



**Views of the Family Support
for Children with Disabilities
(FSCD) program:**
strengths, challenges and
opportunities for improvement

Report on the FSCD review engagement

Alberta 

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Views of the Family Support for Children with Disabilities (FSCD) Program: Strengths, Challenges and Opportunities for Improvement – Report on the FSCD Review Engagement

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Executive Summary

In July 2020, the Ministry of Community and Social Services (CSS) began the process of reviewing the FSCD program as part of the Government of Alberta's mandate to identify cost-effective approaches to service delivery and sustainability. Over the past few years, the number of families accessing FSCD supports has increased steadily. The intent of the review was to understand how well the FSCD program is supporting families and children with disabilities and recommend options for improving the program and service delivery so it can continue to support families now and in the future.

From October 2020 through May 2021, the Ministry of Community and Social Services engaged stakeholders as part of the review. Engagement activities included a series of virtual roundtable sessions with families, parent advisory committees, academics and subject matter experts, and advocacy organizations. In total, 128 participants took part in virtual discussions over 20 sessions.

The engagement also provided families and Albertans an opportunity to give feedback through an online questionnaire. A total of 11,551 Albertans responded to the questionnaire and provided 2,844 written comments with suggestions on how to improve the program. An additional 18 written submissions were provided by families, organizations and others.

This report summarizes the main themes of the feedback provided throughout the engagement. Participants shared thoughts on what they valued most about the program, the challenges they faced and ideas on how FSCD should be improved.

Many people described FSCD as a crucial support for families raising a child with a

Who We Talked To

- Academics & subject matter experts
- Advocacy groups/professional organizations (Inclusion Alberta & Autism Society Alberta)
- Families accessing FSCD
- Families that previously accessed FSCD
- Friends/relatives of a family accessing FSCD
- Government of Alberta employees
- Interested Albertans
- Provincial Parent Advisory Committee (PPAC)
- Regional Parent Advisory Committee (RPAC)
- Service providers/Service provider leadership

disability. Some families called the program 'life saving' and credited FSCD with providing their children opportunities to learn important skills and take part in the community. Others said FSCD supports made it possible for them to stay employed while caring for children at home.

FSCD Questionnaire Respondents

FSCD Questionnaire (posted on Alberta.ca – open to public): 11,551 respondents and 2,844 comments; 46% (5,291) identified as families accessing FSCD supports; 54% (6,260) was comprised of a variety of self-identified participant categories:

- Interested Albertan (24.9%)
- A friend/relative of a family accessing FSCD supports/services (20.2%)
- A service provider to a family accessing FSCD supports/services (18.4%)
- A family with a child who has a disability not currently accessing FSCD supports/services (13%)
- Government of Alberta employee (9.3%)
- A family that previously had an agreement for FSCD supports/services (7.7%)
- Advocacy group/professional organization (3.7%)
- Service provider leadership (e.g. agency director, board member) (2.7%)

Many participants praised the program's eligibility criteria that supports children with disabilities from birth to 18 years of age, and encouraged government to maintain a needs-based approach and program model. Many people also indicated the current definition of disability should be maintained (and not narrowed) to keep the program accessible to as many families as possible, and to avoid gaps in services.

Comments made on FSCD's program budget indicated strong support for maintaining or increasing funds for the FSCD program and discouraged budget cuts that could be detrimental to the well-being of families who rely on these supports.

Although the program has many strengths valued by families and others, participants also described challenges with the program. People described FSCD as complex and difficult to navigate and said the wait times for supports were lengthy, making it difficult for vulnerable families to access supports.

FSCD provides program information to Albertans through the Government of Alberta FSCD website and program caseworkers. Many people identified their worker as their primary source of

information on the program. Some participants indicated it was difficult to get program information from caseworkers and/or the website and felt staff should be more transparent and forthcoming with program information. Others mentioned concerns with relationship instability with FSCD staff due to turnover and changing case assignments, and advised the ministry to look at staff development and compensation to improve retention.

Participants discussed the value of informal FSCD parent networks that provide voluntary, peer-to-peer coaching and mentoring to families who are new to the program. People expressed a desire for government to support and sustain parent networks so they are available to families who are still learning how the program works.

Families and other stakeholders feel there is a need for greater consistency in the way FSCD is implemented across regions, especially in how supports are distributed to families. Some saw a need for province-wide, standardized rates and billing processes. Others identified a need for better coordination, collaboration and service alignment between families, ministries, schools and other organizations (e.g. service providers).

Participants identified specific aspects of the FSCD program that may need further review and improvement. The feedback proposed Multi Disciplinary Team (MDT) panels be reviewed to improve family experience and process efficiency. While many people praised their FSCD caseworkers, some felt their workers could show families more respect and empathy during home visits and other interactions. Others felt the quality of some FSCD services could be improved and the program could provide greater financial oversight of service providers. Some families indicated a desire for better transition plans for older children moving from FSCD to other government or community programs at 18 years of age.

