

JANUARY 2025

Too Little, Too Late.

Experiences with Family
Support for Children with
Disabilities (FSCD)

The logo for Inclusion Alberta features the word "Inclusion" in a blue sans-serif font with an orange underline beneath the "In", and the word "Alberta" in a blue sans-serif font below it.

Inclusion
Alberta

Supporting children and adults with
an intellectual disability for 60+ years

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Acknowledgments

We would like to express our gratitude to all families who participated in our survey. While this required time, and sometimes having to share painful experiences, we are hopeful that it will lead to improvements to the FSCD program, and ultimately a renewed focus on empowering parents of children with disabilities and strengthening the family's ability to promote their healthy development and community inclusion.

Executive Summary

For twenty-one years, the Family Supports for Children with Disabilities (FSCD) program has played an essential social and economic role in Alberta by enabling families of children with disabilities to stay together, children with disabilities to thrive, empowering parents to remain in the workforce, and preventing reliance on more acute and costly government systems. Approximately twenty thousand families receive some support from FSCD, but thousands are now finding FSCD inadequate and unresponsive. Families wait years after applying, only to be offered supports that fall short of what they need. Accessing the full range of FSCD's supports requires on average, waiting an additional one year more during which persistent advocacy may be needed.

It has been three years since the Ministry of Seniors, Community and Social Services (SCSS) [released](#) how many families who are eligible for FSCD and have requested supports are waiting without support. Throughout this time, Inclusion Alberta has requested updated information to better understand wait times, eligibility decisions and support approval. In the absence of updated data from government, Inclusion Alberta launched a survey to hear the experiences of the growing number of families receiving or waiting for FSCD supports. 746 families from 81 of Alberta's 87 provincial electoral districts completed the survey in October and November 2024. This report presents findings from the survey and calls upon the government to take immediate action to ensure FSCD fulfills its purpose for those it was intended to support.

58% of respondents reported negative effects due to going without required supports, including losing employment, missed developmental opportunities, physical or mental health challenges, and being unable to meet the needs of family members.

Based on survey results, we estimate that families are waiting three years after applying before having access to full range of services that FSCD was created to provide, many of which are only available through Child Focused Services (CFS). Compared to CFS, Family Support Services (FSS) is a more limited level of services. 79% of respondents with only FSS say that that the support they really need is CFS, but 73% have not been informed how they could access CFS.

The following sections articulate the common challenges families are facing which include wait times, strenuous and time-consuming bureaucratic processes, and increased barriers to access for families like newcomers and Indigenous families.

To better support families in need of FSCD funding, we recommend that the Government of Alberta increase FSCD funding to match inflation and caseload growth of the past 2 years, provide funding and invest in the development of services to address gaps in FSCD services for rural and Indigenous families, reduce wait times and shift policies to focus on outcomes of inclusion.

Introduction

This report presents survey research on experiences with the Family Supports for Children with Disabilities (FSCD) program. Approximately 3.7% of Canadian youth and children have a disability, which means approximately 37,500 Albertans ages 0 to 17 have a disability.ⁱ Children with disabilities bring innumerable gifts, talents and contributions to their families and our communities, enriching our lives and expanding our perspectives. To create the conditions in which their children can thrive, these families often need different support than families who do not have children with disabilities. Some families find their financial resources overextended by the costs of caring for a child with a disability. Accurate costs estimates are not available in Canada but in the United States, the estimated average yearly cost of caring for a child with a disability, including lost employment earning and spending on care and services was \$10,830 US Dollars in 2012.ⁱⁱ The overwhelming majority of children with disabilities grow up at home with their families, but they are more likely than other children to end up in care of the child intervention system, with it being estimated that 40-70% of children in care in the United States have a disability.ⁱⁱⁱ Although similar data is not collected in Alberta or Canada, a review in 1997 found that 64% of children in care in Calgary region and Edmonton region had one or more disabilities.^{iv}

In 2003, Alberta MLAs passed the Family Support for Children with Disabilities Act to empower parents and strengthen the family's ability to promote their child's healthy development and participation in society.^v The FSCD program that was created as a result of this legislation also aims to prevent families from going into crisis and children from going into government care in instances "where disability related supports and services might otherwise be available to strengthen the family's ability to continue caring for their child in the family home."^{vi} Reimbursements and services provided by FSCD are for the extraordinary costs and services required because of the child's disability, not for typical parental responsibilities. 20,003 families accessed FSCD in 2023-24.^{vii} Assuming that some families include more than one child with a disability, this means that more than 53% of children with disabilities in Alberta access FSCD.

Inclusion Alberta is a family-based, non-profit federation that advocates on behalf of children and adults with intellectual disabilities and their families. We share a dream, with our partners and allies, where children and adults with intellectual disabilities are valued, participating and welcomed community members. More than 40 non-profit organizations, along with thousands of families from every corner of the province, belong to Inclusion Alberta. Through workshops and webinars, an annual conference, an annual family leadership series, opportunities for families to learn from each other, and the consultation and advocacy of staff, Inclusion Alberta assists families to effectively utilize FSCD funding and services to support their children with intellectual disabilities to be fully included in community life.

For twenty-one years, FSCD has played an essential social and economic role in Alberta, yet thousands of families now find that FSCD does not achieve its original, intended goals. In August and September of 2024, Inclusion Alberta had conversations with nine organizations that serve families of children with disabilities to understand what families are experiencing. The organizations were from several regions and differed in the types of services offered and age of children served. Information gathered from these conversations, and from the experience of Inclusion Alberta's advocacy team in working directly with over 140 families of children with disabilities in the preceding twelve months, was used to develop a survey on family experiences with FSCD.

Methods

Inclusion Alberta designed a survey to learn about the experience of families with FSCD. The survey was open to families of children with any disability who have applied for FSCD. Anonymous survey responses were accepted from families from October 22 to November 15, 2024. A separate survey on the Persons with Developmental Disabilities (PDD) program was conducted at the same time. Over fifty local, regional and provincial organizations shared the survey with families, and it was distributed by Inclusion Alberta through social media and in an email to over 15,000 individuals.

Some multiple-choice questions were mandatory as responses led to different follow up questions being asked. All short answer questions were voluntary. Short answers were analysed, and codes were developed and applied through an iterative inductive process. The full list of questions is presented in an appendix to this report.

The information presented in this report is based upon the actual experience of individuals and families. We have made repeated attempts to gain clarity about how FSCD is operating and tracking information. In the absence of any publicly released data for three years and our repeated attempts to gain clarification, this report is based on the best information about FSCD available to us at the time of writing.^{viii} Results and quotes from the survey are presented thematically together with information from other sources to piece together a picture of FSCD's current state.

Results

746 responses to the survey were received. Respondents live in 81 of Alberta's 87 provincial electoral districts. The proportion of respondents identifying as a visible minority matched the proportion reported in Alberta's 2021 census data. The median annual family income of respondents was lower than that reported for Alberta in the 2021 census.^{ix}

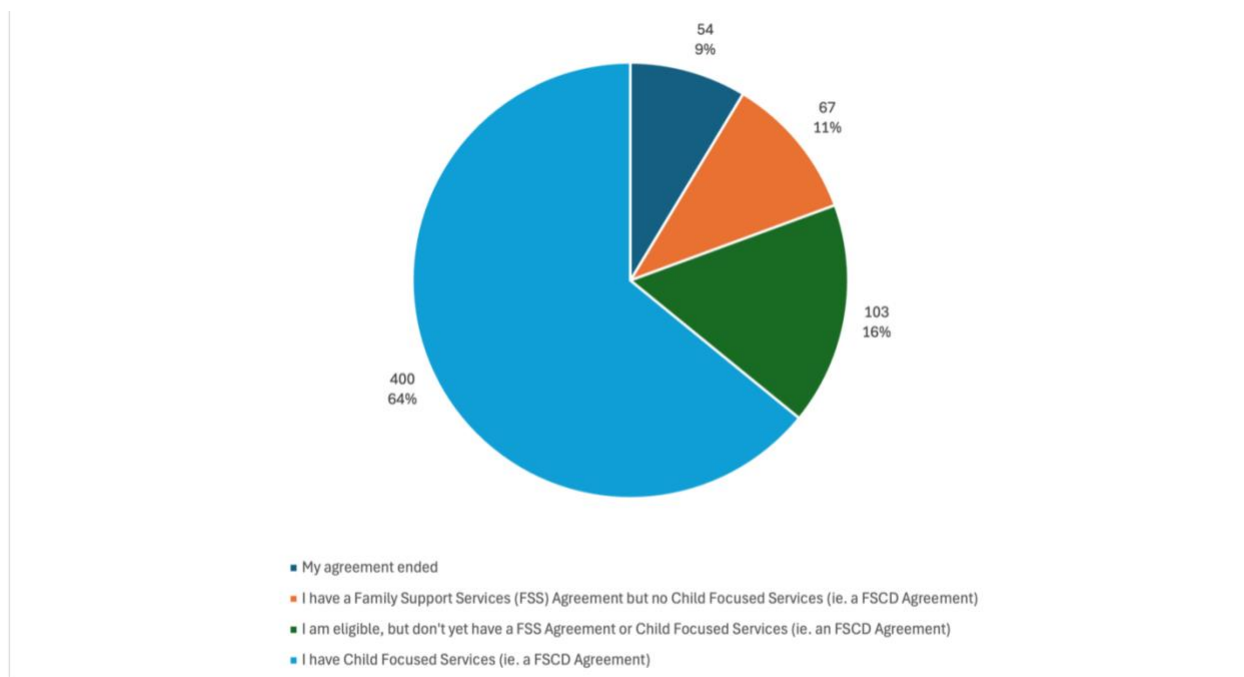
Respondents were parents whose children were distributed across the range of ages at which FSCD can be accessed (Figure 1).

