



**FAMILY SUPPORT**  
Institute of **BC**  
*families supporting families*

**Budget Submission**  
Budget 2021

# Family Support Institute of BC - Introduction

---

*The Family Support Institute (FSI) is a provincial non-profit charitable society registered in 1985. FSI supports approximately 10,000 families who have a family member with a disability each year. This support stems mainly from our large volunteer network of Resource Parents (RP's). Currently, FSI maintains a RP Network of over 260 volunteers who support families across the province by sharing experiences and expertise, connecting families with each other, guiding families to supports and services and community supports in their regions, and facilitating training and educational sessions including building capacity in the areas of innovation and creative solutions. FSI's supports and services are free to any family. FSI is unique in Canada and is the only grass roots, parent to parent support organization with a broad volunteer base. FSI believes that families are an effective agent of change and ultimately the strongest voice to speak on the needs of their sons and daughters. We support all families, with children of all ages and all disabilities including mental health challenges.*

---

## **Issues of Concern for Families in BC** What do we hear consistently all over BC

Families of children, youth and adults living with various disabilities and special needs in BC rely on many services and supports as well as community-based resources to keep their family connected and healthy. Many of these supports and services have eroded over time, or are under-funded, fragmented, and have eligibility requirements that seem to be so rigid and narrow that the needs of the child/youth/adult slip through cracks and their disability-related “needs” aren’t all taken into account when assessing what supports would be the best fit. Instead, in many instances, the diagnosis is the only requirement that is considered.

We have been heartened to hear many stakeholders referring to family and person-centered models as the best practice from a system and community-based approach. At FSI we fully support this. We have seen many government partners striving towards this model and we give applause for that. So far, however, in some programs across BC, this has not yet met the needs people are seeking. This budget submission will highlight where we see the need for those investments to be made to attain a family and person-centered approach while focusing on “needs-based” in the disability sector focusing on the best interests of people with disabilities and their families. This submission will focus in the areas we hear from most from the over 6500 support calls we took in the past year, and during COVID 19 which has been of significant impact in different ways.

We are going to focus on and highlight:

- [Community Living British Columbia – Request for Service Lists \(wait times\)](#)
  - [Community Living British Columbia – Supports for Transitioning Youth](#)
  - [Community Living British Columbia – Residential Services \(Housing options\)](#)
  - [Ministry of Child and Family Development – CYSN supports](#)
  - [Ministry of Child and Family Development – Early Intervention Therapies](#)
  - [Ministry of Child and Family Development – Kids in Care \(supports to keep kids at home where possible\)](#)
  - [Ministry of Education – K-12 funding levels to support Inclusion for all kids](#)
  - [Health Services – Re-Instatement of Provincial Medical Consultant](#)
- 

## **Community Living British Columbia / Adults with Disabilities** Investment to address Requests for Service/ Transitioning Youth/ Flexible Residential options

Youth transitioning into CLBC are met often with significant wait times for the services and supports they need to access their home community, employment supports, social supports, or to support them to consider living in different arrangements outside of their family home. These same wait times are being faced by individuals at all ages across the life span as their circumstances change and they need to approach CLBC for something different; something more.

CLBC has done some great work in the creation of a new service option, their [L.I.F.E. based program](#). However, this option is not yet scaled provincially and does not address long wait times or other issues faced by older individuals in the province who need/want to explore residential services. Some individuals are often met, upon requesting new or different supports when their circumstances change, with the response of needing to wait. Often those unmet needs leave them in situations of risk or situations that leave them vulnerable, in undesirable conditions, or with limited supports to keep them safe. Many times, their families are left doing more support than they can manage, and this leaves them facing undue pressures that could be avoided should adequate resources be in the system to respond when the individuals need them right away.

