



Kids Can't Wait Partnership: 2019-2020 Update

Reflections on an extraordinary year & next steps in advancing meaningful system reforms

January 2021

Introduction

2020 was an extraordinary year. It's been particularly intense for families of children with diverse abilities and for our evolving provincial partnership to advance systemic reforms to improve BC's supports for children, families and community inclusion. The interlude created by COVID-19 has given us a chance to pause, reflect on what we've learned from the whirlwind of the past year and where we need to focus in 2021.

Language matters

The focus of this work is children with diverse developmental profiles or disabilities whose needs have been poorly served by traditional child and family support models. The term "children and youth with special needs" is still widely used, but a label we are striving to get past. It implies a problem that rests with children whose differences are "special" instead of recognizing the range of childhood developmental profiles that naturally reflect human diversity and vulnerability as a dynamic state driven by many complex factors. This diversity is only special or problematic when "universal" systems are designed in ways that fail to understand, accommodate and include them. Our goal is therefore systemic reforms to ensure ALL children and families are equitably supported through truly inclusive models. Pending reforms, we try to identify this disadvantaged group where necessary as children with diverse needs or children with disabilities. The report also refers to systemic labels that still use the term "special needs."

Background

The “Kids Can’t Wait” initiative to strengthen supports for children with disabilities emerged from our [2016 research partnership](#) led by the Family Support Institute of BC (FSI-BC) and the BC Association for Child Development & Intervention (BCACDI), which sought to better understand challenges and gaps in supports for children with developmental disabilities. In 2016, we hosted a gathering of community service providers from around BC, whose advice drove the launch of our [#KidsCantWait campaign](#) focused on early years supports. Then, as BC and Canada worked to advance a universal childcare model, our efforts focused on strengthening inclusion in BC’s childcare system.

In 2019, Inclusion BC secured a 3-year Vancouver Foundation grant that has allowed us to aim higher, broadening our work and partnerships to collaboratively drive long-term, transformative systemic change to achieve true inclusion in BC’s system of supports for children, youth and family caregivers. We are deeply grateful for this support, without which this work would not be possible.

The Kids Can’t Wait initiative is led by a Working Group whose members include:

- BC Association for Child Development and Intervention (BCACDI)
- BC Centre for Ability
- Family Support Institute of BC (FSI-BC)
- First Call – BC Child and Youth Advocacy Coalition
- Inclusion BC
- Inclusion Langley
- Provincial Advisor for Aboriginal Infant Development Program (AIDP)
- Provincial Advisor for Aboriginal Supported Child Development Program (ASCDP)
- Richmond Society for Community Living (RSCL)

Partnership and collaboration are central to our work of supporting systemic change to advance inclusion and equitable access for all and we want to acknowledge and thank the many groups and individuals whose contributions make this work possible. Our work is also supported by our provincial membership (families, agencies, community groups, adults with intellectual disabilities); BC’s Ministry of Children & Family Development (MCFD), BC’s Representative for Children & Youth (RCY-BC), and our broader community partnerships and collaborations.

For More information, visit: <https://inclusionbc.org/our-campaigns/kids-cant-wait/>

2019 Kids Can't Wait Gathering

In October 2019, the Kids Can't Wait Working Group hosted 65 participants from across BC in a one-day facilitated workshop to gather fresh insights and guidance for our ongoing work. The objective was to secure direction for a new 3-year community action plan to guide our collective efforts, with clear direction on:

- Priority needs of families and community partners;
- How to improve outcomes for children and families; and
- Identify actions to guide our work going forward.

The Community Gathering brought together families, advocates, agencies, other organizations and government representatives for an in-depth conversation on how to improve inclusion supports and outcomes for children with diverse needs and their families. Facilitator Sheila Beauchemin led us through a series of presentations, plenaries and breakout work sessions that explored three questions:

1. In a world where the needs of children and family are met, **what does successful early years support look like** so they can thrive?
2. **Where has good progress been made?**
3. **Where are the big gaps** – where are families, community allies and agencies asking for more and/or something different?