Figure 1: Ages of children of respondents

Age	Percentage of respondents
0 - 4 years	19%
5 - 7 years	26%
8 - 10 years	18%
11 - 13 years	16%
14 - 17 years	17%
18 - 19, but I am answering about my experience with FSCD in the past 2 years	4%

Of the 746 respondents, 18 had applied for FSCD and been deemed ineligible, and 104 were awaiting an eligibility decision. The other 624 respondents had confirmed FSCD eligibility, and their distribution based on FSCD status is shown in Figure 2.

Figure 2: FSCD status of respondents with confirmed eligibility



How many years will we wait?

Wait times

In the absence of SCSS providing the data on expected wait times, families are left in a state of flux, not knowing whether they need to weather six weeks or three years. Inclusion Alberta estimates families are waiting three years after applying before accessing the full range of services that FSCD was created to provide, many of which are only available through Child Focused Services (CFS). In 2023, SCSS changed the process through which new families can access FSCD. Now families go through three stages:

- Stage 1: Apply and wait for an eligibility decision.
- Stage 2: Receive an eligibility decision and if eligible, wait for a Family Support Services (FSS) agreement which offers reimbursement for a limited number of expenses such as respite, mileage and parking for out-of-town medical appointments, and counselling.
- Stage 3: Request Child Focused Services (CFS) and wait for a FSCD caseworker to be assigned to do an assessment of needs. CFS includes childcare supports, assistance with extraordinary personal care needs, aide support for participation in community activities, behavioural or developmental support aides, and Specialized Services to support the development of communication and independence skills.

Before applying to FSCD, most families wait more than 6 months, sometimes longer than two years, to have their child assessed by a diagnostic clinic to confirm a diagnosis that provides eligibility for FSCD. While waiting for a full assessment some children receive a provisional diagnosis from their family doctor. Families can apply to FSCD after receiving a provisional diagnosis, but it will provide access only to FSS, not to CFS, which includes the childcare

supports without which a parent may be unable to continue working and the Specialized Services that are most urgent for children to receive to support their development in the early years.

Inclusion Alberta's survey asked respondents how long they waited at each stage, and if they are still waiting how long it has been. Respondents waiting for an eligibility decision (stage 1) have been waiting an average of 7 ½ months. In the absence of timelines or service standards from government, we do not know how much longer they will wait for a decision, but we know that half of respondents who have recently received an eligibility decision waited more than 9 months after applying to receive a decision, and 30% waited more than 12 months.

After finding out that they are eligible, individuals will wait again in stage 2 to begin receiving Family Support Services (FSS). Respondents in this stage have been waiting an average of 10 months since receiving a positive eligibility decision. We do not know how much longer they will be waiting before commencing FSS but estimates based on survey data are presented below in Figure 3. A family whose wait for FSS in stage 2 of the process has been 12 months wrote,

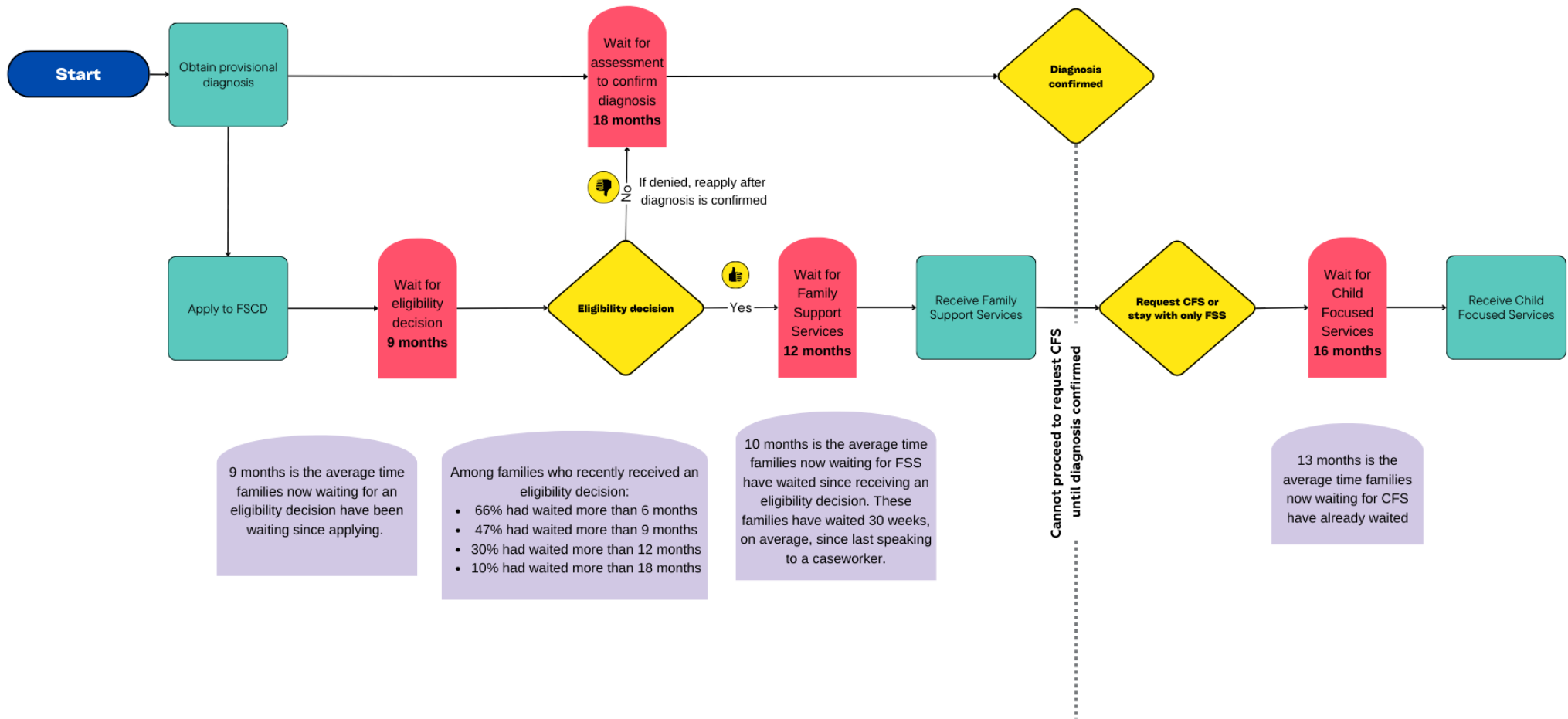
- “My son is diagnosed with autism, we apply for services, we are deemed eligible, we get a call from someone and they tell us a bunch of information and then tell us someone else is supposed [to] connect with us about an agreement. That was Nov. 2023... radio silence. I know there are people who have been waiting longer than I have. All this while my child's most precious years for development are slipping away.”

A family whose wait for FSS in stage 2 of the process has been 9 months wrote,

- “This wait has been hard I waited long enough to be able to afford to get my daughter diagnosed. She has Autism, ADHD severe anxiety. . . . I don't even really know what to say here I'm so overwhelmed and burning out having to do everything on my own to support her and her needs.”

