

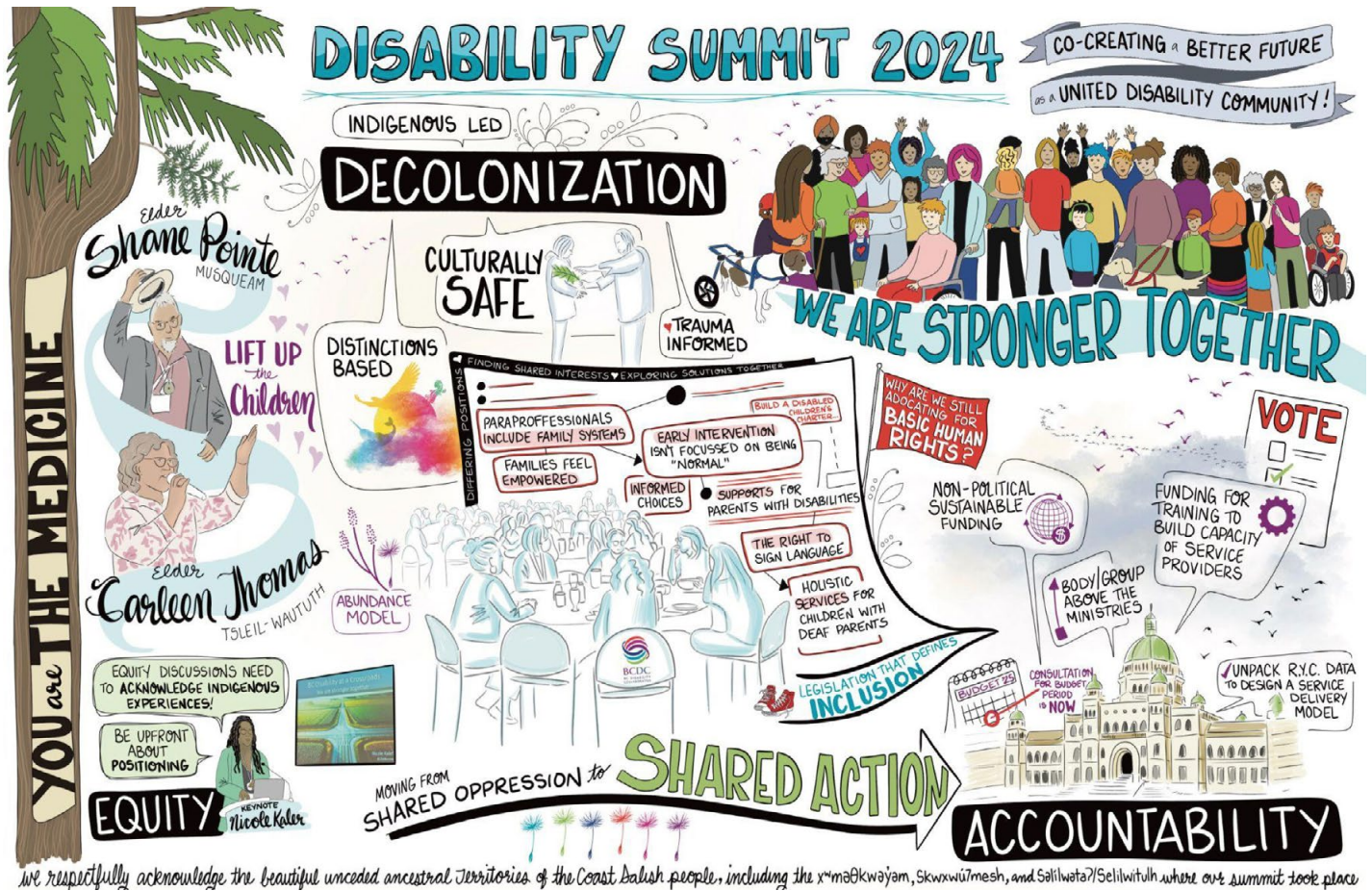
A FAMILY- DRIVEN MODEL OF CARE

**Setting the table for
disability rights in BC**

Report from the 2024 BC Disability Summit



BCDC
BC DISABILITY
COLLABORATIVE



We respectfully acknowledge the beautiful unceded ancestral Territories of the Coast Salish people, including the x'ma8kwajam, Skwxwizmesh, and Sellwata/Sellwutlh where our summit took place

INTRODUCTION

IN JUNE 2024, 77 participants from 43 provincial organizations that represent children and youth with disabilities (CYD) came together in person for the first ever **BC Disability Summit**. The Summit was co-sponsored by the BC Disability Collaborative (BCDC) and the Office of the Representative for Children and Youth. The agenda for the 2-day Summit and a list of the organizations that registered to attend are available in the Appendix to this document.

