



December 13, 2024

Emily Horton
Ministry of Children and Family Development

Re: Down Syndrome Resource Foundation's MCFD Engagement Project

Dear Ms. Horton,

On behalf of the Down Syndrome Resource Foundation (DSRF), I am pleased to present this report on DSRF's MCFD Engagement Project, which began in September 2024.

Introduction

The mission of the Down Syndrome Resource Foundation is to support people living with Down syndrome and their families with individualized and leading-edge educational programs, health services, information resources, and rich social connections so each person can flourish in their own right.

DSRF offers a level of Down syndrome expertise unmatched in Canada. Our caring therapists and teachers are Down syndrome specialists who work almost exclusively with individuals with Down syndrome. They have a deep knowledge of this population's unique learning strengths and needs. Our team members truly appreciate and understand the individuals and families with whom they work.

DSRF offers a wide variety of programs, services, and resources for individuals with Down syndrome of all ages and their families. DSRF is a one-stop-shop for Down syndrome, or as one parent put it, "a boutique of supporting our son for success."

Currently, support for children and youth with Down syndrome in British Columbia is severely lacking. There is no financial or therapeutic support offered purely on the basis of a Down syndrome diagnosis, despite the fact that all children with Down syndrome require speech therapy and occupational therapy in order to maximize their development. Instead, in order to receive funding, children must either qualify for the At Home Program (a subjective, stressful and often contentious process that has resulted in less than half of children with Down syndrome receiving funding), or receive a secondary diagnosis of autism. This has created an inequitable reality in which some children and youth with Down syndrome receive essential services, while others look on from the sidelines and fall further behind.

DSRF appreciates MCFD's commitment to improving the provincial supports for all children with developmental disabilities, and we are grateful for the opportunity to engage BC's Down syndrome community to inform the ministry's work.

Demographics

A total of **43 families** have been engaged thus far, with 38 families having received services this fall and 5 families set to begin in January. None of the participating families were receiving funding through the At Home Program or Autism Funding Unit prior to this project.

Location: One requirement of our funding was to prioritize reaching families outside the Lower Mainland, and this has been achieved. **11 families from rural and remote areas** have received services, representing locations including Hixon, Invermere, Keremeos, Saanichton, Chilliwack, Penticton, Kelowna, Kamloops (2), and Victoria (2). This represents 26% of participating families.

Age breakdown of children receiving services:

- 5-9 years: 24
- 10-13 years: 13
- 14+ years: 6

New vs returning families:

- Families new to DSRF: 16
- Families not new to DSRF but receiving funding for the first time: 27

Spoken Languages:

- English
- Spanish
- French
- Tagalog
- Japanese
- Fanti
- Ga

Services Received:

- Speech Language Pathology only: 26
- Occupational Therapy only: 3
- Both SLP and OT: 9

Use of Funding

Funding from the MCFD Engagement Project has been used for the following purposes:

- Providing **free speech language pathology and/or occupational therapy** sessions on a weekly or biweekly basis (43 families)
- Hosting an online **Family Information Series** with presentations by members of DSRF's therapy team on key topics related to Down syndrome. 11 families have participated thus far; another series will run in the spring of 2025. Topics include:
 - Common health and medical issues in Down syndrome
 - Communication: speech, language, social skills, augmentative and alternative communication
 - Learning profiles: why learning is difficult for children with DS and how they learn best
 - Occupational therapy topics: sensory and motor skills, executive functioning

- Positive behaviour support: why challenging behaviour occurs; positive behaviour support strategies for parents
- **Information gathering**, in the form of a 15-minute online survey sent to all participating families, in-depth personal interviews conducted with four families, and feedback from individual therapists

Success Stories

The funding that families have received through this Engagement Project has been a gamechanger, highlighting how essential this support is for children with Down syndrome and their caregivers.

Based on our survey completed by 30 families, **86% say this project has enabled them to access therapy more regularly** (and for 5 of the families, for the first time in their child's life). Notably, **76.7% say this project has provided them access to Down syndrome-specialized services**, which **100% of participants identified as being very or extremely important** to them.

The impact has been profound. **100% of participants say the project has reduced their financial burden.** One mom shared that therapy would not be an option for her child were it not for this support - her child will stop coming if the funding ends.

No less important are the emotional benefits. **60.7% of participants say the project has reduced their emotional burden, while 82.1% say it has reduced their stress.** This is so important for the wellbeing of the entire family.

The aim of this project is to improve developmental outcomes for children and youth with Down syndrome, and in that regard, we are already seeing tremendous results in a very short time. **75.9% of families report that their child is demonstrating skills learned through DSRF in home and school settings on a daily basis** (with a further 17.2% reporting such generalization of skills being evident at least a couple times per week). This demonstrates the tangible difference that adequate, specialized support makes in the life of a child.

As one parent put it: "The most valuable thing we have gained through this program is a sense of empowerment and progress for (our daughter). With continued therapy, she could practice engaging in structured social interactions, such as initiating conversations and responding appropriately, which would help her build stronger connections with peers and teachers. Therapy could also support her in managing emotions more effectively, helping her adapt to changes and challenges with greater ease... The services at DSRF have had a profound impact on how I view her future and what she can

Parent Feedback

"DSRF is THE place to be for our child. She is seen, valued, celebrated and receives excellent support via her therapies."

"In the short time we've had the grant, everyone has noticed a huge increase in his sounds and words!"