A minority of families only require Family Support Services (FSS). The wait for these families will end approximately 21 months after applying for FSCD. 79% of respondents with only FSS say that the support they really need is Child Focused Services (CFS). After being offered FSS, these families now wait in stage 3 of the process, where some will access FSS while they wait for CFS but for others, they only continue to wait because FSS provides little or nothing that they require. Respondents with only FSS who are waiting for CFS have been waiting 13 ½ months on average since obtaining FSS. It is only towards the end of stage 3 that families finally are assigned to a caseworker with whom they can have ongoing contact. 85% of respondents who require CFS but only receive FSS have not been assigned a caseworker to handle their request for CFS. While waiting for a caseworker, families wonder how long they will be waiting and have no way to find out where they are in the queue. If they inquire by email, they receive a generic auto-reply message which states that no timeline can be provided.

Figure 3: Process flow chart for timelines accessing FSCD support



A family whose wait for CFS in stage 3 of the process has been 12 months wrote,

- “I have requested child focused services (specialized services) from the moment we applied . . . we have not yet been assigned a caseworker nor has my son been assessed for his eligibility for specialized services. We have basic services - but we REQUIRE specialized services. My son has a rare genetic disorder which is associated with intellectual disability. He has already been diagnosed with severe language / speech disorder (both receptive and communicative) and the WAIT for even an assessment is very distressing.”

A family whose wait for CFS in stage 3 of the process has been 7 months wrote,

- “We are all frustrated, aggravated, and especially concerned for my son. My son has so much potential if he had more in-home specialized supports yet he is falling through the cracks. I feel alone, unsupported, and unequipped. I feel lost on how to manage his disability without SLP, OT, and behavioural specialists providing that guidance. My child has self-injurious stims that I don't know how to manage without the help of an OT specialist which breaks my heart as a mother. I feel stress and depressed with being told "we don't know when" by FSCD about when my child will receive a caseworker. It's all very disheartening.”

A family whose wait for CFS in stage 3 of the process has been 11 months wrote,

- “Child is in desperate need of intervention and we have none because FSCD has not assigned a caseworker. This [is] impacting his development and family structure for us”.

The bureaucratic process of FSCD

Major access barriers

9% respondents with confirmed FSCD eligibility mentioned caseworkers who stood out for their empathy and responsiveness. Positive experiences with caseworkers were contrasted by respondents with what they described as their typical experience with FSCD: their genuine needs not being recognized and having to make repeated requests in multiple meetings just to get any response. 18% described negative experiences with caseworkers. They described a system that ignores their individual needs, provides no transparency in terms of what families can expect, and often treats families as if suspected of trying to take undue advantage of the program.

Families wrote about how stressful and challenging it was for them to obtain what they need from FSCD:

- “Process is still incredibly difficult and inefficient for families.”
- “There are so many cases for one worker that they leave everything until the last minute and make you feel pressured to agree to something in order to renew your contract. Dealing with FSCD and review meetings etc. leaves me in tears every time and it is so confusing and not well explained at all.”

- “Paperwork and reporting is cumbersome and intrusive, and it feels like it creates more work than it alleviates.”

Many respondents mentioned repeatedly contacting caseworkers, receiving no response, and not being notified when their caseworker was changed. Over 150 respondents mentioned how difficult it is to get information about what to expect from FSCD, what it offers, and how long you can expect to wait.

- “it’s extremely hard to get anyone on the phone or to call you back and your never notified when your caseworker changes which causes confusion.”
- “Every time we try to contact someone which just get pushed around to different people never getting answers or getting the same answer that we’re on a wait list for a caseworker.”
- “We have tried everything to advocate, including meeting with our MLA who happens to sit at the cabinet table, & gotten exactly nowhere. My husband did get a rather useless call from an FSCD manager who could provide zero timelines nor interim support. It ended up making us wonder how many staff we are paying salaries to call parents of disabled children day in & out without offering any assistance. I simply had no idea that supports for our vulnerable citizens wasn’t much more than lip service. I can only imagine how much more difficult this journey would be if we had less income, education & knowledge on our side. It makes me angry frankly.”

Families face mounting obstacles to access support

SCSS is aware of the challenges families face in accessing FSCD but rather than shortening wait times it has introduced process changes that require families to go through additional steps. One respondent summarized the opportunities for SCSS to better support families:

- “Our experience with FSCD has been challenging and often disappointing. The limited access to critical services leaves families like ours feeling unsupported and overwhelmed. We believe FSCD could significantly improve by offering more accessible funding and timely, individualized support, particularly for families with children who have higher support needs. Streamlining the application and renewal processes and improving communication would help reduce the stress we face trying to secure necessary resources. A more responsive and flexible approach would enable us to focus on our child’s development and wellbeing rather than constantly advocating for the basics.”

These same opportunities for improvement were identified in the government’s 2021 review, ‘Views of the Family Support for Children with Disabilities (FSCD) Program’, that called for “faster, easier access to supports and services.^x Budgetary pressures in FSCD mean that SCSS has had little incentive to make these improvements. Since 2021, the time it takes after applying before families can access services appears to have lengthened (though no official timelines are available), and SCSS changed the intake process so that families now begin with Family Support Services (FSS), a limited level of services, so not all families now have access to the full range of services that FSCD was created to provide, many of which are only available through Child Focused Services (CFS). Families must overcome additional hurdles to access CFS. These changes have the effect of making FSCD less accessible and consequently reducing FSCD’s spending.

73% of respondents with only FSS say that FSCD staff have never explained to them how they could access CFS. By not providing this information and by waiting as long as two years after receiving an FSCD application before a family can speak with a caseworker about their specific requirements for CFS, FSCD has created barriers to families accessing CFS.

79% of respondents with only FSS say that that the support they really need is CFS. 13% are not sure if they require CFS because CFS has not been adequately explained. Only 8% said they do not require CFS.

In PDD, many adults have no services because their needs are not deemed critical and urgent today. Many of these adults may never receive services in the future. In contrast, nearly all families eligible for FSCD will eventually receive FSS funding. Survey results show that many of these families will not eventually receive CFS because the additional meetings and further year-long wait required before accessing CFS led many respondents to give up on trying to access CFS. Since FSS was not what they needed, and they expected they would need to really fight to get access to CFS, some respondents stopped accessing anything from FSCD.

One respondent wrote “it’s not worth it”. This captures how other families reacted to waiting more than two years to access a minimal level of services that does not provide what they need, they decided not to continue trying to access support. Another respondent wrote, “Too frustrated to deal with all of the red tape.”

- “The system is very punishing. Workers are hard to reach. Don’t return calls. Don’t seem to care they are dealing with peoples lives - families trying their very best to provide supports for their children.”

Families that persist trying to get what they require will encounter more challenges. Finally meeting with a caseworker to discuss a request for CFS does not mean that all required CFS services will be offered. Again and again, respondents described making a clear request for services based on a documented need, only to have FSCD deny the request. Families who receive a denial should have the options of requesting an Administrative Review of the decision by a manager, or of bringing their dispute to an appeal panel. However, among respondents with agreements that failed to provide what they needed, 58% were never advised that they had the right to appeal a decision by the FSCD program (Figure 4).

Figure 4: Percentage of respondents informed of their right to appeal



Some respondents reported being given incorrect information about what decisions were appealable. Of respondents who participated in an appeal, 64% found the process to be unfair. Respondents who had tried getting what they needed through an Administrative Review or Appeal experienced FSCD as having the default posture of putting up barriers to families:

- “I don’t think there should be these reviews. The simple fact is families shouldn’t have to wait years for funding and then made to prove the need to such extreme extents its already hard enough trying to get the needs of neurodivergent kids met let alone struggling to constantly prove time and time again and creating longer wait time for coverage.”

- “To appeal an FSCD decision is a fight that no parent should have to make. We fight everyday for our children. We want what’s best for them and should exhaust ourselves to do that! I am already exhausted.”

After waiting years to access FSCD, the experience families have with the program is that caseworkers are slow in responding to their requests, and the eventual response is often to challenge and deny the genuine needs they express for support. When FSCD refuses to provide what a family should be offered and fails to inform the family of the dispute mechanism process and right to appeal, its representatives fail to uphold the [FSCD Act's](#) guarantee of the right to appeal.^{xi}

Inequitable access

Families in rural areas, Indigenous families, newcomer families, and families with English as an Additional Language face more barriers accessing FSCD.

- “I think the process is designed to have as many people fall through the cracks as possible. English is my first language and I am highly educated. If I can’t understand the process, I’m sure it’s too confusing and convoluted for many others as well.”

The 2021 review of FSCD pointed out that “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.”^{xii} This confirms the finding of earlier research prepared for the Government of Alberta that families from lower socio-economic status neighbourhoods access FSCD at far lower rates than other families.^{xiii} Parents with low incomes have fewer internal and external resources that support them in navigating complex systems in such as FSCD. Some families experience compounding disadvantages due to intersecting factors. For instance, a significant proportion of families headed by parents with disabilities experience poverty. One parent with a disability described how difficult it was for them to access FSCD in the absence of support from caseworkers:

“The case worker and her supervisor have been rude and abrasive when I request them to speak to me in simplified terms due to my inability to comprehend information due to my own learn disability [*sic*].”

