

FOR IMMEDIATE RELEASE – November 15, 2023

Family Support Institute of BC calls for urgent action as children with disabilities remain underserved

(November 15, 2023 – New Westminster, B.C.)—The Family Support Institute of BC (FSI) urgently calls on the Government of British Columbia to swiftly implement a flexible, choice-driven, culturally safe, and healing-centered system to support BC children with disabilities and their families. This initiative must address Nursing Support Services for medically fragile children and reduce agonizing wait times that lead families to place their kids in care. Immediate action is crucial to creating a more inclusive and supportive environment for BC children with ADHD, FASD, learning disabilities, Down syndrome, cerebral palsy, rare genetic conditions, and many other diagnosed and undiagnosed conditions.

The Family Support Institute is a provincial not for profit society committed to supporting families who have a family member with a disability. It says a recent report by the Representative for Children and Youth (RCY) — *Still Left Out* — emphasizes a concerning lack of progress in supporting children and youth with disabilities in BC.

“The report underscores the critical issues faced by families across the province,” says FSI Executive Director Angela Clancy. “Prolonged waits for Children and Youth with Support Needs (CYSN) services, health assessments, and various essential programs continue to leave families in a state of uncertainty.”

Financial hardships compound these challenges, with families shouldering the burden of expenses for equipment, medications, and caregiving, often resorting to borrowing or accumulating debt, Clancy says. The sacrifice of employment due to caregiving responsibilities not only results in a loss of income but also triggers a ripple effect of losing crucial benefits that support therapies and mental health services.

FSI finds the lack of support for children with Fetal Alcohol Spectrum Disorder (FASD), learning disabilities, ADHD, Down syndrome, and other rare genetic conditions, leaves these children and their families struggling year after year. The situation is exacerbated by the discrepancy in support between foster parents and biological/adoptive families, emphasizing the need for equitable support to prevent the displacement of children solely due to financial pressures and limited-service access.

Clancy says families often face heart-breaking choices, considering placing their children in the care of the Ministry to access essential services, a sentiment echoed by a distressing 21% of RCY survey respondents. Some families encounter invasive child protection investigations or pressure to place their children in care, contributing to feelings of shame and guilt.

Critical issues within the Nursing Support Service program in particular leaves children with complex medical needs vulnerable to policy restrictions and narrowing criteria, hindering regular school attendance.

Mental health emerges as a recurrent theme, with families struggling to access specialized services in a timely manner, compounded by the lack of professionals experienced in disability.

These longstanding issues, previously brought to the government's attention, remain largely unaddressed, says Clancy. FSI stands with the Ministry of Children and Family Development (MCFD) in advocating for a needs-based model and a family-centric system, emphasizing the urgency for government intervention.

Read the full report from RCY here: <https://rcybc.ca/?p=7939>

– 30 –





About Family Support Institute of BC:

The Family Support Institute (FSI) supports families who have family members with disabilities and mental health challenges. FSI is unique in Canada and is the only grass-roots, family-to-family support organization. FSI believes families are the best resource to support one another and the most vital voice for their family members. FSI supports all families with children of all ages, disabilities, and concurrent conditions. FSI's supports are free to any family.

For media inquiries, please contact:

Angela Clancy

Executive Director

Family Support Institute of BC

aclancy@fsibc.com

(604) 540-8374 ext 6


Corrections [November 15, 2023, 1:15 p.m. PST]

The original version of this article misquoted Clancy as referring to "Children and Youth with Special Needs (CYSN)". This has been updated to say "Children and Youth with Support Needs (CYSN)" to accurately reflect her quote and the name of the service. We deeply apologize for the harm caused by mentioning the outdated terminology.

The original version highlighted the need for support services for "BC children with ADHD, FASD, learning disabilities, Down syndrome, and rare genetic conditions." We have added "cerebral palsy" and "many other diagnosed and undiagnosed conditions" with thanks to Dina Smallman for the suggestions. We apologize for the lack of inclusiveness in our original language. Clancy wishes to clarify that it is in no way an exhaustive list, and there are too many people who are not served, so the conversation needs to be had to ensure those that require support have access to it in a timely and accessible manner.

227 6th Street New Westminster, B.C., Canada V3L 3A5


 www.familysupportbc.com

 Email: fsi@fsibc.com

 Tel: 604-540-8374

Charity #: 105629497RR0001

 Fax: 604-540-9374

 Toll Free: 1-800-441-5403