We came together, stirred by a clear sense that the current system is not serving the needs of the CYD we support. We all share a belief that through collaboration, even across our differences, we can find new ideas and take real actions towards measurable change. We came with two main questions:

- **What do we need?** As the united disability community in BC, starting with a focus on children and youth, how do we clearly articulate our shared needs?
- **How will we get what we need?** What actions can we commit to taking in order to ensure these needs are met?

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Throughout two days of robust learning and dialogue, we attempted to answer those questions, as reflected in this document. To put it simply, we need **a new family-driven care model** — one that truly puts disabled children, youth, and their families at the centre.

The vision described in this document was co-designed by members of the disability community who attended the Summit. This co-design is worth noticing, as it is remarkable in itself:

- We convened of our own initiative; we do not otherwise work together in the same organization, which required bridge-building.
- We gathered despite obstacles and barriers that were placed in our way by the system that we seek to change, which took perseverance.
- We have compiled this document, believing that change is possible, despite the challenges our members continue to face, which took vision, grace, and creativity.

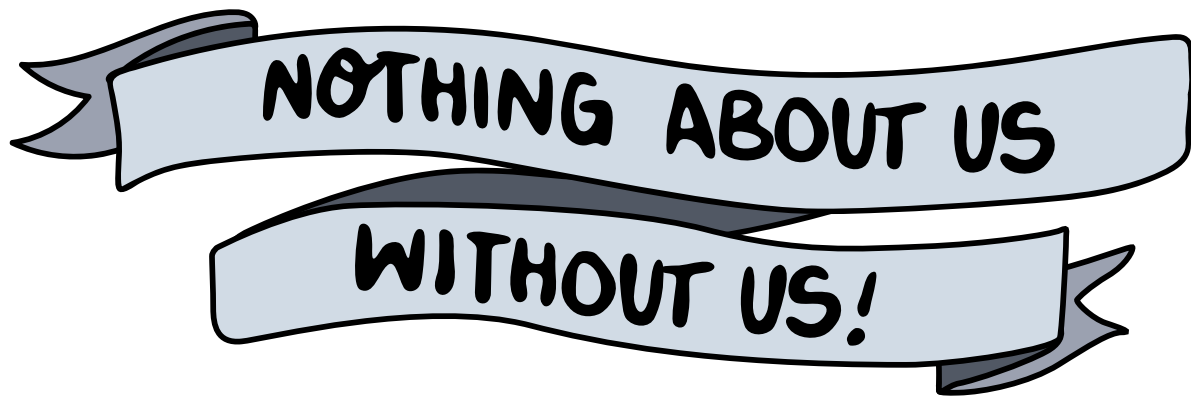
Why have we done this? It is **not** because we thought these would be “nice-to-have” tweaks to a fractured and dysfunctional system, if government, at some year down the road, were to feel generous. Rather, these are clear-minded and coherent articulations from some of the province’s most marginalized citizens, asking government to fulfill its legal duties in response to daily experiences within an extremely challenging system. We encourage you to read it with this in mind.

Why Change is Needed (and Needed Now)

- The current system is **grossly underfunded**. Because current funding limits the availability of services and supports, most young children with disabilities wait several months to access essential speech-language, occupational, and physical therapy services that are essential for early skill development. Most children over age 6 cannot access these therapies at all and have minimal or no access to social and life skills supports. Respite care, mental health services, and medical supports to families are similarly underfunded and difficult to access.