While some respondents who needed support in planning and navigating how to get help found caseworkers to be supportive and trusted guides, others described being denied this help.

- “When I told my FSCD caseworker about the issues my family were having and that I’m on my breaking point she signed me up for triple P program which was not helpful at all I felt like it wasn’t helpful to my situation not relevant. I felt like I wasn’t listened to. It is also really hard to find supports. My daughter is nonverbal and I can’t even get a speech therapist. You get your agreement from the FSCD and then you feel like you’re just shoved out the door and on your own.”

Survey results provide information about four additional populations that face access barriers: families in rural areas, Indigenous families, newcomer families, and families with English as an Additional Language. Many families from these communities require additional navigational support, flexibility, or cultural responsiveness that is not available from FSCD. We highlight specific challenges for these communities in the sections to follow.

Newcomer families and English as an Additional Language families

The absence of accessible and clear information and options about how to access FSCD pose added barriers to families who are new to Canada or who have English as an Additional Language. This was a concern observed by respondents who were not themselves newcomers or English language learners.

- “Many of the clients and their families are losing their hope to have the services in place; It is even more complicated for newcomers who have more barriers to understand why their requests are being ignored.”
- “Because I was able to advocate for myself I was able to get more support. Sadly not all parents are like me. The newcomers are living difficult and stressful time with their disabled children.”
- “there is a lot of buried/coded language required that likely disadvantages people with English as a second language.”

One organization that supports newcomer families told Inclusion Alberta about newcomer families who have not been able to navigate the process of getting the supports they require from FSCD and then end up in crisis. They said that in the absence of FSCD services, many of these families end up facing children’s intervention involvement from the Ministry of Children’s and Family Services.

Indigenous families

According to SCSS data, during 2023-24, FSCD supported 584 Indigenous children, a decrease from 650 the year before.^{xiv} If FSCD was accessed by Indigenous children at the same rate as by the population at large, 833 would access the program. In 2023-24, only eight First Nations children on-reserve accessed FSCD. If accessed at the same rate as the Alberta population, this would have been 145 First Nations children.

Indigenous families are eligible for FSCD, but FSCD was not created with Indigenous families in mind.^{xv} FSCD policies present barriers for Indigenous families. The requirement that only a parent or guardian can request FSCD services blocks the many Indigenous children living in the care of family members who are not their parents or guardians from accessing FSCD. Also, many reserves are not served by any FSCD service providers. A barrier that exists both on reserve and for Indigenous families elsewhere in Alberta is that many service providers do not have policies, staff training and cultural knowledge to support the delivery of services that are culturally relevant.

76% of Indigenous respondents to the survey reported negative impacts from going without funding, services and supports they need. This is significantly higher than the 60% found across all respondents. Looking at responses from the 6% of survey respondents who identified as Indigenous provides some information about their interactions with caseworkers and the barriers they encountered.

- “The process was beyond stressful, it made me out to be a villain and that I was asking for more than I should [Caseworker]’s comments were rude, dismissive and bullying.”

- “Every single request for assistance and supports was denied!! To be told to drop the youth off at a youth emergency shelter is absolutely disgusting!!!!!!”
- “We have had a worker for the last 2 years that always disagrees with our comments and puts blame on our family circumstances that we are in crisis to us not doing enough.”
- “We live in the country on a First Nation community and we have very limited options for respite. . . . It seems like his agreement is focused on providing very little as possible and not focused on where he’s at and not matching him to what services he can help assist him.”

Some stopped trying to access FSCD because of the hurdles they encountered, and one reported being told by a caseworker that families could receive FSCD for a maximum of two years, which is untrue. One family said it was unhelpful that a caseworker expected them to apply for Jordan’s Principle funding, even though, as Métis, they are not eligible for Jordan’s Principle.

Indigenous families experienced a range of negative impacts due to going without needed FSCD supports, including having to pay for services they could not afford and having to leave the workforce due to being unable to access childcare support.

Rural Families

Families of children with disabilities in rural areas face unique challenges due to the lack of availability of services locally, and the time and expense required to travel to access services. 72% of respondents from rural areas reported negative impacts from going without funding, services and supports they need, as opposed to only 60% of respondents from the Calgary and Edmonton metropolitan areas and Alberta’s five next largest cities.

Families struggling without needed support

Minimal supports that fall short

467 respondents receive FSCD services (including FSS and CFS). Among those, 70% of families with FSS and 40% of families with CFS say their agreement does not provide what they require (Figure 5).

Figure 5: Percentage of families with FSS getting the supports they require



More families with FSS are not getting what they require from FSCD because FSS is more limited than CFS. Only CFS can provide childcare support, and services from occupational therapists, speech language pathologists, behaviour consultants and physical therapists (provided through the categories of Specialized Services or Behavioural and Developmental Supports). CFS can also provide a greater number of hours of respite, and provides support for

a child's participation in recreation, leisure, clubs and other community groups. However, an agreement that includes CFS may not include specific funding and services that a family requires. Figure 6, below, presents results of the question "how does FSCD funding, services and support differ from what your family requires?"

Among respondents whose agreements do not provide what they require, **43% have an unmet need for either Specialized Services or Behavioural and Developmental Supports.**

This unmet need exists for 55% of families with FSS, and for 39% of families with CFS. For families with CFS, caseworkers have discretion as to what to put in an agreement, and the decision to offer Specialized Services comes from a provincial review committee which usually will not approve services until a Multi-Disciplinary Team panel has reviewed the request and recommended approval. Specialized Services and, a similar but lower level of service called Developmental and Behavioural Supports were the top thing mentioned by families that they needed and were not receiving from FSCD.

Families with the youngest children feel the greatest urgency to access either Specialized Services or Behavioural and Developmental Supports, because they know that interventions before a child begins school usually have the greatest benefits. Many of these young families see critical early years slipping away while they wait for a diagnosis, wait for an FSCD eligibility decision, wait for a FSS Agreement, wait to be assigned a caseworker, wait for a decision on their request for CFS, wait for an MDT panel to convene and make a recommendation on Specialized Services, and then either wait for a service provider to have availability or instead undertake the process of assembling their own team of professionals to provide services.

Not only does Specialized Services begin years later than would be optimal for many families who need it, but it also may be discontinued before the family has received services for a sufficient length of time. Many respondents expressed concern that caseworkers impose the rule that Specialized Services can continue no longer than three years, regardless of the child's ongoing need. This maximum does not exist in FSCD's regulation or Policy Manual.^{xvi}

Among respondents with FSS whose agreements do not provide what they require, **36% have an unmet need for childcare support from FSCD.**

Though many children with disabilities require no additional support while attending childcare, some require FSCD funding for one-to-one support in Early Learning and Child Care or before-and-after-school care, or funding for in-home childcare when day homes and childcare centres are not accessible.

Among respondents whose agreements do not provide what they require, **14% of families say that the rates paid by FSCD are too low for them to be able to hire qualified support staff or professionals.**

Comments mention being unable to use respite funding because of the challenge of recruiting skilled staff at FSCD's rates. Families report having to pay out of pocket for SLP, OT and psychologist services because the rates reimbursed by FSCD are far less than those charged by professionals.

Figure 6: Responses to the question "How does FSCD funding, services and support differ from what your family requires?"

How support differs from your requirement	Percentage of respondents with only FSS	Percentage of respondents with CFS	Percentage of all respondents
Specialized Services AND/OR Behavioural and Developmental Support	55%	39%	43%
Amount of funding/hours of support	55%	28%	34%
Child Care Support	36%	12%	17%
Respite	5%	20%	17%
Rates of Pay	19%	13%	14%
Limitations and conditions of support	2%	11%	9%
Total respondents #	42	148	190

Supports being cut

There are indications that cuts are being made to funding and services when agreements are renewed. Among respondents with FSS, three times more families (18%) had their funding reduced as had it increased (6%) when their agreement was last renewed. Among respondents whose FSS funding either decreased or stayed the same, 69% had requested an increase and had the increase denied. FSCD received no budget increase in Budget 2024, so it is unsurprising that it is making cuts or limiting supports as it tries to spread the same funding across an increasing number of families.