Reducing red tape and administrative burden on families was another prominent theme. Participants commented on the opportunity to reduce the amount of paperwork required to obtain FSCD supports and encouraged government to make use of technological solutions to improve family service experience and increase efficiencies within the program. Service providers indicated a need to use technology to streamline organizations' interactions with families (e.g. collecting parent signatures) to make administrative transactions more efficient and cost-effective.

Background

The FSCD program works with eligible families to provide a wide range of supports and services for families and their children with disabilities to promote their development and participation in family routines and activities at home and in the community. The program helps families offset extraordinary costs related to a child's disability. FSCD is designed so supports and services are focused on the unique needs of the child and family, incorporating the parents' vision for their

child's future. The program operates from an evidence-based service approach that involves families as active partners in planning and decision making on supports for their child and family.

Engagement Process

The FSCD review engagement process prioritized reaching out to families and key stakeholders to obtain feedback on the program and ideas for sustainability. The process included a series of online, virtual discussions with families and stakeholders who have experience with the FSCD program. In addition to holding discussions with families involved in the FSCD program, engagement sessions were held with academics and subject matter experts, members of community advocacy organizations, parent advisory committees and service provider organizations. Public engagement took place between October 2020 and May 2021.

Discussion guides described the topics for discussion and asked questions to uncover what was working well and what could be improved. The first round of discussions included 30 participants – academics and subject matter experts, advocacy organizations and parent advisory committees – occurring over nine sessions. The second round of discussions included 86 family members, occurring over 11 sessions. At the end of the discussions, families, community groups, service providers, Government of Alberta employees and others submitted an additional 18 written submissions on issues and concerns with the program and suggestions for improvement.

Stakeholder Group Discussions

Virtual stakeholder group discussions involved 42 participants over 9 virtual sessions, including:

- Inclusion Alberta – 1 participant
- Autism Society of Alberta – 1 participant
- Cerebral Palsy Kids and Families – 3 participants
- Academics and subject matters experts – 8 participants
- Provincial Parent Advisory Committee (PPAC) – 8 participants
- Regional Parent Advisory Committees (RPAC) – 9 participants
- ALIGN Association of Community Services – 12 participants

Engagement Survey Results

Following the virtual roundtable sessions, all participants were provided an opportunity to comment on the sessions through an online survey. Responses indicated:

- 91% agreed the engagement process gave them a way to participate in the discussion
- 77% felt heard by the facilitator
- 100% agreed the facilitator treated people with respect

Albertans were also invited to share their ideas on the program by responding to an online questionnaire posted to Alberta.ca. The ministry promoted the online questionnaire through social media and community advisory groups and organizations. In addition, families accessing FSCD supports were notified by email and provided with a link to access the questionnaire.

A total of 11,551 Albertans responded to the FSCD questionnaire – 46% (5,291) identified as families accessing FSCD supports, representing about 33% of all families in the FSCD program. The remaining 54% (6,260) was comprised of a variety of self-identified participant categories (e.g. families not currently accessing FSCD, interested Albertans, service providers). In addition, the participants provided 2,844 comments in the questionnaire offering a range of ideas on how to improve the program.

Summary of Feedback

The information in this report is a high-level thematic summary of the feedback provided through all methods of engagement and represents an overview of what was heard.

In the virtual discussions, families and other stakeholders spoke passionately about the value of FSCD for families raising children with disabilities. Participants were open in sharing their thoughts and gave examples of challenges based on their experience, offering ideas about how to make improvements going forward. Survey results and additional written submissions were similar in voicing how the program made a positive difference, areas of concern and ideas for improvement.

Program Strengths

Many families reported having a good experience with FSCD and called supports ‘life saving’ and ‘crucial’ for families raising children with disabilities. Some described the program as the ‘glue’ keeping families together and spoke specifically to the benefits for children. These parents felt the program provided children with opportunities to get involved in their communities (e.g.

participating in community swimming lessons) and to interact socially with their peers. Participants mentioned how FSCD supports helped children learn important skills and develop increased independence. Families credited FSCD with enabling them to care for their children at home and, for some, to maintain employment.

Families praised the needs-based approach of FSCD, calling it one of the program's greatest strengths. Others mentioned that many other provinces in Canada consider FSCD a model program for families raising children with disabilities. Since FSCD was originally created with input from Alberta families, feedback from families and other key stakeholders should continue to drive future program changes.