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- The current system is **discriminatory**. When viewed through the lens of the daily experiences of people with disabilities, we believe that the system is in violation of the Canadian Charter of Rights and Freedoms as well as the United Nations Convention on the Rights of Persons with Disabilities.
- The current system is **trauma-inducing**: Eligibility for disability services from key Ministries (Education and Child Care, Health, and Children and Family Development) requires parents to focus on their child's deficits in order to convince decision-makers that they are "disabled enough" to "deserve" support. Furthermore, the Ministry for Children and Family Development (MCFD) has twin mandates related to (1) child protection and (2) disability supports. Many families, especially those with Indigenous and/or intersectional identities, view MCFD from a child protection lens and are reluctant to access disability supports. In combination, these policies illustrate how a legacy of trauma and pain is intertwined with service delivery functions.
- The current system is **inequitable**: Disability services and supports are entirely dependent on a child or youth having the "right" diagnosis (for example, autism or medical complexity) and living in a place where the "right" services are readily available. Partly as a result, among the more than 1,000 families responding to a 2023 survey by the Representative for Children and Youth (*Still Left Out*), 14% said they considered placing their child/youth in care to get the services they need and deserve. Service availability based on diagnosis and location is inherently inequitable and induces additional trauma.
- The current system is **fragmented** and **difficult to navigate**. Between the siloed Ministries of Education and Child Care, Health, Children and Family Development, and others, there are many gaps, resulting in missed opportunities for collaboration and oversight. A system of siloes is reflective of deeply embedded colonialism and does not serve people well.
- The current system **leaves many kids out**: Currently, more than 80,000 BC children with disabilities are ineligible for services (*Still Left Out*, 2023). For their entire childhoods, these children and youth have not received relevant care for their unique disabilities, and as a result, they will become adults without having the supports that would enable them to thrive. The number of children who do not receive the supports they require continues to grow each year.



If you are a person in government, please see this as your reference point for the types of change our community needs and seeks. This change is yours to co-create with us, reflecting the disability community’s Call to Action: “Nothing about us without us.”

If you are a member of the public without living experience with disability, remember that we are all connected. This is not just a “disability” issue — this is a societal invitation. “The test of a civilization,” wrote Pearl Buck, “is the way that it cares for its helpless [sic] members.” **But we are far from helpless** — we are simply **helped-less**. Let us raise our standard of care in this province so it is not only the “able” who benefit.

If you or a family member experience life with a disability— if you are a child, youth, or family member with support needs, as today’s wording goes — this document is for you. Let us continue to unite our voices. Let us move into action. Join us in our movement to seek change. The change needs to happen **quickly** because kids today are not being served. Change also needs to be **long-lasting**, because generations ahead of us will continue to need these types of supports.



THE VISION

We call for a new family-driven care model for people with disabilities in BC, based on continuing and full engagement with families, with a focus on empowerment.

We visualize this model as a round table — a table with no head and no tail, but one that is joined in connection and represents hospitality and family, with a spirit of welcome and nurturing care. Just as the family dining table, at its best, serves the family, so too must this new model: a just, co-created model of care that is carefully developed to serve people with disabilities and their families.

We come to the Table with shared **values**:

- **Potential-based:** Seeing people as whole, human, and full of possibility, rather than deficit-based
- **Abundance mindset:** Assuming that a system can be designed to meet needs in a fulsome way, when sufficient resources are allocated
- **Decolonized:** No longer built on colonial, top-down authoritative approaches to knowledge exchange and decision-making
- **Trauma-informed:** Meeting people in the midst of real, living experiences, approaching them with a support mindset, and understanding the impact of diverse and complex facets of trauma

- **Culturally safe:** Tending to each individual's and each community's unique cultural needs.