In addition, housing challenges are leaving people living with their families far longer than their families can manage, or having them living in options that are not a true choice for them but instead the only option presented. With the rising housing costs in many parts of BC, and the rental market rates at extremely unaffordable levels, individuals living on [Persons with Disabilities Benefits](#) will never be able to afford the standard of living our province provides. The options presented to people with disabilities for residential services through CLBC, while meeting some peoples' needs, requires a more fulsome array of options in order to support more people and their desired choices and options. While we appreciate this responsibility does not fully lie inside the scope of CLBC fully, the current model and suite of services provides limited supply to people who want to live independent from Homeshare, yet want to live separate and independent from their family. Creative options in this area would allow for people to have choice, flexibility, and more fulsome lives in community. We know that many families are caring for their sons/daughters well in the later parts of the senior years due to there being limited options for housing/residential supports for their loved ones. This leaves them feeling overly stressed and has them performing the caregiver duties much longer than they ever anticipated. Flexible and more creative options would possibly alleviate this from occurring and have much stronger planning for their sons/daughters in place earlier.

## **Recommendation:**

- Significant Investment into CLBC funding to allow for newly transitioning youth to access the supports and services they need, when they need them.
- Investment to address CLBC's full request for service list.
- Significant investment into CLBC residential support contracts to enable individuals to have a host of choices to choose from when living outside of their family home.

## **Outcomes of these Provincial investments will:**

- ✓ Support youth to obtain access to employment.
- ✓ Support families and the family unit to strengthen and heal from caregiver burnout.
- ✓ Support community development and proactive approach to people with disabilities playing active roles in society that are not drenched in poverty and isolation.
- ✓ Enable individuals with disabilities to have more choice in their residential options and live in more appropriate housing choices at relative stages of their lives across their life span.
- ✓ Enable families to support their sons/daughters in "typical" family roles and avoid family burnout in the latter parts of their lives.
- ✓ Support people to play active roles in their community with the supports they need, when they need them.

---

## **Supports to Children and Youth with Special Needs and their Families** CYSN Supports / Early Intervention Therapies / Kids in Care / Family Support to address provincial and regional needs

Family supports and the needs of children with disabilities and special needs are unique. As such a system is required that is family centered and focused on those individualized circumstances. The Family Support Institute receives hundreds of calls each year from families whose stories are all varied, compelling and vastly different from one another. The one thing they have in common is they are trying to work inside of a system that has generalized them as much the same. They are not receiving the services they require to ensure their children with disabilities thrive and develop in the way they could if they were obtaining all the services offered through the ministry (MCFD). Many of these families sit on waiting lists for years to obtain services for their children, missing out on the critical early intervention supports that could assist their children in the prime early stages of development. In addition to this, they wait for much needed respite supports and face caregiver burnout at a very early stage in parenting. When many of these parents do in fact receive some supports, and their situations change, as they approach their social workers to ask for just a little bit more to assist them, they are, again placed on a very long waiting list. When they can no longer manage waiting and ask again for supports, they can sometimes be offered the dire and deeply traumatic decision of putting their child into care (temporarily or permanently). This is not an acceptable option to them and should not be on the menu of available options to consider for families raising a child with a disability.

There are many services and supports available inside of the Ministry for Child and Family Development that could and should assist a family to stabilize and support their children. With many of these supports the family

would be able to see their child obtain the Early Intervention therapies necessary to have their best chance at speaking or articulating, walking or mobility, range of motion and flexibility and other critical supports that early intervention therapies can offer. Many families, due to extensive wait times, miss out on these crucial therapies and age out, before they ever even access any of the programs and their children miss out on these critical opportunities to thrive. The next stage after this is school therapies, which are also extensively wait listed, and the supports are minimally offered for duration of time.

In addition, the Children and Youth with Special Needs (CYSN) programs in MCFD require a significant investment of funds to alleviate the wait times for many families who sit and cannot access before and after school programs, respite programs, youth care, behavior support and many other such services that afford families a much needed break from their parenting responsibilities, extremely expensive equipment that their sons/daughters cannot live without for mobility and communication, or interventions their children need to develop and grow.

We were heartened to see that in 2018, with the support of the bi-lateral federal-provincial agreement on child-care, an additional investment of \$30 million was attributed over 3 years in 2019 to build upon the much-needed Supported Child Development (SCD) and Aboriginal Supported Child Development (ASCD) programs. The purpose of this funding was to reduce wait lists for vulnerable and eligible children to enter these programs. This was/is a start, but it is not enough to address the extremely long wait times families face with their children – wait times that will often lead kids into school, where they will be met with other exceptionally long assessment or service wait times. With the many levels of wait times vulnerable children miss out on essential supports and services at critical stages of their development. An investment to contracted agencies to enable longer term planning would allow for children to access the supports they need over a longer period and eliminate the obstacle of wait times, leaving them awaiting assessment after assessment. This fragmented system needs to be fluid and malleable to meet the needs of all children in a flexible and adaptable manner.

