



DOWN SYNDROME BC

downsyndromebc.ca | hello@downsyndromebc.ca | [@downsyndromebc](https://www.instagram.com/downsyndromebc)

November 2, 2021

The Honourable Mitzi Dean
Minister of Children and Family Development,
Via email: MCF.Minister@gov.bc.ca

Dear Minister Dean,

We are a non-profit organization working to share information that supports the health and wellbeing of individuals with Down syndrome.

We are concerned that children with Down syndrome are not getting the help they need in a timely fashion, or at all, and the help they are getting is, in most cases, insufficient. The CYSN Report, Dec 2020, "[Left Out: Children and youth with special needs in the pandemic](#)" is heartbreaking to read. The report makes it obvious that problems in providing services have existed for years. This needs to change.

In September 2021 we made a number of [recommendations to the Select Standing Committee on Finance and Government Services](#) regarding the 2022 BC Budget, including funding for the creation of Down Syndrome Funding Programs to provide a baseline of individualized direct funding to every British Columbian with Down syndrome, **based solely on the diagnosis of Down syndrome:**

- Funding allowances to be given directly to families or individuals, to be spent, as needed, on registered therapy providers such as Speech Language Pathology (SLP), Physical Therapists (PT), Occupational Therapists (OT), Applied Behaviour Analysis (ABA) Therapy, counselling/psychology, associated tools (communication devices, mobility aids, etc) therapy related travel expenses, and respite services for caregivers.
- Recommended funding of \$25,000 per year, for every individual with Down syndrome, across the lifespan.

We are aware of [MCFD plans](#) to phase out the At Home Program School-Aged Extended Therapies and Autism Funding by 2025, and transition to a system of “family connections hubs” that will provide information, interventions and therapies in a “one-stop” model. Information about this new framework is thin, and we remain concerned about expensive, time consuming and demoralizing assessments, the bureaucracy that such a system would create, and the lack of autonomy of disabled individuals and their families to decide what care is right for them. Existing programs that operate on a similar model, such as Child Development Centres, do not offer timely access and children are [waiting over a year](#) to see an SLP in some parts of the province. Leaving all these details aside, this program will take at least 4 years to implement province-wide and the transition is likely to cause upheaval of supports that currently exist; what can be done to support children with Down syndrome and their families NOW?

A medical diagnosis-based approach does away with the need for time consuming, expensive, unnecessary and very subjective assessments. Other programs that require an initial assessment and diagnosis, such as the Autism Funding Program, have unacceptably long wait times; The current wait time for Autism assessment in BC is [over 84 weeks](#), a length of time that is beyond unacceptable. The subjective and arbitrary assessments required by the At Home Program are demoralizing. We have heard stories of families who are so desperate for help that they feel they must set their child up to fail, which is demeaning to the child, to the family and to human dignity in general. And, to add injury to insult, these families of children who need support are often turned away, repeatedly. It is clear that a solution with less bureaucracy and less subjectivity is required.

Down syndrome is a permanent condition that is usually identified prenatally or soon after birth. It is very well understood, and although each person is unique in their own way, there are a few very common physical traits, such as low muscle tone, which impacts physical and communication development. This means almost all persons with Down syndrome will need and will benefit from the support of OT, PT, and SLP services, as is stated on [HealthLink BC's Down syndrome webpage](#). Delaying these services causes children to miss out on critical learning and development opportunities. A diagnosis based approach for children with Down syndrome enables them to start services quickly and it gets them out of the line up for assessments so that other children who do need assessments can get them quicker.

We believe that direct individualized funding, where spending decisions are made by individuals and their families, results in more effective, more accessible and better quality services. There are limited or no services available in some parts of the province, especially if a family is looking for a service provider who is experienced and knowledgeable about Down syndrome. Families are having to travel long distances to access care, or settle for substandard or no care. Given the opportunity, families and individuals will use resources to access the best care that works for them. Providing adequate funding for services to families will incentivise providers to live and

work where they are needed, and to provide specialized services to meet demand. Additionally, [studies](#) have shown that direct funding models promote feelings of “self-determination in all aspects of [life], a reduced sense of vulnerability, greater independence, a stronger sense of self-esteem, more fulfilling personal relationships and greater social participation,” all of which speaks to increased wellbeing.

Individuals with Down syndrome have a right to access health care. The [UN Convention on the Rights of Persons with Disabilities](#), which was ratified by Canada in 2010, states in Article 25 that parties to the convention shall “take all appropriate measures to ensure access for persons with disabilities to health services” and “Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.” At present, people with Down syndrome are not receiving adequate services in this regard.

BC already has a model for individualized direct funding of diagnosis specific interventions in the Autism Funding program. We strongly recommend that a similar diagnosis-based funding program be developed for individuals with Down syndrome.

We would like to meet with you, or your designate, as soon as possible, via Zoom or Google Meet, to discuss these proposals.

Best Regards,

Tamara Taggart
President, Down Syndrome BC

Rebecca Rubenstein
Vice President, Down Syndrome BC

CC:

The Honourable Katrina Chen,
Minister of State for Childcare,
Via email: CC.Minister@gov.bc.ca

The Honourable Selena Robinson
Minister of Finance
Via email: FIN.Minister@gov.bc.ca