The impact on families of going without supports

58% of respondents reported negative effects due to going without required supports. This includes all categories: those waiting for an eligibility decision, eligible but waiting for services, with FSS, with CFS, or those whose agreement ended. 60% of families with only FSS reported negative impacts due to not getting required supports, a larger percentage than the 38% of families with CFS who reported negative impacts. Families who did not have access to CFS reported a greater number and severity of negative impacts.

Among respondents who reported negative impacts due to going without required supports, **24% reported employment impacts.**

This includes job loss, reduced work hours, having to discontinue schooling, or having to miss work.

- “My autistic twins have lost 3 spots in childcare settings, have been denied from many more, we finally secured a spot for both of the twins, and jumped through all the hoops demanded by FSCD, for them to say “the files have been updated we cannot give an estimated time on when you’ll be contacted by a worker if you lose your placement please let us know so [we] can note that in the file” which is exactly what will happen. I told them when we started jumping through their hoops that I NEED THEM in daycare due to returning to work / full time schooling and was assured these hoops would make it happen. Now I face being thrown out of my programs and the financial strain of hiring someone or losing my job.”

- “I can't work because I have to take care of my son, I am not receiving any service or support. I feel . . . abandoned”
- “Impact our physical and mental health since my son [does] not sleep [the] whole night, kept awake for a few hours which cause[s] us [to be] extremely tired, [I] couldn't handle my work sometimes. My son had behaviour problem, no daycare accepted him, one of parent has to stay home to take care of him. [This] impacted our marriage as well since we disagreed with the way we treat our son at home, we need rest, need professional support to teach us how to educate my son, we need to find a daycare”

Among respondents who reported negative impacts due to going without required supports, **34% reported financial hardship.**

This includes challenges paying for services/supports, having to relocate, and impacts on employment that cause loss of income.

- “My son has been kicked out of multiple preschool / child care programs. We are struggling to manage his behaviour at home, in the community, and at school. . . . We have had to privately hire 1:1 support for the end of last school year and the summer. We had to take out a personal loan to be able to do this, and it has placed us in significant financial hardship. . . . It has impacted our ability to work, because we get constant calls that we need to come get him. Emotionally, physically, and mentally our family is struggling. . . . I am worried not receiving early intervention will exasperate the challenges. We need to not be waiting months without acknowledgement, support, or services.”
- “I am in serious need of support as a widowed, working mom of 4. My natural supports are dwindling as grandparents are less available and teen children are unable to babysit due to their own commitments. I am hiring support privately when I can, which is causing financial strain.”
- “The extraordinary costs & impact on mental health are very real. The amount that we've spent on psychology, both in getting diagnosis & on-going visits to help family members navigate, adapt & process, would be staggering to most households.”

Among respondents who reported negative impacts due to going without required supports, **50% reported missed developmental opportunities.**

This includes lost access to Early Learning and Child Care, and consultation with Speech Language Pathologists, Occupational Therapists, Physical Therapists, behaviour consultants or psychologists.

- “My son is diagnosed autism . . . and he is 7 years old now he is eligible but still waiting for caseworker as what the email send to me. My son need support for his speech therapy occupational therapy and other kind of service he most of the time got anxiety attack, behavioral breakdown and as I mom I do my best but the professional only can help my son better. This crisis our salary is only enough for our basic needs.”
- “We are coming up to a year since my son's diagnosis, with zero financial support in place. Thousands of dollars later, he is getting the intervention he needs. Luckily, I am paid well and we are able to take these hits in the short term (though to be clear, they

have had a severe impact on our life). I get physically ill thinking about families that do not have the resources available to shell out thousands a month on care, all when you are told over and over again that the first five years of your child's development are the most important. . . with respect to early intervention and the associated long-term outcomes. I don't understand why there are such severe delays in accessing FSCD funding. These delays are having massive impacts on early childhood development for a bunch of kids in need.”

- “missing opportunities for intensive therapies that are would be most effective at this stage in his development - which can then impact his educational, social, relational and employment outcomes down the road; missing opportunities that can enhance his capacity to be in educational settings and social community”

Among respondents who reported negative impacts due to going without required supports, **10% reported impacts on their child’s capacity to consistently attend school.**

This includes school absences, behaviour or learning challenges at school, or a child not having developed the skills and tools that would enable their inclusion or learning at school. FSCD services are not intended to directly support a child’s needs related to school, but going without FSCD services that support a child to develop independence and communication skills, and to be included in Early Learning and Child Care, can make it much more difficult for a child to be successfully included at school. Children’s lives are not siloed, and so what happens at home and in the community impacts school.

- “My child was unable to attend over 50% of grade 2 due to lack of available interventions. As her parent, I was laid off (Sept 2023) shortly before [she] got her diagnosis (Nov 2023, \$6k paid out of pocket) and have been unable to find employment due to my lack of availability given the lack of resources and support to get her back into school, whether those were psychological therapy, occupational therapy, or respite. We are paying out of pocket for therapies and I am going into debt to afford the minimal therapy we can provide her (psychologist every 2-3 weeks). I am unable to afford the occupational therapy that she desperately needs in order build her social skills and adapt away from violent and abusive responses to discomfort We have no financial support with her psychological therapy appointments, as she needs more. We are desperate for respite, as my child has high social needs. But we cannot afford respite rates for caregivers and especially not supportive activities like AAFS.”

Among respondents who reported negative impacts due to going without required supports, **18% reported impacts on community inclusion.**

This includes not receiving support to address barriers to community inclusion. Missing opportunities for inclusion contributes to isolation or lack of social support.

- “My son has been kicked out of multiple preschool / child care programs. . . . I am worried not receiving early intervention will exasperate the challenges. We need to not be waiting months without acknowledgement, support, or services.”
- “It has a be a huge impact as we have applied for both children. . . . The children will not get [to be] involved in normal activities outside of school”

Among respondents who reported negative impacts due to going without required supports, **47% reported impacts on family wellness.**

This includes physical or mental health challenges, burn-out, family relationship problems/conflict, and being unable to meet the needs of other family members.

- “I am unable to work as I need to be home with my son, he struggles with school challenges as well, so I am often home with him when he is unable to attend school or is sent home. My other child is greatly impacted as well from lack of support for my son. Having respite would help with me engaging with my other child one-on-one since my disabled child takes up a lot of my time. My child with the disability has been really secluded from the community over the last year and having no supports is really hard to navigate that. Our family would benefit from counselling services as well but since I am a single parent that cannot work due to my child's disability it is hard to be able to afford counselling without assistance. Overall, I am disappointed that I have yet to even receive a call from anyone and it's been 8 months since I was approved.”
- “We were in an incredibly vulnerable time in the last year and I just can't stress enough how much that help, sooner, would have meant. I had to quit my part time job out of the home to be more available to my son, and to attend many appointments and therapies both locally and 2 hours away, and my hours to work from home are extremely limited as my son needs to be supervised non-stop. Working outside of the home would provide more income as well as improve my mental health but it hasn't been realistic. This disability has made it hard for our other children as well; and has limited their outings, their time with their parents, and the attention we can give. Respite would help with all of this.”
- “medical conditions worsening for me due to exhaustion and stress being sure my children get the support they need as both children require hand to hand support for dressing, bathing, brushing teeth”

Family breakdown

Family breakdown occurred when partners separated or when a child was placed in care of the Ministry of Children's and Family Services. A few respondents mentioned that the not receiving needed support caused strain between partners and contributed to partners separating. Inclusion Alberta has seen repeatedly that when families of children with complex and resource-intensive support needs experience a crisis and are not supported, there is a high risk of the child intervention system placing the child in a group home or foster care. One survey respondent described this experience, “We are about to give up and give our child to foster care”.

The Office of the Child and Youth Advocate released a Special Report in 2024 that found that FSCD's unresponsiveness contributes to children and youth with disabilities ending up involved in the criminal justice system, homeless, or placed by child intervention away from their family. The report quoted a stakeholder who stated, “Lots of kids come into the child intervention system because of the lack of support from early intervention and FSCD.”^{xvii} We have chosen to include quotes from the Child and Youth Advocate's report's interviews with young people with disabilities who ended up in government care. The voices of these children and youth are so important but they were not part of our survey.

- “Parents need way more support. If I didn’t have to come back into care, I think things would have turned out way better for me.”
- “I wish there had been more money and help for my mom to take care of us and keep her kids. Where we came from community and family was important and now none of us have any.”
- “Help families more so their kids with disabilities can stay at home.”
- “There was never enough help for my adoptive mom and sometimes I wonder if that’s why my birth mom couldn’t keep me. Like was there no help for her either?”