Additionally, we know that as of March 31, 2018, 6,698 children and youth were living in government care and 2,668 more were living outside the parental home in kinship care or on their own with some government support<sup>1</sup>. Some statistics have cited numbers as high as 50% or more of kids in care being kids with special needs. With a family-centered approach, and a re-allocation of funding, families can be provided with the necessary supports to care for their children at home and be given the flexibility and acknowledgement that they know their children best and be considered an equal team player on the collaborative team looking at the best interests of children with special needs. We also know that when kids are placed in care, they will need special help to overcome the significant impact of trauma of their life experiences, the turbulence of being removed from their permanent home and family, and that they have not had the benefit of stability to support their development. We know that many extended families and other surrounding support people are willing to help, but they need adequate financial and service supports in order to do so. With the flexible support of MCFD, families can support their kids in flourishing ways and keep their kids at home with them, with the supports and services to help them thrive.

**Recommendation:**

- Invest in MCFD to eliminate wait times for young children with developmental challenges who need access to assessments, early intervention therapies, early childhood education, infant development programs and before and after school programs (IDP/AIDP/SCD/ASCD).
- Provide a significant investment into CYSN programs so that all eligible families can access this program when needed without waiting. In addition, loosen eligibility to enable more families to have access to the benefits of this much needed program and consider the criteria to be based on need rather than diagnosis.

- Provide funding to MCFD and support families to keep their kids at home with the services and supports they need, when they need them. Provide a thorough, external look at Child Protection Practices, and ensure that families are not investigated unnecessarily.
- Add an investment to MCFD to strengthen the system of guardianship workers, foster parents and other caregivers when children with disabilities do require going into care, focus on the MCFD Kinship agreements, and make all efforts to keep children linked to family when that is in the best interests of the child.
- Invest in MCFD to provide all kinship/family care providers with the full and equitable benefits and supports available to foster parents or paid caregivers under voluntary care agreement or special care agreements, to ensure that families are supported to keep their children at home wherever possible in alignment with the [Ministry Service Plan](#).

**Outcomes of these Provincial investments will:**

- ✓ Support children to have access to the critical supports and services when they need them at the appropriate developmental stages that will set them up for the best success as they transition into school settings and beyond.
- ✓ Support families to have more opportunities for employment in their family units when their children have access to the quality supported and inclusive care they need before and after school.
- ✓ Support family well-being to increase as families gain access to the much needed support they need to stabilize their family units; Support balance inside and outside of the family home while utilizing flexible services and supports to meet the need of individual family circumstances.
- ✓ Support a system to be in place that values the role of families and the strength of permanency when it is safe to keep kids at home, and intrinsically recognizes the innovative and flexible options available for families that keeps benefits in place that are family-centered and child-focused.
- ✓ Support children and families to have access to a full range of supports when their circumstances change, enabling them to have fluid and flexible access to a range of services for their ever-changing life-events. This will promote family permanency and stability in the family home and focus on kinship and relationship.

---

**Health Services Medical Health Director Role**

During COVID 19 and the uncertain times of the pandemic it has highlighted the inequities of the Health system for people with disabilities when accessing Health Services for themselves or for their loved ones. This is a historical concern that has not been rectified with a long term solution but instead been exacerbated and magnified during the pandemic and created growing fear and isolation if people with disabilities leading to growing concerns as people increasingly share they have not been going to hospital to have their acute care needs met due to the treatment they have received or fear they will receive. In addition to this the Health Policy during the COVID pandemic that limited “Essential Visitors” or essential supports to people with disabilities instilled even more fear as we heard about people being admitted into hospital without support people they trusted for supported decision making, communication. Feeding, mobility, end-of-life care and other related supports critical to make admissions to hospital equitable to all citizens.

When we eventually did see the new [Health Policy](#) for “Essential Visitors” land, we saw holes in the appeals process still leaving people vulnerable to the same discriminatory processes as has been seen for decades before. There is no clear process that people can go through to see success and have their Civil and Human Rights upheld in the Health Care system.