What We Heard

The vision for successful early years support (Question 1) shared by the participants consistently emphasized the following key messages as essential to driving successful outcomes:

- Universal design and inclusive practice as a **central standard for system design**, not an add-on or aspirational feature.
- A shift to equitable, **needs-based access** instead of program silos and simplistic eligibility criteria that reinforce existing barriers, inequity and exclusion.
- **Community-based embedding** of inclusion supports in existing community systems, such as Friendship Centres, Indigenous and Metis Nations organizations or agencies, community centres, libraries and public schools.
- **Navigation** supports as critical to unlocking access by helping families understand and connect with a complex system.

The participants of the Gathering **identified progress made** in recent successes to learn from and build on (Question 2), such as the following key examples:

- **Growing social acceptance** and commitment to inclusion.
- **Inclusive childcare investments**, pilots, childcare with inclusion embedded.
- **Strengthened partnerships**, stakeholder engagement, community & family leadership, peer-to-peer supports.
- **Acknowledgement of systemic gaps/commitment to reforms**: Movement towards family navigators for early years, service integration (Richmond connections to facilitate early years/kindergarten transitions), new provincial Early Years Framework, Early Learning Framework for ages 0-8, work on new CYSN framework.
- **One-stop community hub models**: Foundry, Autism Information Services.
- **Jordan's Principle** funding.

Despite optimism over recent progress, **significant gaps and daunting challenges remain**, particularly those driven by inadequate public investments and superficial commitments to inclusion (Question 3). These include:

- Lack of clear commitment to inclusion & community connection/embedding funding, standards, accountability.
- Inadequate planning & support to deliver systemic reform, new expectations.
- Inflexibility; focus on system needs instead of child & family-centered practice.
- Staffing challenges: recruitment, retention, training, quality of supports, inequitable/inadequate compensation, shortage of specialists, support for implementing best practices.
- Denial of access/perpetual crisis mode due to insufficient resources: waitlists, wait times, service rationing, assessment backlogs.
- Other access barriers: families struggle to navigate a complex & unresponsive bureaucracy, frontline staff with limited understanding of complex child needs, program access criteria mismatched to needs, cultural barriers, rural service gaps.
- Inequity: "squeaky wheel" response, private assessments, diagnostic barriers, lack of supports for older children and youth, FASD gaps, supports for foster vs biological families, geographic inconsistency in access & standards, language & poverty barriers, child apprehensions due to lack of family supports.

- Boundary issues created by funding structures: transition challenges, fragmented programs & services, lack of case management, coordination & integrated supports for complex needs, lack of wrap-around supports, whole family lens for vulnerable families, difference in access to services through Jordan's principle for Indigenous families who live on or off reserve.
- Increased burden on families forced to home school, unable to work.

The advice we gathered led to identifying **four key themes** that became the foundation of the Multi-year Action Plan:

1. **Data collection and resources** – the actions are driven by community-based research and data is collected using credible and transparent systems to highlight the gaps and inform solutions.
2. **Intersectoral collaborations** - create multi-level, cross ministry, community and service provider committee/advisory group to provide strategic support and collaboration to collectively address the needs of vulnerable children, youth and families in BC.
3. **Family-centred practice** – the supports offered to families build their capacity to care for their children; families feel welcomed and included in their community and can access support and services when and where they need it.
4. **Equitable access** – families access services based on their needs, not a diagnosis, and services are accessible and available in a variety of options, locations, modes and languages.

Before going into the details of the Multi-year Action Plan found in the last section of this update, it is important to consider other developments that happened during 2019 and 2020, which have impacted the work of the Kids Can't Wait Partnership.