FSCD’s Positive Outcomes

Parents of children with disabilities are committed to their children. The survey’s responses show them to be frequently supporting their children when parents typically would be at work or asleep, and to be relentless advocates as they attend countless meetings with government, service providers, medical professionals, and educators. Their support for their children is impossible to replace, though in the past governments did displace parents through institutions at enormous expense and horrifying human cost. The families who responded to the survey were not asking FSCD to do anything that is considered a typical parental responsibility in Canada. Twenty years of FSCD’s operation in Alberta confirms what the research on families of children with disabilities shows, that a small amount of support for families enables significant positive outcomes across a range of domains.

Although, 70% of respondents with FSS and 40% of respondents with CFS are not getting services that adequately meet their needs, the services they do receive have positive outcomes for nearly all recipients. 52% of respondents with FSCD services wrote about positive outcomes that FSCD allows them to achieve for themselves or their family. The positive outcomes they mentioned were coded into categories, and some responses mentioned multiple outcomes. Survey responses show that while many families are experiencing negative impacts due to going without needed supports, FSCD still has the capacity to play a significant positive role for those families that have services.

Among respondents who described positive outcomes,

55% reported benefits through developmental opportunities for their child.

These families reported that FSCD enabled their child to access Early Learning and Child Care or recreation environments that fostered developmental gains, or that FSCD engaged professionals who worked with the child and family to promote the child’s development and generalize skills and strategies across the child’s natural environments.

- “The importance of my FSCD program is that it provide [*sic*] me and my child the support he needs to become more independent and it also set strategies to help him build communication and interaction with other individuals”
- “My son has had a contract for the past 2 years and it has saved our life. Our family circumstances were very tenuous when we applied. . . . Now we are all thriving, my husband and I are still married, and my son is in a regular kindergarten class. . . . We have a much greater understanding of his disabilities (ADHD, SPD, GAD, chronic

constipation, strabismus) and all the ways that he can be supported at home and in the community.”

Among respondents who described positive outcomes, **42% reported enhanced family wellness.**

Families reported that FSCD supports allowed the family to maintain physical or mental health, maintain healthy relationships within the family, and to meet the needs of other family members.

- “My child is almost 18 years old and will soon be done FSCD. She has had FSCD since she was a toddler and it has been integral to our family's well being. . . . Without those services, our family would likely not be in one piece. Not only would our marriage have fallen apart, but we would have needed to find a out of home living placement for our daughter For us, the supports we have been given have not been adequate, but they have taken the edge off. Both my husband and I have made great sacrifices in our careers in order to balance her needs and our own well-being. Financially we are much further behind than we would have liked to have been, both due to the costs of raising her and the lower paying jobs we've taken that allow us the flexibility we need. . . . But, despite this, we are deeply grateful for the services we have received throughout the years from FSCD and cannot image what our lives would have been like without it.”

Among respondents who described positive outcomes, **33% reported improved financial security.**

Families saw improved security due to FSCD sharing costs for services, supports, childcare, treatment, therapy, or equipment, or because of FSCD supports enabled a parent to maintain employment income.

- “Without the FSCD program we would not be able to afford the supports that our daughter and family needs. With our OT, our daughter is able to make progress with her personal and social skills which enriches her life and ours by extension. Having respite support helps us to become better parents by giving us time to rejuvenate our minds. Psychological support also helps us work through tough issues”

Among respondents who described positive outcomes, **12% reported a parent being enabled to remain employed.**

Some children with disabilities require an enhanced ratio of support to attend Early Learning and Child Care or before-and-after-school care, and by providing funding for this support FSCD made it possible for a parent to remain employed. For a small number of families who were unable to access a day home or childcare centre, FSCD enabled continued employment by funding in-home childcare. FSCD services may indirectly support the maintenance of employment, for instance by relieving parents of physically demanding personal care responsibilities, allowing the parent to maintain health and wellness to the degree required for paid employment. Families describe the important role FSCD supports play in supporting their child to develop independence and self-regulation that support their consistent school attendance. This is significant because many survey respondents described missing work or having to change jobs because of how often their child was sent home from school.

- “As a single mother, without the FSCD agreement, I could not continue to work as a school vice principal.”

- “Life changing. Our family would not be able to function without these services. My husband and I both had to take leaves from work before the funding. Three years later we are an extremely happy and well functioning family and it is due to the services we receive through FSCD funding. But we have had to fight very hard to receive every penny.”
- “The most important things FSCD provides for us is domestic childcare and overnight care for our medically complex child. Without this support, one parent would have had to give up their career and we would be much worse off financially. The support we get from FSCD allows our family to find time to rest, earn, and take care of ourselves physically and emotionally. We need all of these things to be the best parents for our profoundly disabled child. Before these FSCD supports, my husband and I spent years not going to any medical appointments for ourselves as we just did not have the time of energy. Life is still incredibly busy and stressful but FSCD’s support make it much more manageable.”

Among respondents who described positive outcomes, **11% reported outcomes of community inclusion for their child.**

This includes participation in recreation, sports, clubs, arts, volunteering, cultural community, faith community or other community activities/groups, developing friendships and a network of natural support. Outcomes of inclusion are significant not just for their immediate pay-off in enjoyment, physical health, and making friends, but also because children who are included gain long-term with improved learning/skill development, cultural literacy, improved communication, improved behaviour, greater likelihood of career and employment, more comparable life outcomes to people without disabilities, and reduced risk of abuse.

Recommendations

The Government of Alberta must act now to renew the FSCD program, ensuring it fulfills its intended purpose and consistently supports the outcomes it was created to achieve. Sufficient funding for FSCD enables families to stay together and children to thrive, empowers parents to remain in the workforce, and prevents reliance on more acute and costly government systems. This survey highlights how failures in FSCD are harming families—harm that extends beyond those with children who have disabilities. With ER’s, shelters, health and mental health services already stretched to the breaking point, the government cannot afford to let families who have children with disabilities fall through the cracks. The time for action is now.

The public finance and moral grounds for supporting families of children with disabilities are clear, but where do we begin addressing the many specific problems with FSCD’s funding and delivery highlighted by families in this survey?^{xviii} Implementing the following four recommendations would make a world of difference to families with minimal new spending required. FSCD accounts for only 0.3% of the Government of Alberta’s spending.

These recommendations address only a slice of the ideas offered by survey respondents for fixing FSCD. Inclusion Alberta is committed to raising the comprehensive range of issues identified by families and to bringing the experiences of families into policy conversations with government, as we seek to work together to develop solutions.

- 1. Increase FSCD funding to match inflation and caseload growth of the past 2 years so that families receive timely access to services that are critically important for their children's development and inclusion.**

Unprecedented population growth is putting additional pressure on the FSCD program as it has in our education and health care systems. FSCD received no budget increase in the 2024 provincial budget. To provide the same level of services available to families in 2010-11 to those eligible for FSCD today, and adjusting for inflation, the FSCD budget would need to double. At minimum, the Government of Alberta must invest in FSCD to bring funding in line with the past two years of inflation and record-breaking population growth. This investment will support financial security, employment, family wellness, and child development and reduce future costs in other government ministries.

Families giving up their child to care of the Ministry of Children and Family Services is only one example of how families who cannot get timely access to FSCD are forced to access other government services. Staff in the fields of healthcare, education, child intervention, and homelessness report that FSCD's unresponsiveness to the disability-related support needs of some families leaves some families to descend into crisis, at which point other systems intervene at greater government expense.^{xix}

Children with disabilities face greater challenges learning when they begin Grade 1 if they did not access support from Speech Language Pathologists, Occupational Therapists, psychologists and behaviour consultants in the critical early years. These are supports FSCD can provide, but most families are now made to wait for years before being assigned a caseworker who could approve this funding. Not only does the prolonged wait to access CFS through FSCD hinder the development and learning of children, but any costs it saves in the FSCD budget are likely to be less than the costs it passes forward to the education system. Children who do not receive these services between ages 2 and 5, years in which children are primed for rapid developmental gains, require more intensive in school support from teachers, educational assistants, Speech Language Pathologists, Occupational Therapists, psychologists and behaviour consultants.

- 2. Provide funding and invest in the development of services to address gaps in FSCD services for rural and Indigenous families.**

Supports should be available regardless of geographical barriers. To support the unique needs of rural and Indigenous families, mileage should be funded, and the government should fund the development of culturally relevant FSCD services for First Nations families on reserve and Indigenous families in other communities, similar to its initiatives in child intervention.