In addition, there are many people in BC who have joint funded contracts between Community Living British Columbia (CLBC) and the Choices in Supports for Independent Living (CSIL) program funded under the Ministry of Health, that have found navigating the Health contracts to be extremely challenging. Despite best efforts, and a responsibility landing with CLBC to manage the majority of the contracts management under the [Guidelines for Collaborative Service Delivery](#), there still seems to be friction and an absence of information and support through Health Authorities for people with disabilities in BC, leaving them and their families vulnerable and lost in this vast abyss of a system.

Many years ago BC had a role of Medical Health Director, and this role acted in a critical link to liaise between health partners, individuals and families, practitioners and service provider partners, to ensure smooth exchange and access for patients receiving supports through Health services, particularly people with disabilities. That role was removed, and the system has since become extremely fragmented and the loss has been felt significantly. A re-instatement of this role would be of huge benefit to improving systems function and access in BC.

#### **Recommendation:**

- Expand the role of the Representative for Children and Youth (RCY) office to have jurisdiction into Health Services for people with disabilities and enable the role of Medical Health Director to be assigned to the RCY to find, oversee, advocate and liaise with as an external body.

#### **Outcomes of these Provincial investments will:**

- ✓ Support people with disabilities and their families to have a trusted independent source to go to for equity and support for health access, information and advocacy supports in all areas Health related

---

## **Inclusive Education** Equitable and adequate funding to students with special needs to ensure inclusion in school is supported for all kids

Throughout the course of 2019-2020 the Ministry has engaged extensively on the inner and external practices of the K-12 Funding Model and how that impacts public education in BC. It has been noted that students with disabilities have been facing an erosion of supports for several years now, and inclusion supports have been hampered as a direct result of the funding model in place at the current time. There is a great deal of tension in BC between the many partners around what the solution may be, but one thing stands strong among all the friction – Inclusive Education is a right for all students. The relationships and education they obtain in the public-school system will be the foundation of the rest of their lives and it is important that the investment be made for all partners so we see that all students have the best start with an inclusive education that works for everyone. We have a responsibility to make this be positive for all kids, and ensure we set every student up with the best chance to succeed for the future. This cannot be done in the current structure of our education system. There

needs to be a complete overhaul with a new model, both in structure and funding. On top of that the implementation of a training regime to follow on the core values on inclusion for every student and the benefits to everyone when each student has a sense of belonging that is meaningful to them.

#### **Recommendation:**

- Invest funding to support the early identification and appropriate educational programming for students with diverse learning needs and to restore other educational programs that have been eliminated by inadequate funding to school districts.
- Make full investment to implement the funding model review panel budget recommendations in full towards inclusive education. This investment will demonstrate a fulsome commitment to inclusion for all students; a vision and value base we want to see modeled throughout our province in every way possible. When inclusion happens for one, it can happen for all.

#### **Outcomes of these Provincial investments will:**

- ✓ Provide supports to all parties that need supports in a meaningful way to alleviate conflict and provide access to a full and equitable education for all students
- ✓ Ensure that student rights are adhered to and that every student has a meaningful place of belonging in the classroom
- ✓ Provide the necessary funding to alleviate pressures on the parties involved and bring coordination and partnership to the forefront of the model in the best interests of student education
- ✓ Highlight that inclusion means every student

---

## **Budget Submission Conclusion**

When our partners and government come together and investments are made to benefit the inclusion and sustainability of programs that support long term strength and resilience of individuals with disabilities and their families, it is an investment that pays off in the future. The outcomes are rich with community benefit, but the people directly impacted by that investment become even stronger and more enriched as citizens in this province. Allies and partners, stakeholders and families – all coming together to the betterment of a systems build with the foundational principles of inclusion for all.

Thanks for the opportunity to submit our budget recommendations for children, youth and adults living with disabilities and their families in BC and the services and supports they rely on!

Angela Clancy  
Executive Director  
Family Support Institute of BC

---

<sup>i</sup> <https://firstcallbc.org/wordpress/wp-content/uploads/2019/06/FC-Submission-to-Finance-Standing-Committee-BC-Budget-June-2019-FINAL.pdf>