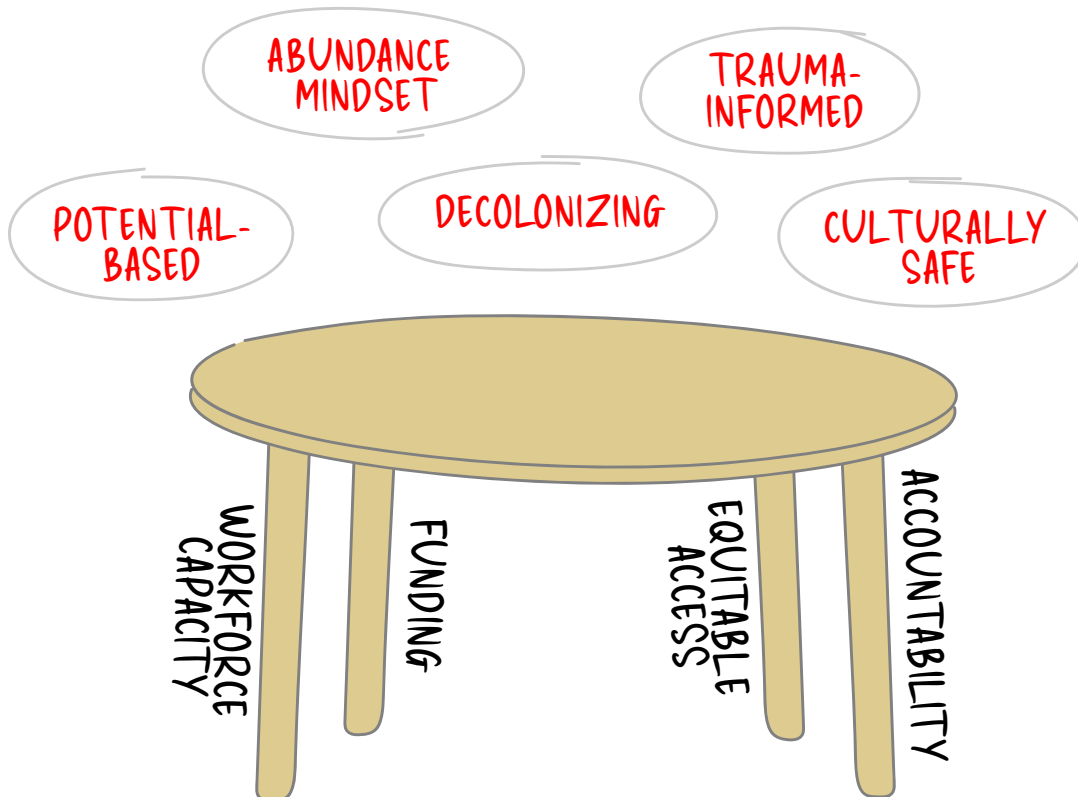
This care model needs the **solid and shared support** of:

- **Sustained, adequate, & appropriate funding:** Appropriate financial support for services that meet evidence-based standards related to quality, intensity, and duration
- **Quality care, including capacity-building:** A workforce of adequate size and training that can accommodate the needs of disabled children, youth, and their families in a timely and responsive manner
- **Equitable access:** Services that are needs-based, not diagnosis-based and provide choices of service options for families
- **Accountability:** A province-wide feedback mechanism for ensuring each element of the system is achieving its intended outcomes



The image below is a visualization of how we see the model. The Table represents the family-driven model of care. The shared values are how each of the parties show up for each other, and the legs are the solid supports that make it last.

A FAMILY-DRIVEN MODEL OF CARE



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VALUES: How We Come to the Table

How we come to the table matters – this is our way of being with each other. A culture of negativity, competition, distrust, disrespect and threat will not enable us to achieve our goals. Rather, we are choosing to step into a new way of being. These are the values of those of us who engage the system and are also how we are appealing to the service delivery system to act and respond.