In the online questionnaire, families currently accessing FSCD supports highlighted the following as program strengths:

- 58.5 per cent strongly or somewhat agreed the roles and responsibilities of those involved with the FSCD program are clear (such as parents/guardians, government staff, service providers, etc.), while 18.6 per cent were neutral and 22.9 per cent strongly or somewhat disagreed.
- 58.1 per cent strongly or somewhat agreed the paperwork needed to get FSCD funding is reasonable, while 18.6 per cent were neutral and 23.3 per cent strongly or somewhat disagreed.
- 56 per cent strongly or somewhat agreed the FSCD program gives them the flexibility needed to manage their family's funding agreement and access needed supports and services, while 17 per cent were neutral and 26.9 per cent strongly or somewhat disagreed.
- 68.9 per cent strongly or somewhat agreed their FSCD worker is knowledgeable about the program and is an effective to support their family and child/children, while 14.2 per cent were neutral and 16.9 per cent strongly or somewhat disagreed.

“As the parent of a child with a disability, FSCD has been our lifeline. Our worker is very knowledgeable and approachable and has always provided us with a fair level of support.” – Online questionnaire respondent

Definition of Disability

There was overwhelming agreement that the definition of disability in FSCD should remain broad to ensure the program remains inclusive and supportive to families who need supports and services.

FSCD Eligibility

Families and stakeholders agreed that FSCD eligibility requirements, including the age range up to 18 years, should be maintained with an interest to avoid service gaps that have the potential to lead some families into crisis.

Program Funding

Those who commented on FSCD's program budget expressed strong support for maintaining or increasing funds for the program to ensure families get the supports they need, especially in the early years of their children's development. Some pointed to a need for increased budget to meet the growing demand for FSCD supports throughout the province. People commented on the importance of adequate program funding, calling it a worthwhile investment in Alberta families. In general, there was strong opposition to reducing the FSCD budget as that approach to sustainability would negatively impact families and children.

Most participants who commented on FSCD sustainability agreed that income testing, cost sharing and other similar measures (e.g. funding caps, age group limits) should not be used to contain program costs. Families currently accessing FSCD supports were asked in the online questionnaire if they would be willing to have limits put on some of their supports and services so that other families would have the

opportunity to access them, with 54.1 per cent of the respondents strongly or somewhat disagreeing, 18.5 per cent remaining neutral and 27.4 per cent strongly or somewhat agreeing.

Respondents were also asked if they

would be willing to share in the cost of some FSCD supports and services so that other families might have the opportunity to access them, with higher income families paying a greater share.

Among families currently accessing FSCD supports, 59.1 per cent strongly or somewhat disagreed, 17.6 per cent were neutral and 23.2 per cent strongly or somewhat agreed.

Commenters recommended the program look within its operations to achieve efficiencies and increase value through a focus on increasing the quality of services and reducing high cost, or over-used services (e.g. services used at an inappropriate intensity level).

“There needs to be adequate funding, especially for children, as it benefits society when individuals can reach their potential.”
– Online questionnaire respondent

Challenges and Opportunities for Improvement

While families and other participants were quick to acknowledge what they valued about the FSCD program, they were also clear about what needs to change.

Access to Supports

The majority of families and other participants indicated families should have faster, easier access to supports and services, including families new to FSCD and those renewing or requesting a change in an agreement for supports. While some people indicated they were able to access FSCD supports in a few weeks, others had waited months to get a funding agreement in place and called the delay unacceptably long. Delays to securing service providers puts additional pressure on families and they face agreement renewal deadlines if they are not able to access providers in a timely way. It was highlighted that timely access to FSCD supports helps protect the health of children, families and caregivers, and promotes achievement of learning outcomes through early intervention. In particular, participants pointed to reducing response times for FSCD applications and reimbursement for out-of-pocket costs, and increasing timely access to caseworkers and FSCD supports and services.

“Many of the families who access FSCD are overwhelmed in many areas of their life, so some assistance to help families navigate the system would be helpful.”
– Online questionnaire respondent

While some participants said they understood how to access FSCD supports, many families reported finding the program overly complex and difficult to navigate. People noted program complexity made it difficult for vulnerable families to access and maintain supports because they lack the time and energy required to understand FSCD processes and procedures. Suggested improvements include providing families with easy to use online navigation tools that provide a clear explanation of how the program works, and guided steps to support families throughout the FSCD journey.

Almost **92 per cent** of families currently accessing FSCD services who responded to the online questionnaire agreed FSCD supports and services should be timely and responsive to address their family and child/children’s needs and avoid more costly services later.

Information and Communication

Participants expressed strong views on communication and information sharing between families and the FSCD program. Some people said they were able to obtain adequate information from their caseworker and the FSCD website, while others felt it was difficult to get information from any available source or that information they received was incomplete. Families mentioned relying on word of mouth and social media sites run by other families who access FSCD

supports. Families and other participants indicated FSCD should improve the dissemination of program information, ensuring it is transparent and tailored to families' needs. Some also suggested the FSCD website could be improved to provide families clearer direction on service providers and more guidance on where to find them.