DSRF provides "a coordinated approach and a team effort between all the different support services."

"She is so close to saying some words... Without the knowledge and expertise of her therapists, we would not be able to help her get where she can go."

"We've always believed in our child's ability to thrive, but with DSRF we see a clear path to achieve this."

"DSRF provides hope and confidence that my child will have a bright future. I do feel like our family is not alone in the journey, but there are people and other families along with us that truly understand."

"I am a sole guardian to my son. Financially we are in poverty. Without this grant I am unable to pay for SLP. I honestly didn't think my son would ever be verbal. Now I see that he likely will."

accomplish. We now have greater confidence that she can grow into a more independent individual, develop meaningful relationships, and contribute to her community in her own unique way. DSRF has helped us realize that her potential is limitless with the right tools and encouragement.”

Another mom, asked how this project has impacted her family, simply said through tears, **“We’re not alone anymore.”**

Lessons Learned

A number of prominent themes have emerged as we have undertaken this project, which we urge MCFD to consider as the new system is developed.

The Value of Specialized Support

When asked to identify the characteristics of their therapist that families found to be most helpful, **93.1% indicated that having a therapist who is knowledgeable about Down syndrome was critical.** Likewise, **96.1% said that having access to an information series specifically about Down syndrome was very or extremely important.** As one mom shared, “You guys really understand what individuals with Down syndrome need, not just what individuals with special needs need.” She explained that DSRF’s therapists understand how to connect with her daughter and bring the best out of her in a way that other non-specialized therapists do not.

Similarly, another grateful parent stated, “The team at DSRF is like no other service provider. **The specialized skills at DSRF are unmatched.**” Yet another highlighted DSRF’s “specialized services that are otherwise unavailable in the community, and deep understanding of Down syndrome.” The new system must provide children with Down syndrome with access to support from those who understand them best.

Family Connections

Families found great value in connecting with other Down syndrome families. **96.2% say these family connections are very or extremely helpful to them** – something that can only be facilitated by a specialized service provider. Down syndrome is not the same as other disabilities; families need relationships with others who are on the same journey.

Inadequate School Support

We heard again and again that the level of support available through the school system is inadequate to the needs of children and youth with Down syndrome. When asked to identify additional services that would improve their child and family’s quality of life (beyond what this project offers), the number one response was educational supports. Various families report that their children receive inadequate time and attention from EA’s and are often removed from the classroom. As a result, they do not learn in the school setting and often exhibit problematic behaviour.

Non-Financial Barriers

While 100% of families needed the financial support provided by this project, there remain other barriers to participation. The ability of various families to attend therapy sessions was limited at times by parental health, life stress, custody issues, work schedules, technological issues, transportation difficulties, and language barriers. The new system must seek to minimize all types of barriers that prevent children from receiving the support they need to thrive.

Need for Increased Capacity

Capacity is a pressing issue. DSRF currently has extensive waitlists, particularly for occupational therapy. We have an immediate need for another occupational therapist, and we anticipate that if all children and youth are provided with funding for therapy, we will need to rapidly scale up our capacity.

Funding Options

Families have differing opinions on whether they prefer family-directed funding or centre-directed funding managed by DSRF. While some families are in favour of managing their own funding, others concur with one mom who shared, “Individualized funding forces me to think about what’s best for her, but I don’t want to have to do that thinking. I have so much decision fatigue.”

- **65.4% of families would prefer that MCFD directly fund DSRF** to provide services at no cost to the family; **34.6% prefer family-directed funding**
- If provided with family-directed funding, **91% of families indicated they would be likely to spend it on DSRF services**

Recommendations

Based on our findings to date, DSRF’s key recommendations for service delivery for children and youth with Down syndrome in BC include:

1. The new system must explicitly include all children and youth with Down syndrome on the basis of diagnosis alone.
 - Funding for speech and occupational therapies should begin at birth for all individuals with Down syndrome, and should continue across the lifespan
 - Funding should not be discontinued for any reason other than if a family decides they no longer need it
2. Funding for positive behaviour support must be provided to families with children with Down syndrome as needed.
 - More than half of families indicated that their child would benefit from behaviour support
3. As the province’s only specialized Down syndrome service provider, the Down Syndrome Resource Foundation should be the primary provincial service delivery resource for people with Down syndrome.
 - Specialized services should remain in place and expand to meet demand, which will rapidly increase as families receive adequate financial support
4. DSRF services should be welcomed and incorporated into the school setting through direct service, consultation, and training of educators.
 - Outreach services at school and/or home are necessary for some individuals with Down syndrome
 - Consider adapting the POPARD model for Down syndrome

5. A hybrid model of funding delivery based on family preference is the best way to ensure that every family receives the support they require. This includes options for individualized funding for families who have the capacity to manage it, or centre-directed funding for families who prefer to receive all their services through DSRF through a collaborative model between the family and DSRF's therapy team.

Once again, the Down Syndrome Resource Foundation appreciates the opportunity to participate in this MCFD engagement process. We look forward to continuing our project in 2025 and gathering more information to aid the ministry in creating a system that truly supports children and youth with Down syndrome to flourish throughout life.

Sincerely,

A handwritten signature in black ink that reads "Susan Fawcett". The script is fluid and cursive, with the first letters of each word being capitalized and prominent.

Susan Fawcett, PhD, RSLP
Director of Therapy, Behaviour & Family Support
Down Syndrome Resource Foundation

