

ENOUGH IS ENOUGH!

BC Families of children with severe disabilities and complex medical needs

Who are we?

We are caregivers of the **most vulnerable children** in British Columbia. Children with multiple impairments and fragile health conditions that require extensive care and support.



Why are we struggling?

We are struggling to meet the demands of everyday life and the extraordinary needs of our children. Due to the **lack of adequate services and supports**, many of our families are falling through the cracks of a broken system and our children are being denied access to the most fundamental rights of children with disabilities. We are **physically and mentally exhausted** and most of us also struggle financially as our employment and economic situation is under heavy pressure.



What are the consequences of the lack of appropriate support?

Our families are reaching capacity. The lack of support is putting us in a situation of **social and physical risk**, hindering our ability to sustain our role as caregivers and **threatening our families' stability**. Without an adequate network of policies and programs to support us, many are left with no choice but to institutionalize their children.



What is the BC government doing to change this?

Unfortunately, the extent and urgency of our struggle is not being understood by government representatives. We have been advocating for change for many years now, and have asked the government on numerous ways and occasions to assess our situation and create a system to meet our needs with extensive parent input. However, our voices are not being heard and the extent and seriousness of our problems are not being considered.



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are calling on the government representatives to **STOP** ignoring our petitions and address our problems immediately.

A **system of family caregiver pay** to support parents who are providing 24/7 care for their severely disabled and medically complex children experiencing financial hardship due to their inability access employment.

01

WHY?

- As unpaid caregivers we are invariably caught in a downward spiral of greater economic needs and lower earning power.
- Many families are single income earners, are under employed and have numerous expenses related to their children's disability.

Sufficient Respite Benefits so that caregivers have access to permanent and effective support to alleviate the emotional stress and physical strain that arises from providing 24/7 care for their children.

02

WHY?

- Respite is exceptionally important to prevent caregiver burnout and is fundamental for keeping children with disabilities at home and providing families with a better quality of life.
- The current base amount for Respite Benefits (\$233/mo) that we receive is definitely insufficient and does not allow caregivers to access the much-needed support they deserve.

An efficient and comprehensive system for **funding therapies** as they are of crucial importance to the health and development of our children.

03

WHY?

- The government is not funding the full cost of therapies and families are topping up the hourly rates, expending a monthly average of \$300 or more to pay for weekly therapies.
- Early Intervention Programs are underfunded and limited in their capacity. They lack staff, resources, and proper plans and programs to accommodate our complex children.

An efficient and coherent system for funding **positioning and mobility equipment** that improves our children's health, quality of life and allows them to participate in society.

04

WHY?

- Some children need 24/7 postural support. Alternative positioning devices are essential to prevent injury and promote the healthy growth and avoid surgeries.
- The cost of this equipment has significantly increased in the last couple of decades, while the funding provided for this equipment has remained steady and families are continuously "topping up" or finding charity support.

Funding for **accessible vehicles and accessible housing** since a great number of our children are wheel-chairs users.

05

WHY?

- There are no programs directed to aid families with the cost of accessible vehicles, this puts children and families at risk of injury and isolation.
- The income threshold for funding in-home adaptations is not allowing families to access important funding to make their homes safe and accessible for their children.

How can the government create an accountable and comprehensive system to address the needs of our children and families?

4 SIMPLE STEPS

- 1 Increase Funding! **Increase Funding!** Increase Funding!
- 2 Every child is different! Create a system of individualized supports where the funding meets each individual child's specific needs.
- 3 Nothing about our kids without our input! Develop an effective partnerships with families in the process of designing policies and creating programs for our children.
- 4 Recognize the economic and social contributions of caregivers! The current system of "at home" care could not function without the countless hours of care and resources provided by our families.

Please share this document!
Thank you for raising awareness and supporting our families

For more information please send an email to complexkids2020@gmail.com

