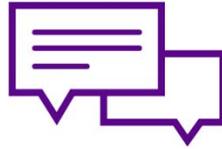
Appendix G: Promotional materials

Samples of posters created and distributed through advisory committee members, social media and a wide distribution list.



Let's talk CP

Be a champion to improve local support and access.



The Children's Health Foundation of Vancouver Island is hosting discussion groups across Vancouver Island to explore how it can continue to play a supportive role in the lives of children and youth living with cerebral palsy and other medical conditions.

WEDNESDAY 11 JULY 2018

4 - 7pm

North Island College, Comox Valley Campus

Puntledge Building, Room 121

2300 Ryan Road, Courtenay BC

Free parking in lots A and B including accessible parking

Who should participate?

Youth, parents/guardians, caretakers, and service providers with experience in children and youth living with cerebral palsy on
_____ Vancouver Island.

All participants will receive an honorarium in recognition of their time and commitment. Barriers to participation (travel, childcare, etc.) may be reduced. Please ask us. Refreshments will be provided.

**Please RSVP by Monday 9 July by contacting Karen Lai
604-889-7961 | karen.lai@telus.net**

children's
HEALTH FOUNDATION
OF VANCOUVER ISLAND

Appendix H: Sample agenda



Let's talk CP

WEDNESDAY 11 JULY 2018
4 - 7pm
North Island College 2300 Ryan Road.
Puntledge Building, Room 121

- 4:00 – 4:20 Welcome
- Background of the Project
 - Land Acknowledgements
 - Introductions
- 4:20 – 5:15 Breakout sessions
- Medical Services
 - Health Well-being of family
 - Programs and Services
- 5:15 – 5:45 Refreshment Break
- 5:45– 6:30 Breakout Session
- Education/Promotion
 - Independence/Life transition
- 6:30 - 6:45 Closing Discussion
(ie. emerging questions/concerns/inspirations)
- 6:45 - 7:00 Graphic "Gallery Walk" Review & Feedback