Other 2019/2020 developments

Inclusive Childcare

In late 2018, MCFD began engaging community partners, including the Kids Can't Wait partners, to advance BC's commitments to build a new and more inclusive universal provincial childcare system with federal support. Under a new minister with responsibility for childcare, this process has included inclusive childcare pilots, external research, including by the Canadian Institute for Inclusion and Citizenship, collaborative provincial policy advisory tables, family and community engagement and development of a policy toolkit to guide movement towards the new system.

As the pilot programs were entering the site evaluation stage, the committee was dissolved by MCFD in the summer of 2020. Given the light that the pandemic shone on the

importance of childcare, we remain hopeful that the Ministry will resume the collaborative table to advance inclusive universal childcare.

New MCFD Service Framework

Also, in 2018, MCFD began laying a foundation for reforms to services under their *Children and Youth with Special Needs (CYSN)* Program. That also included new collaborative policy development tables engaging Kids Can't Wait Working Group partners, external research and community engagement. This work guided the development of a new draft service framework, with a final version currently pending.

Kids Can't Wait partners reviewed the draft framework at MCFD's Provincial Partners table and offered a preliminary endorsement, commending MCFD for acknowledging key flaws in current service deliver. A promising development was MCFD Minister's acknowledgement that MCFD need to remove artificial and often unfair access barriers by shifting to needs-based service deliver. However, there is broad agreement that adequate funding will be key to whether any new framework can help to drive meaningful systemic reforms.

COVID-19 response/RCY process

The dramatic and unexpected new challenges posed by the COVID-19 pandemic hit vulnerable children and families particularly hard, exposing and highlighting the deep flaws in MCFD's existing CYSN program. Systemic exclusion, medical fragility and/or retrenchment of school and other community support programs placed a heavy extra burden on families of children with complex support needs. While other ministries struggled but managed to adapt, sometimes with commendable results, MCFD appeared paralyzed and unable to support families as they grew increasingly desperate.

Community partners came together to shed light on these challenges with an April 2020 BC [Family Survey – Children and Youth with Special Needs](#), which guided subsequent advocacy and collaboration with the MCFD minister, senior staff and the office of the Representative for Children and Youth (RCY). Alarmed by the results, the RCY established an ad hoc provincial advisory table that included Kids Can't Wait partners, to assess the gaps. The partners at this table collaborated with the RCY on the development of the report [“Left Out: Children and youth with special needs in the pandemic”](#) released in December 2020.

2019-2020 Lessons Learned

As outlined above, 2019 and 2020 have posed enormous challenges, exposed deep systemic flaws and highlighted the daunting task ahead if we are to achieve meaningful systemic reforms instead of tinkering with the margins of a deeply flawed family support model. Inherent in the failures are traditionally program design assumptions that viewed inclusion and support for vulnerable children and families as an optional, charitable add-on

to mainstream universal public services, instead of embedding inclusion, universal design and equitable, needs-based access as core design standards.

But these extraordinary challenges have also created new opportunities, sharpening our focus on what needs to change and what must be prioritized. COVID-19 highlighted the vital importance of strong partnerships in leveraging the ability to respond quickly and effectively to crisis needs, a lesson that applies broadly across all aspects of service design and delivery. The lack of a strong collaborative foundation initially hampered MCFD's ability to respond but we're confident this experience will ultimately strengthen emergent efforts to build true partnerships and help MCFD leverage community strengths to build a more integrated, effective and responsive system of community supports.

Multi-year Action Plan

Successful early years support (0 to 8 years) consists of equitable access to resources that ensure families have timely, universal access in every part of British Columbia to a core suite of early intervention therapies; timely assessments; family respite; health, medical and in-home supports; and access to before/after-school programs. The Kids Can't Wait Partnership developed this Multi-year Action Plan based on four themes that emerged as priorities from their 2019 Community Gathering.