- **It's about potential, not deficits.** While the “medical model” of disability focuses on deficits and pathologies, we see each other's inherent worth. We ask that the system does, too. We are human beings in our fullness, to be given what each of us requires in order to achieve our potential — we are not problems to be solved.
- **Look for abundance, not scarcity.** As we envision a new model of care, we need to shift our mindset from focusing on what's broken and missing to what's possible. We need to become believers in what is yet to be created.
- **It's about decolonization:** Colonialization has led to cultural alienation, intergenerational trauma, systemic discrimination, territorial dispossession, and socioeconomic marginalization (Government of Canada, Department of Justice). Colonial structures and habits have influenced healthcare, child and family services, education, and the structures propping up these systems. Inherently, colonial structures force out and isolate Indigenous peoples, communities, families, and individuals. When we **decolonize**, we find a heart that is authentically connected to “all our relations.” This interconnectedness needs to be honoured. As Indigenous people have long known, we need to centre people, place, and culture to ensure community well-being. We will not accept colonial defaults that value hierarchy, mechanization, and dehumanization. We seek the re-humanization and reconnection of the whole.
- **Be trauma-informed:** Pain and suffering have been the defaults for those living with disability and their families, navigating and interacting within a system that doesn't seem to care – a system that is meant to help but that often causes harm. Intentional or not, unintended harm is still harm. While potential exists, while humanity is always present, the barriers faced by people with disabilities have been great. The pathway to healing means exposing the truth and acknowledging the harm and, as we go about the work of rebuilding this table of care, we must ensure we incorporate each other's needs.

- **Be culturally safe:** Too often, connecting with services has required shifting into the language, practices, methods, and modes preferred by a dominant, ableist culture. This can take the shape of impersonal bureaucracy, corporate values, or — worse — harmful practices, especially for newcomers to Canada. In contrast, our vision endeavours to learn and respect the needs of the diverse cultures of those who interact with the system by systemically building supports and using safe language as part of the foundation.

SUPPORTS: What Holds Up the Table

This care model needs to be supported by:

1. **Funding:** Adequate and sustainable funding is needed.
 - **A transparent, community-designed model:** Without adequate funding, no system can function -- regardless of how it is designed and where in government it is situated. This requires a transparent funding formula, co-developed with communities and Indigenous partners and based on current data and/or data-based estimates about the number of CYD in BC.
 - **Adequate, protected funding:** Sustained, adequate funding means funding that is protected from political whims, is referenced against the cost of living and inflation, and adapts in relation to the number of CYD in need as well as the nature of their needs.
2. **Quality care, including capacity-building:** This includes increasing the workforce, investing in staff training, and strengthening family capacity.
 - **An increased workforce:** There is a critical shortage of clinical and support staff who are qualified to provide effective services to CYD and their families. Both short- and long-term investments in recruitment, training, and retention are required to resolve this shortage within a trauma-formed lens of care intersected with culture.
 - **A qualified workforce:** Beyond numbers, specific training and development is needed for those providing the services so that they are equipped to deliver effective services aligned with the values of this model. In addition to service providers within the MCFD system, professionals in many public institutions — school, medical facilities, community centres, and more — also require training and support to meet the needs of CYD. Adequate funding that supports ongoing access to such training is essential across systems.

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- **Family capacity:** We envision training that extends to the entire family system — parents, aunts, uncles, and extended family members — in order to strengthen the informal systems of support where life is lived.
- 3. Equitable access:** The system must be designed to serve the entire province — with rural, remote, and urban access — with special consideration for people with accessibility barriers. BC is a large province, yet services are clustered primarily in Metro Vancouver. This means that people living in rural, remote or Indigenous communities do not have access to many of the services that those living in Metro Vancouver take for granted. CYD who are in need of specialized assessment and support are most disadvantaged, with their families either being forced to relocate, or endure expensive, lengthy, challenging journeys (e.g., 20-hour drives, disrupted family schedules) that are often not achievable. Where one lives should not determine whether they live or thrive.
- 4. Accountability:** The system must be held accountable toward its aims in order to ensure that the needs of people with disabilities, their families, and their family cultures, are always at the center.
- **Accountable government:** We envision a body or group with an overarching lens that holds individual ministries accountable and is resistant to political changes. There is long-term work to be done, and it requires continuity and long-term follow-through.
 - **Uplifting of families and communities:** Uplifting of families and communities needs to be seen as the ultimate measure of success. The question should *not* be, “How well is the system functioning?” but “How well are communities able to act on their love and care for their family members?”