There are geographical gaps in the availability of the in-home supports FSCD can pay for. Rural families rarely can get support in their homes because the cost to travel to and from rural family homes often exceeds the wage for a 3-hour shift. FSCD does not cover mileage and travel time for service providers, support workers or therapists. FSCD does partially reimburse mileage to attend medical appointments. If rates were adequate, this could be a significant benefit for rural families, some of whom make multiple trips each year to Calgary or Edmonton for appointments for their child with a disability. The mileage rate (\$0.12/KM), and the rates for childcare for siblings, hospital parking, meals and accommodations have not increased in more than 13 years, a period in which inflation has risen 35%.

3. Reduce wait times.

a. Offer CFS to families as soon as their FSCD eligibility is confirmed.

This will significantly reduce red tape and wait times since 79% of respondents with only FSS say that that the support they really need is CFS. There is no reason to require families who have already been waiting for an FSCD eligibility decision to go through another long and opaque process. This is especially important because CFS includes Specialized Services and Behavioural and Developmental Supports that are most effective when accessed early, and because delays in accessing childcare support (available only in CFS) can jeopardize parent's employment. Families with a provisional diagnosis would still be able to access FSS while awaiting a confirmed diagnosis to qualify for CFS.

b. Establish service standards that limit how long families will wait and ensure regular and timely communication.

The SCSS Business Plan includes a performance indicator for the median time between when an Assured Income for the Severely Handicapped (AISH) application is ready for medical adjudication and an eligibility decision is made.^{xx} The target is 9 weeks. SCSS has not released any target for how long families should expect to wait to access FSCD. SCSS should introduce service standard time limits for each stage of the process of accessing FSCD, and publicly report on its progress to meeting those standards. Standards should also mandate communication protocols for regular communication and timely responses from caseworkers.

4. Shift policies to focus on outcomes of inclusion.

FSCD funding and services have the greatest positive outcomes when used to support children with disabilities to be included in their communities. Children with disabilities who are included show greater developmental and educational progress, and over time they may require less paid support as they participate with non-disabled friends in sports, leisure, arts, faith and cultural communities. Currently, FSCD will pay registration fees for children to attend segregated summer camps that are only for children with disabilities, but parents wanting to register their children in inclusive programs usually receive no support from FSCD.^{xxi} Also, families with FSS can access Respite funding to pay staff to provide one-on-one support for their child at home to give the parents a break, but cannot receive Community Support to facilitate their child's participation in inclusive community activities and groups, a natural form of respite available to families of children without disabilities.^{xxii} Community Support has the same outcome as Respite of providing a break for parents and has the superior outcome of facilitating a child's community inclusion. Shifting FSCD's emphasis from segregated programs towards inclusive recreation, and from Respite towards Community Support will maximize the outcomes of FSCD spending.

Conclusion

Inclusion Alberta hopes that the survey data and this summary report highlights that the challenges families are facing are unfortunately, not unique to an individual, but rather the reflection of an approach that has been taken to the administration of the program. The recommendations within the report are intended to ensure those the legislation was created for, can realize the outcomes it was intended to achieve.

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- ⁱ Canada. Human Resources and Skills Development Canada. “Disability in Canada: A 2006 profile,” (2011): 5. https://publications.gc.ca/collections/collection_2011/rhdcc-hrsdc/HS64-11-2010-eng.pdf; Canada. Statistics Canada. *Populations estimates on July 1, by age and gender, 2022*. 2024. <https://doi.org/10.25318/1710000501-eng>
- ⁱⁱ M. Stabile & S. Allin. “The economic costs of childhood disability,” *The Future of Children* 22, no. 1 (2012): 65 – 96. <https://files.eric.ed.gov/fulltext/EJ968438.pdf>
- ⁱⁱⁱ L.E. Powers, S. Geenen, J. Powers, S. Pommier-Satya, A. Turner, L. Dalton, et al. “My life: Effects of a longitudinal, randomized study of self-determination enhancement on the transition outcomes of youth in foster care and special education,” *Children and Youth Services Review* 34, no. 11 (2021): 2179–2187. <https://www.sciencedirect.com/science/article/abs/pii/S0190740912002927?via%3Dihub>
- ^{iv} Inclusion Alberta, in partnership with what was then the Ministry of Family and Social Services, conducted an independent review in 1997 of children in the child welfare system on Edmonton and Calgary regions and found that 64% of children in care had one or more disabilities.
- ^v Family Support for Children with Disabilities Act, SA 2003, c F-5.3. <https://canlii.ca/t/5542b>
- ^{vi} Alberta. Community and Social Services/Children’s Services. “A cross-ministry protocol between children’s services and community and social services: Supporting Alberta’s children, youth and parents/guardians with disabilities,” (2019): 10. <https://open.alberta.ca/dataset/de4418fe-fde0-4615-a3a8-25d5ea7223d6/resource/96e1529c-81b2-42e5-ae0d-aa75e697ee3e/download/supporting-albertas-children-youth-parents-with-disabilities.pdf>
- ^{vii} Cindy Tran, “Why are so many Ontario families flocking to Alberta for autism support?” *Edmonton Journal* (Edmonton, AB), Sept. 26, 2024. <https://edmontonjournal.com/news/local-news/ontario-families-alberta-autism-funding>
- ^{viii} Appendix B provides background information on the gaps in publicly available information about FSCD and Inclusion Alberta’s requests that information be released; Alberta. OpenData. <https://open.alberta.ca/opendata?q=fscd&sort=score+desc&tags=FSCD>
- ^{ix} Canada. Statistics Canada. “Table_98-10-0057-01 Household income statistics by household type: Canada, provinces and territories, census divisions and census subdivisions,” (2022). <https://doi.org/10.25318/9810005701-eng>
- ^x Alberta. “Views of the Family Support for Children with Disabilities (FSCD) program,” 11. <https://open.alberta.ca/dataset/a6856421-d373-4f65-b6d9-7f7565def43e/resource/c9545110-73a6-48be-b59f-043b8562e813/download/css-views-of-the-fscd-program-report-2021-12.pdf>
- ^{xi} Family Support for Children with Disabilities Act, SA 2003, c F-5.3, s.7. <https://canlii.ca/t/5542b>
- ^{xii} Alberta. “Views of the Family Support for Children with Disabilities (FSCD) program,” 11. <https://open.alberta.ca/dataset/a6856421-d373-4f65-b6d9-7f7565def43e/resource/c9545110-73a6-48be-b59f-043b8562e813/download/css-views-of-the-fscd-program-report-2021-12.pdf>
- ^{xiii} Child and Youth Data Laboratory. Policy Wise for Children and Families. “Early childhood services and outcomes for Albertan children with disabilities,” (2019): 7. https://policywise.com/wp-content/uploads/2019/07/2019-07JUL-10-EarlyChildhoodServices_final.pdf
- ^{xiv} Alberta. Seniors, Community and Social Services. “Annual report 2022 – 2023,” (2023): 43. <https://open.alberta.ca/dataset/3a6b50d8-c1f2-4e9a-94ec-62f1e0a34e59/resource/417f8027-7b9f-4fe3-a123-a4fe3473a030/download/scss-annual-report-2022-2023.pdf>; Alberta. Seniors, Community and Social Services. “Annual report 2023 – 2024,” (2024): 45. <https://open.alberta.ca/dataset/3a6b50d8-c1f2-4e9a-94ec-62f1e0a34e59/resource/552b6d31-c765-46b6-917a-10b24a7d97c4/download/scss-annual-report-2023-2024.pdf>
- ^{xv} The Government of Alberta bills Indigenous Services Canada for any FSCD services provided on reserves.
- ^{xvi} Family Support for Children with Disabilities Regulation, Alta Reg 140/2004. <https://canlii.ca/t/56b4s>; Alberta. Seniors, Community and Social Services. “FSCD Policy Manual,” (Last modified July 2, 2024). <https://manuals.alberta.ca/fscd-policy-manual>
- ^{xvii} Alberta. Office of the Child and Youth Advocate. “Beyond Barriers: A Special Report on Young People with Disabilities in the Child Intervention and Youth Justice Systems,” (2024), 12. https://www.ocya.alberta.ca/wp-content/uploads/2024/06/SpRpt2024January_Beyond-Barriers.pdf

^{xviii} For a summary of research on the costs of delaying supports for children with disabilities, see Jennifer Zwicker and Stephanie Chipeur, “Children with neurodisabilities and public policy: Universal design for function rather than diagnosis,” in *Developments in Neuroethics and Bioethics*, Volume 6, edited by W. Ben Gibbard (Academic Press, 2023): 254. <https://www.sciencedirect.com/bookseries/developments-in-neuroethics-and-bioethics/vol/6/suppl/C>

^{xix} Alberta. “Beyond Barriers,” 12-14. https://www.ocya.alberta.ca/wp-content/uploads/2024/06/SpRpt2024January_Beyond-Barriers.pdf