1. **Data collection and resources** – the actions are driven by community-based research and data is collected using credible and transparent systems.
2. **Intersectoral collaborations** - create multi-level, cross-ministry, community and service provider committee/advisory group to provide strategic support and collaboration to collectively address the needs of vulnerable children, youth and families in BC.
3. **Family-centred practice** – the supports offered to families build their capacity to care for their children; families feel welcomed and included in their community and can access support and services when and where they need it.
4. **Equitable access** – families access services based on their needs, not a diagnosis, and services are accessible and available in a variety of options, locations, modes and languages.

Theme	Year 1 (2020)	Year 2 (2021)	Year 3 (2022)
Data collection and resources	<ul style="list-style-type: none"> • BCACDI - BC's Specialized Children Services Report 2018/19 & 2019/20 • Family Survey – CYSN 2020ⁱ • The Impact of COVID-19 on BC's Children with Medical Complexity and their Families by Jennifer Baumbusch, et alⁱⁱ • The impact of COVID-19 on Mental Health, Quality of Life, and Service and Support Needs in Families of Children with ASDⁱⁱⁱ • Left Out: Children and youth with special needs in the pandemic by RCY^{iv} • First Call - BC Child Poverty Report Card^v 	<ul style="list-style-type: none"> • ASCDPSCDPService Access Sample Survey (2nd) • Priorities to integrate policy and practice • BCACDI's Specialized Children Services Report • AIDP, BCACDI, & Gerlach, A., project "Structural Barriers to Trauma and Violence-Informed Early Intervention"^{vi} • AIDP, BCACDI, & Gerlach, A., project "Community Voices on 'Tapping into Tech'"^{vii} • FSI – ACCESS Project^{viii} • First Call - BC Child Poverty Report Card^{ix} • Monitor "Pathways to Hope" early years mental health pilots 	<ul style="list-style-type: none"> • BCACDI's Specialized Children Services Report • AIDP, BCACDI, & Gerlach, A., project "Community Voices on 'Tapping into Tech'"^x • FSI – ACCESS Project^{xi} • First Call - BC Child Poverty Report Card^{xii} • Monitor "Pathways to Hope" early years mental health pilots
Intersectoral collaboration	<ul style="list-style-type: none"> • MCFD CYSN Service Framework • Early Learning Framework • RCY – CYSN ad hoc group • Inclusive Childcare Framework 	<ul style="list-style-type: none"> • Meetings with new cabinet members • Staying engaged in the Early Learning Framework • Collaborate with RCY, MCFD, and partners as invited • Navigation Summit by KBHN 	<ul style="list-style-type: none"> • Transition KCW Working Group to a Community of Practice • Collaboration with Vantage Point, Changemakers Network.
Family-centred practice	<ul style="list-style-type: none"> • MCFD CYSN Service Framework • Highlighting the work of IDP/AIDP • Learning Explorations by FSI • Training weekend for Resource Parents by FSI 	<ul style="list-style-type: none"> • Inclusion BC Virtual Learning Series • Highlighting family-centred practice • Family Leadership Series • Family Support Workers Network • Highlighting the work of AIDP and ASCDP • Learning Explorations by FSI • Training weekend for Resource Parents by FSI 	<ul style="list-style-type: none"> • Inclusion BC Annual Conference • Highlighting family-centred practice • Family Leadership Series • Family Support Workers Network • Highlighting the work of AIDP and ASCDP • Learning Explorations by FSI • Training weekend for Resource Parents by FSI
Equitable access	<ul style="list-style-type: none"> • MCFD CYSN Service Framework • Investing in Inclusion and Equity for All, submission to BC's Standing Committee on Finance 	<ul style="list-style-type: none"> • Diversity Includes • Submission to Standing Committee on Finance • MCFD Minister's Advisory Council 	<ul style="list-style-type: none"> • Diversity Includes • Submission to Standing Committee on Finance