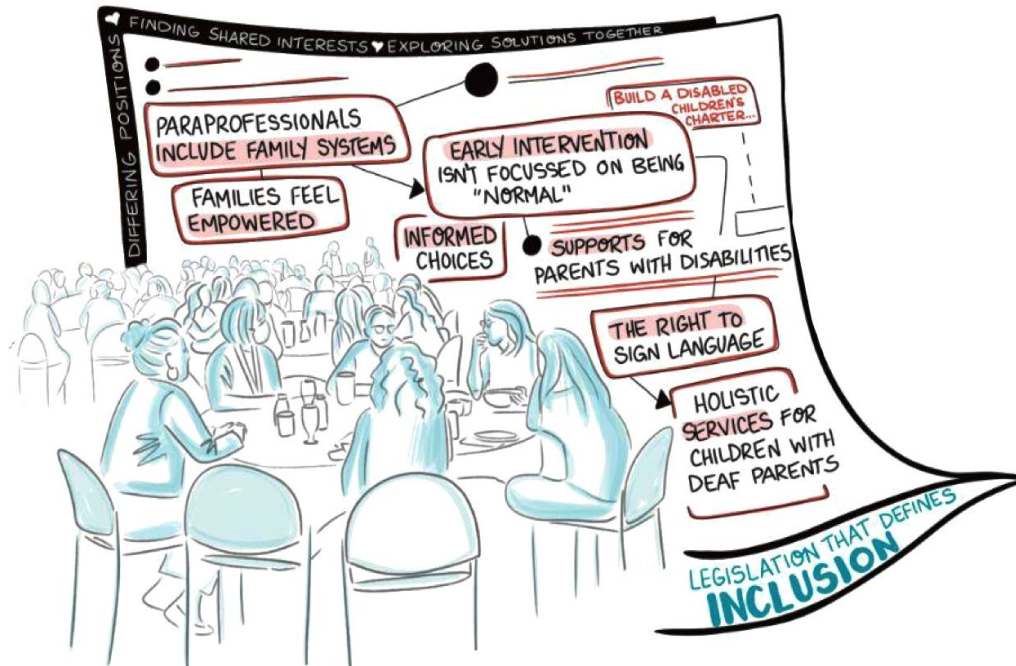
ACTION PLAN

How We'll Pursue the Vision

The BCDC is committed as a collaborative to moving this vision forward. Our participants have formed task forces and committees to pursue the following actions, in support of the vision:

- Establish a **government relations and legislation** affairs team
- Participate in **service delivery & design**, to co-design a new model
- Launch a **human rights initiative**, to advocate for disability justice
- **Develop communications & publicity campaigns**, to shift public opinion and raise awareness
- Strengthen connections with the **disability community by continuing to gather & share stories**

The sections that follow offer more detail on these key steps.



1. Create a government relations and legislation working group

Recognizing that the current and future leaders of BC will be responsible for making changes to better serve the disability community, the BCDC aims to invest in relationship-building and knowledge-sharing to support these efforts. We aim to bring mutual respect, make space, and celebrate wins as we go about engaging government. Here is what we are planning:

- **Creation of a draft statement** to provide to the government of BC. This will be shaped by members of the BCDC and the organizations who participated at the Summit, providing the government with a clearly-stated point of view – this document is part of that effort.
- **Create a legislation working group:** The BCDC will establish a legislative working group with diverse representation, incorporating input from various disability rights frameworks (such as the World Federation of the Deaf’s Declaration on the Rights of Deaf Children). We have already initiated this work by providing feedback about the draft Accessible Service Delivery Standard and the draft Employment Accessibility Standard under the Accessible British Columbia Act (ABCA). Our overarching goal is to develop concrete recommendations for legislation change.

2. Participate in service delivery & design, to co-design a new model of service delivery.

Through the Office of the Representative for Children and Youth, Ministry of Children and Family Development, Ministry of Health, and the Ministry of Education and Child Care, the BCDC has access to disability prevalence, funding, and other relevant information. By utilizing this data, and leveraging the subject matter expertise within its network, BCDC will assemble a collection of experts to help design a **service delivery model**. It will take into account:

- **What's working today:** Various infrastructures and programs are already working in individual communities (e.g., child development centres, and, for some families, direct/individualized funding). Our goal is to build upon these existing programs across the province, to create a hybrid model rather than replacing them. At the same time, the current community-based model of support is not preferred by and does not work for all families. We envision a hybrid model that combines direct funding and community-based supports
- **Designing *with* families and communities:** The collaborative design of a new model will involve close engagement with families currently living with disability, ensuring that their input shapes the future direction.
- **Engaging the workforce:** When considering the professionals serving the disability community, how can these professionals contribute to defining the needs, services, and training plans for the new model?
- **Procurement and service provision:** The procurement process for serving the disability community is severely flawed and causes significant dysfunction. We will work to co-create a new model that addresses these issues and seeks guidance and expertise from the sector to shape its design.
- **Who's being missed?:** Many CYD currently lack access to the support they needs. These children, youth, and families must be prioritized.
- **Indigenous Partnerships:** We must actively work in partnership to support community and culture throughout the province, including the ways of learning of First Nations, Métis, and Inuit peoples.



THE LIVING EXPERIENCES OF SUMMIT PARTICIPANTS CLEARLY DEMONSTRATE THAT THE TREATMENT OF CYD LACKS A TRAUMA-INFORMED LENS AND IS UNFAIR.



3. Organize a human rights initiative, to stand up for disability justice

The BCDC believes that the province of British Columbia is currently engaging in discriminatory and unjust treatment towards people with disabilities. Despite its legal commitments, the living experiences of Summit participants clearly demonstrate that the treatment of CYD lacks a trauma-informed lens and is unfair. Section 15 of the Canadian Charter of Rights and Freedoms states that “Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.” Additionally, The United Nations Convention on the Rights of Persons with Disabilities, adopted in 2006, outlines the legal obligations of accepting nations to “prevent discrimination, eliminating barriers to accessibility, and working to promote the capabilities and contributions of people with disabilities.” While Canada as a nation accepts these obligations, the government of British Columbia has not taken adequate steps to fulfill them.

The disability community in BC recognizes the need to organize and file a **formal Human Rights complaint**. This effort will be supported by the collective stewardship of the BCDC. Therefore, the BCDC will recruit a legal team to act as technical support and assist us to:

- **Ensure specificity:** Clearly define the human rights violations that require action so that our organization can gather relevant testimonials.
- **Focus on actionability:** The legal team will assist in selecting stories that are most actionable.
- **Respect privacy:** Follow legal procedures to protect privacy, ensuring we capture necessary information while safeguarding individuals from potential reprisal/retribution.
- **Consider intersectionality:** Acknowledge and address the diverse and interconnected realities of the individuals we represent.
- **Centre on children and youth:** Recognize the specific needs of CYD and tailor our approach to address this focus.

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4. Communications & publicity campaigns

Members of the BCDC and participants at the Summit understand the power of public opinion in influencing government decisions. While individual family advocates and specific disability rights groups have seen limited success with media engagement and publicity campaigns, what might happen when the collective voices of the BC disability community unite? Here's what we're planning:

- **A toolkit for common language:** As BCDC members and Summit participants return to their home organizations, how will we ensure that our goals and requests remain consistent and united? We plan to create a guide for messaging as it evolves over time to incorporate new learnings, to ensure communication that is clear and consistent.
- **Provide resources:** Many existing resources are available but may not be widely recognized or utilized in BC. For instance, the World Federation for the Deaf has a toolkit for resources that can be used for advocacy.
- **Public campaigns:** To support and communicate our unified message, we plan to develop compelling and clear media campaigns to enhance public understanding of the realities facing CYD:
 - **"I am one of them."** Highlighting the alarming statistic that 80,000+ children are excluded from services each year, this campaign will invite parents and children to tell their stories, with the tag line: "I am one of them."
 - **"Disability is; disability is not."** This campaign will be strengths-based, designed to clarify what disability truly means and what it does not.

As these initiatives unfold, it's important to adhere to a few key principles:

- Families should be able to share their stories without fear of retribution. Their participation will be compensated, with childcare and travel costs covered.
- Data currently hidden in dense reports must be made accessible and compelling, engaging both the minds and the hearts of the public.