Flexible Service Agreements

There was clear support for increasing the flexibility of FSCD agreements to allow families more choice in how they used supports to meet their child and family's needs. While some participants were content with the structure of FSCD agreements, others supported more flexible ways to use FSCD funding to address the changing needs of their child/children and families, especially in locations where service provider availability is low (e.g. hiring family members for specified services). Families said they want access to supports they need, when they need them most (including pausing them), without the fear of losing supports in future agreements. Parents stated a preference for being able to manage within a set amount of funding across a variety of related services, rather than managing those services in prescriptive, individual service allocations.

"I think there should be some flexibility in funding and ways to support unique needs if a family is not using much funding for other things." – Online questionnaire respondent

Over **83 per cent** of families currently accessing FSCD services who responded to the online questionnaire agreed that they want to make their own choices about supports and services that meet their family's unique needs.

FSCD Program Policy and Operations

Throughout the engagement, families and others commented on FSCD program policies and operations. In many discussions, families and others called on FSCD to assess Multi-Disciplinary Teams (MDT) for high-cost services and impact on families. FSCD MDTs are comprised of health professionals who provide information to support FSCD in making decisions about providing specialized services for families that have children with severe disabilities. There was little support for the current MDT process with almost all comments pointing to the process as overly stressful, costly and potentially duplicative of additional assessment processes. Most participants

who had been through the MDT process suggested it requires immediate review and improvement.

“I would ask for more guidance when it comes to transition into adulthood. It is helpful to get a list of resources, but it would be great if the FSCD worker would also support the parents better in the process so that the transition can be made more effectively.” – Online questionnaire respondent

Some participants indicated access to supports should be influenced by the severity of a child’s disability, family structure and support system (e.g. families raising children with severe needs, single parent families and families without natural supports). Others strongly advocated that eligible families should all have equal access to program supports regardless of severity of need.

Participants felt the quality of some FSCD services could be improved. Families mentioned program oversight of service provider administrative costs, identifying clear measures of service provider

accountability for families to assess quality of services, and a desire for better transition plans for older children moving from FSCD to other government or community programs at 18 years of age.

Parent Networks

During discussions with families and other groups, many people praised the role of informal parent networks in supporting families through the FSCD journey. Participants suggested government could invest more in parent-run networks to strengthen peer-to-peer coaching and other types of mentoring supports. In their view, building capacity in parent networks provides a stronger “bridge” between families and the program by creating or extending families’ natural support systems.

“I have parent mentors who I could not survive without.” – Family roundtable participant

Consistent Service Delivery

Families and other stakeholders saw an opportunity for greater consistency in the way FSCD is delivered across the province. Many commented on delivery differences they saw between regions (e.g. experiencing different program decisions after moving from one region to another), caseworkers (e.g. families hearing different information about services to meet their needs depending on the caseworker) and between service providers (e.g. different costs of services across providers). Families noted there are areas in the province where they are competing for a small number of service providers and cannot access the services they need (e.g. psychiatrist,

staff to provide respite). Other groups saw a need for province-wide, standardized service rates and billing processes to improve efficiency and reduce administrative burden for families, service providers and staff.

“More consistency between FSCD workers is needed to ensure that policies are interpreted and applied to individual families fairly.” – Online questionnaire respondent

Collaboration and Coordination

Participants supported improving the overall collaboration and coordination of FSCD with programs in other government ministries (e.g. Education, Children’s Services, Health). Many of these participants said their experience of cumulative program reductions negatively impacted their child’s access to services and they saw a lack of coordination among ministries has created service gaps for families. Participants also noted the program should collaborate more with community organizations and families to ensure the program is enabling families to access appropriate, evidence-based supports.

Technology Solutions to Reduce Inefficiencies and Red Tape

Many people felt the FSCD program needs to improve the way it interacts with families. Some noted the program’s “red tape” (e.g. paper-based application and assessment processes) resulting in what some families consider to be too much paper work to complete (e.g. signatures and mailing paper-based forms). As an example, service providers said the current process used to collect parent signatures could be improved to make it more cost-effective and efficient, both for them and families. Technology solutions, such as online applications, online self-serve screening tools and use of digital signatures were suggested to reduce administrative burden. Participants cautioned against moving all services online since some families have limited or no access to a computer or the internet. A number of people supported the idea of giving families a choice between in-person and virtual FSCD services (e.g. meetings with FSCD workers).

“I would like to sign amendments and contracts virtually. This would take way less time.” – Family roundtable participant

Looking Forward

Throughout the entire engagement process, participants demonstrated their interest in preserving the strengths of the FSCD program while pointing to areas for change. The FSCD review engagement enabled families accessing services, stakeholder organizations, service providers and others to provide their thoughts on how the program can be improved while keeping a focus on sustainability to ensure the program meets the needs of families now and in the future.