1. Data collection and resources

- **ASCDP/SCDP Service Access Sample Survey (2nd)** – apply a second round of the Supported Child Development Access Sample Survey to understand the extent of barriers to access Aboriginal Supported Child Development and Supported Child Development services around the province.
- **Priorities to integrate policy and practice** – the KCW Working Group will identify opportunities to better integrate policy and practice and, to focus their group advocacy, will select the three top issues in which better alignment of policy and practice would lead to improving outcomes for children with disabilities.
- **BCACDI's Specialized Children Services Report** – continue monitoring service demand and service access for some of the main programs delivered by BCACDI member agencies. Service demand is being monitored by the number of referrals received and the number of children served, and service access is being monitored by tracking the average wait time from the date a child is assigned to a program to the date when service is initiated.
- **Aboriginal Infant Development Program (AIDP), BC Association for Child Development and Intervention (BCACDI), & Dr. Alison Gerlach project "Structural Barriers to Trauma and Violence- Informed Early Intervention"**^{xiii} – this investigation utilized surveys and focus groups with agency leaders and clinicians to understand the organizational and structural barriers inhibiting trauma and violence-informed practice in early intervention services.
- **AIDP, BCACDI and Dr. Alison Gerlach, research project "Community Voices on 'Tapping into Tech'"**^{xiv} – the main objective of this project is to improve the early health and development of children with disabilities and complex health conditions by tailoring the use of information and communication technologies for diverse rural and northern family and communities (pending approval).
- **Family Support Institute of BC (FSI), Dr. Jennifer Zwicker, et al, research project "ACCESS"**^{xv} – the objective of this project is to understand disparities in access to existing health, education and social services for youth with neurodevelopmental disabilities and their families in two provinces, and the impact of these disparities on outcomes of youth with neurodevelopmental disabilities across the life course. The findings from this analysis will be used to co-design policy recommendations with stakeholders to enhance the access to services across the life course.
- **First Call - BC Child Poverty Report Card** - every November, First Call, with the support of the Social Planning and Research Council of BC (SPARC BC), releases a report card with the latest statistics on child and family poverty in BC and recommendations for policy changes that would reduce these poverty levels. This is

done in conjunction with the release of a national child poverty report card by Campaign 2000.

- **Monitor “Pathways to Hope”** – the Working Group will be monitoring the implementation and results of the actions taken for the early years mental health pilot projects that are part of BC’s plan for mental health and addictions care.

2. Intersectoral collaboration

- **Meetings with new cabinet members** – the Working Group will make formal requests to meet with new cabinet members and will emphasize the importance of cross-ministerial collaboration based on the experiences of families and service providers and to explore how this can be improved at all levels of government and community.
- **Early Learning Framework** – stay engaged in the work of BC’s Early Learning Framework which includes the Ministries of Children and Family Development, Ministry of Education and the Ministry of State for Childcare.
- **Engagement with government** – continue to engage with the Ministry of Children and Family Development on the Service Framework for Children and Youth with Special Need and with the Representative of Children and Youth. Engage with the Ministry of Health to open a collaborative discussion of the Nursing Support Services program.
- **Navigation Summit by Kids Brain Health Network** – members of the Working Group are engaged in this initiative led by Sunny Hill Health Centre to explore the role of “navigation” of services and supports for children and youth with neurodevelopmental differences, disabilities and special needs.
- **Create a Community of Practice** – transform the KCW into a community of practice for longer-term integration of policy and practice. The Community of Practice will include multi-level, cross-ministry, community and service providers.
- **Vantage Point** - collaborate with their Changemakers Network to explore the creation of a cohort that focuses on early years’ supports.

3. Family-centred practice

- **Inclusion BC Virtual Learning Series** – offer workshops to agencies and service providers on family-centred practices.