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5. Strengthen disability community connections, by continuing to gather & share stories

While the Disability Summit represents a historic “first” in BC and while less than a year has passed since the BCDC was formally established, recent activities underscore a crucial message: we must remain united. It is more important than ever to connect our shared experiences of oppression and transform them into shared action. Here’s how we will achieve that:

- **Build trust between our organizations:** We will continue to strengthen connections among disability organizations, to foster a unified movement.
- **Share stories:** We will gather and share stories of common experiences, to highlight that we are not alone. Our stories are not confined to individual, isolated disability communities but are interconnected. By recognizing these connections, we can build solidarity.
- **Stay positive:** As we advance into campaigns, let’s maintain a positive outlook. It is essential to focus on the fact that the **system** is flawed – not individuals with disabilities and their families – to ensure our message is heard and understood.

APPENDIX

Disability Summit Agenda, June 19 (Day 1)

- 8:30 Registration, breakfast
- 9:30 BCDC: Land acknowledgement, comfort notes
- 9:35 Musqueam Elder Shane Pointe – territorial welcome
- 9:50 Tsow'tun Ielum Society cultural support workers – introduction to ceremony
- 10:05 BCDC welcome
- 10:15 Dr. Jennifer Charlesworth, Representative for Children & Youth: Introduction
- 10:25 Keynote: Nicole Kaler, President BCEdAccess, *BC Disability at a Crossroads: We are Stronger Together!*
- 10:50 BCDC: Introducing the support team and final housekeeping
- 11:00 Break
- 11:20 BCDC, facilitators: History/context, introduction to the “Starter List”
- 11:40 Meet the “Starter List”: “What we have now” and “What we want”
- 12:15 Large group discussion about the goals, Starter List
- 12:45 Lunch
- 1:30 Table discussions: What’s good about the Starter List? What’s missing? What should be the priorities?
- 2:20 Table report-outs
- 2:50 Summary
- 3:10 Closing

Disability Summit Agenda, June 20 (Day 2)

- 8:30 Check-in, breakfast
- 9:30 BCDC: Land acknowledgement, welcome, comfort notes
- 9:40 Tsleil-Waututh Elder Carleen Thomas – territorial welcome
- 9:55 Samantha Cocker, Deputy Representative for Children & Youth: Reflections on Day 1
- 10:10 Graphic facilitators: Audio descriptions from Day 1
- 10:30 Facilitators: Creating the table topics -- Intro and format; building the table topics
- 11:00 Table Conversations, Part 1: Goals, actions/steps needed to get there
- 12:00 Lunch
- 12:45 Table Conversations, Part 2: What can each of us commit to?
- 1:30 Short break
- 1:45 Table reports (7-10 minutes per table)
- 2:45 Review and zoom-out
- 3:00 Closing handshakes and celebration
- 3:30 Closing



Disability Summit Organization Registrants

ACT- Autism Community Training Society	Community-Led Collaboration Project
ADHD Advocacy Society of BC	Deaf Children's Society of BC
Asante FASD and Neurodevelopmental Services	Disability Alliance BC
Autism BC	Down Syndrome BC
Autism Support Network of BC	Down Syndrome Resource Foundation
BC Aboriginal Child Care Society	Dyslexia BC
BC Association for Child Development and Intervention	Family Network for Deaf Children
BC Blind Sports and Recreation Association	Family Support Institute of BC
BC Complex Kids Society	Federation of Community Social Services of BC
BC Family Hearing Resource Society	First Call Child and Youth Advocacy Society
BC Prader-Willi Syndrome Association	Inclusion BC
BC Association for Behaviour Analysis	Indigenous Disability Canada / BC Aboriginal Network on Disability Society
BC Federation of Parent Advisory Councils	Inspire Kids FASD Support Society of BC
BCEdAccess	Learning Disabilities Association Fraser South Chapter
Blind Beginnings	Pacific Autism Family Network
Burnaby Association for Community Inclusion	Physiotherapy Association of BC
Canadian Deafblind Association - BC Chapter	Regular Equitable Authentic Lives (REA-L)
Canucks Autism Network (CAN)	Reach Child and Youth Development Society
Canadian Association of Occupational Therapists – BC Chapter	Speech and Hearing BC
Cerebral Palsy Association of BC	Spina Bifida Hydrocephalus Association of BC
Children's Autism Federation of BC	The Asante Centre at PLEA Community Services
Children's Hearing and Speech Centre of BC	Tseil-Waututh Nation



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