- **Highlighting family-centred practice** – explore and highlight examples of strong family-centred practice through community support programs, activities and stories shared by members of the KCW Working Group.
- **Family Leadership Series** – Inclusion BC partners with local members of their provincial federation, local family groups and the Friendship Centre Network to co-host leadership development weekends and reunions in different parts of the province.
- **Family Support Workers Network** – offer learning and training opportunities to a network of professionals whose job is to provide support to families of children with disabilities to improve their capacity to locally support diverse families.
- **Highlighting the work of AIDP and ASCDP** – explore opportunities to highlight the family-centred approach that is used by the Aboriginal Infant Development Program and Aboriginal Supported Child Development Program.
- **Learning Explorations by FSI** – series of events by which the Family Support Institute supports families and their loved ones to become informed, engaged and connected.
- **Training weekend for Resource Parents by FSI** – opportunities for FSI Resource Parents to acquire skills and knowledge that support them in their volunteering role of supporting other parents from a family-centred perspective.

4. Equitable Access

- **Diversity Includes** – civic engagement campaign by Inclusion BC which aims at meeting with all provincial elected officials to raise the sector's profile, including issues relevant to families with young children with disabilities who need early years supports.
- **Submission to Standing Committee on Finance** – members of the KCW Working Group will make their respective submissions to the Standing Committee on Finance to highlight the areas where more funding and better allocation of resources are needed to provide equitable access to services and supports needed by children with disabilities/diverse needs.
- **MCFD Minister's Advisory Council** – members of the Working Group will apply and engage with the newly announced Minister's Advisory Council on Children and Youth with Support Needs.

ⁱ BC Family Survey – Children and Youth with Special Needs, April 2020, online: <https://inclusionbc.org/bc-families-need-flexibility-financial-support-and-clarity/>

ⁱⁱ Baumbusch, J.L., Lamden-Bennett, S.R., & Lloyd, J.E.V. (Nov 30, 2020), The Impact of COVID-19 on British Columbia's Children with Medical Complexity and their Families, Vancouver, BC: Supporting Progressive Inclusive Child-centered Education (SPICE) Lab, School of Nursing, University of British Columbia.

ⁱⁱⁱ The impact of COVID-19 on Mental Health, Quality of Life, and Service and Support Needs in Families of Children with Autism Spectrum Disorder, report by Simon Fraser University and Autism Community Training (ACT), November 2020.

^{iv} Left Out: Children and youth with special needs in the pandemic, report by the BC Representative for Children and Youth, December 2020, online: https://rcybc.ca/wp-content/uploads/2020/12/CYSN_Report.pdf

^v First Call – BC Child Poverty Report Card, online: <https://still1in5.ca/>

^{vi} Dr. Alison Gerlach's research project in collaboration with the Aboriginal Infant Development Programs (AIDP) and the BC Association for Child Development and Intervention (BCACDI): "How Organizational and Structural Factors Shape the Delivery of Trauma and Violence-Informed Early Intervention with Indigenous Families and Children: Findings from a Province-wide Study in BC."

^{vii} Dr. Alison Gerlach's research project in collaboration with the Aboriginal Infant Development Programs (AIDP) and the BC Association for Child Development and Intervention (BCACDI): Community Voices on 'Tapping into Tech': Fostering Equity for Children with Disabilities/Medical Complexity in Northern and Rural British Columbia (pending approval).

^{viii} Dr. Jennifer Zwicker's research project in collaboration with the Family Support Institute of BC (FSI) and other community partners: ACCESS – Assessing the Continuum of Care and Eligibility for Services and Supports for Children with Neurodevelopmental Disabilities and their Families.

^{ix} First Call – BC Child Poverty Report Card, online: <https://still1in5.ca/>

^x Gerlach, AIDP and BCACDI research project 'Tapping into Tech' referenced above in vii.

^{xi} Zwicker, FSI, et al research project ACCESS referenced above in viii.

^{xii} First Call – BC Child Poverty Report Card, online: <https://still1in5.ca/>

^{xiii} Gerlach, AIDP and BCACDI research project "Structural Barriers to Trauma and Violence- Informed Early Intervention" referenced above in vi.

^{xiv} Gerlach, AIDP and BCACDI research project 'Tapping into Tech' referenced above in vii.

^{xv} Zwicker, FSI, et al research project ACCESS referenced above in viii.