^{xx} Alberta. Seniors, Community and Social Services. “Seniors, Community and Social Services: Ministry Business Plan,” (2024): 123-24. <https://open.alberta.ca/dataset/07018f4e-1d10-499a-96d0-1d7c869134a0/resource/c3ab4560-d123-4ce7-a309-4da76f79afa1/download/seniors-community-and-social-services-business-plan-2024-27.pdf>

^{xxi} Alberta. “FSCD Policy Manual,” s.8.2. <https://manuals.alberta.ca/fscd-policy-manual/section-8-child-focused-services/8-2-child-focused-respite-services/>

^{xxii} Alberta. “FSCD Policy Manual,” s.7.5. <https://manuals.alberta.ca/fscd-policy-manual/section-7-family-support-services/7-5-family-support-respite/>; Alberta. “FSCD Policy Manual,” s.8.7b. <https://manuals.alberta.ca/fscd-policy-manual/section-8-child-focused-services/8-7b-community-support/>

Appendix A: Definitions

1. **Family:** Two or more people, living together or apart, related by blood, marriage, adoption or by a commitment to love and support one another.
2. **Family Supports for Children with Disabilities (FSCD):** The [Family Support for Children with Disabilities Act](#) created FSCD to empower parents and strengthen the family's ability to promote their child's healthy development and participation in society. FSCD also has the goal of providing disability related supports to prevent families from going into crisis and children from going into government care. Reimbursements and services provided by FSCD are for the extraordinary costs and services required because of the child's disability, not for typical parental responsibilities.
3. **Disability:** FSCD defines disability as a chronic developmental, physical, sensory, mental or neurological condition or impairment but does not include a condition for which the primary need is for medical care or health services to treat or manage the condition, unless it is a chronic condition that significantly limits a child's ability to function in normal daily living.
4. **Family Supports Services (FSS):** FSS agreements from FSCD are available to families of eligible children with disabilities to help with the extraordinary demands of caring for a child with a disability. Family support services include:
 - individual and family counselling
 - clothing and footwear
 - an array of medical appointment supports
 - out-of-province medical appointment supports
 - respite supports
 - Triple P (Positive Parenting Program)
5. **Child Focused Services (CFS):** FSCD's current practice is to offer Family Support Services (FSS) to all families eligible for FSCD after they reach the front of the queue. Families who also want access to Child Focused Services (CFS) face an additional wait to be assigned a caseworker who will complete an assessment of need and agree which elements of CFS will be offered in an FSCD agreement. Child focused services include:
 - respite services
 - child care supports
 - aide supports
 - health-related supports
 - specialized supports for children with severe disabilities
 - out of home living arrangements
6. **Ministry of Seniors, Community and Social Services (SCSS):** The Ministry of the Government of Alberta that delivers Disability Services, including FSCD.
7. **Specialized Services:** FSCD-funded supports delivered by a multi-disciplinary team who works with a family and their child who is deemed to have severe/complex disability-related needs that impacts their ability to function in daily living.

8. **Caseworker:** Staff representing FSCD who are responsible for assessing the support needs and understanding the goals of families eligible for FSCD, and planning with them what services or funding to put in place.

Appendix B: Public information about how FSCD is operating

Lack of transparency was a problem identified in government's own review in 2021, *Views of the Family Support for Children with Disabilities (FSCD) Program: Strengths, Challenges and Opportunities for Improvement – Report on the FSCD Review Engagement*, based on 11,500 questionnaire responses and discussions with 128 participants in virtual discussions.¹ The report identified the need for FSCD to improve transparency so that families would not continue having to rely on information shared by other families through word of mouth and social media to understand how to navigate FSCD.

It has been three years since the Ministry of Seniors, Community and Social Services (SCSS) released how many families who are eligible for FSCD and have requested supports are waiting without support.²

¹ Alberta. "Views of the Family Support for Children with Disabilities (FSCD) Program: Strengths, Challenges and Opportunities for Improvement – Report on the FSCD Review Engagement," (2021): 11-12. <https://open.alberta.ca/publications/views-fscd-program-report-on-the-fscd-review-engagement>

² Alberta. OpenData. <https://open.alberta.ca/opendata/fscd-in-planning-caseload>

Appendix C: Survey Questions

Family Survey on FSCD

Who can fill out this survey:

- Whether you are a family waiting to get FSCD, receiving it, receiving it but with inadequate supports stopped receiving it in the past 2 years, or perhaps been denied, we need to hear from you.

Submitting this survey will not lead to Inclusion Alberta responding to your individual circumstances. No personal information of any kind will be collected.

The survey will take no longer than 15 minutes to complete. Please share the survey within your network. **Please complete the survey by November 14, 2024.**

* Indicates required question

1. How old is your family member with a disability? *

Mark only one oval.

0-4

5-7

8-10

11-13

14-17

18-19, but I am answering about my experience with FSCD in the past 2 years

2. What is your current FSCD status? *

Family Supports Services (FSS) [is explained here](#).

Child Focused Services (CFS) [is explained here](#).*

*To receive CFS you must have an FSCD Agreement as opposed to the FSS Agreement that provides or FSS.

Mark only one oval.

- I applied and was deemed not to be eligible
- I have applied and am waiting to have eligibility determined *Skip to question 5*
- I am eligible, but don't yet have a FSS Agreement or Child Focused Services (ie. an FSCD Agreement) *Skip to question 6*
- I have a Family Support Services (FSS) Agreement but no Child Focused Services (ie. a FSCD Agreement) *Skip to question 10*
- I have Child Focused Services (ie. a FSCD Agreement) *Skip to question 26*
- My agreement ended *Skip to question 35*

Not eligible for FSCD

3. Please share the reason(s) given for the decision that you are not eligible for FSCD.

4. Describe the impact on your family of not receiving the funding, services or support you require from FSCD. This could include specific effects on your child's development, their inclusion in early learning and child care, their inclusion in community, your employment, and the wellbeing of your family.

[This chart](#) outlines the supports and services that FSCD can provide.

Skip to question 42

Families waiting for FSCD

5. On what date did you submit your FSCD application?

Provide your best guess. If you are not certain you can select the 15th of the month. This provides us with the number of days families have been waiting.

Example: January 7, 2019

Skip to question 9

Families eligible and waiting

6. How long had you been waiting after applying to FSCD when you received an eligibility decision?

Mark only one oval.

- 3 months or less
- 4-6 months
- 7-9 months
- 10-12 months
- 12-18 months
- Longer than 18 months

7. On what date did you receive the decision that you are eligible for FSCD?

Provide your best guess. If you are not certain you can select the 15th of the month. This provides us with the number of days families have been waiting.

Example: January 7, 2019

8. If you have met with FSCD staff since receiving the decision you are eligible, when did the last meeting or phone call happen?

Provide your best guess. If you are not certain you can select the 15th of the month. This provides us with the number of days families have been waiting.

Example: January 7, 2019

Skip to question 9

Impact of going without needed funding, services or support

9. Describe the impact on your family of not receiving the funding, services or support you require from FSCD. This could include specific effects on your child's development, their inclusion in early learning and child care, their inclusion in community, your employment, and the wellbeing of your family.

[This chart](#) outlines the supports and services that FSCD can provide.

Skip to question 47

Families with Family Support Services but not Child Focused Services

10. What was the date you received your Family Support Services (FSS) agreement?

Example: January 7, 2019

11. Did your Family Support Services (FSS) funding increase or decrease when your agreement was last renewed?

Mark only one oval.

- funding increased *Skip to question 13*
- funding decreased *Skip to question 12*
- funding stayed the same *Skip to question 12*
- This was my first FSS agreement *Skip to question 13*

Skip to question 13

Did you request an increase?

12. Did you request an increase and it was denied? *

Mark only one oval.

yes

no

Skip to question 13

Need for Child Focused Services

13. Have FSCD staff ever explained to you how to request Child Focused Services?

Mark only one oval.

yes

no

14. Do you require Child Focused Services? *

Child Focused Services includes:

-additional respite

-child care supports

-health-related supports (prescription, dietary, nutritional or dental services)

-support to participate in community activities

-Behavioural and Developmental Supports

-Specialized Services provided by speech-language pathologists, occupational therapists, physical therapists, and/or psychologists

More [information on Child Focused Services is found here.](#)

Mark only one oval.

yes Skip to question 15

no Skip to question 32

unsure Skip to question 32

Skip to question 32

Families requiring Child Focused Services

15. Were you assigned a caseworker to handle your request for Child Focused Services? *

Mark only one oval.

Yes Skip to question 16

No Skip to question 17

Skip to question 17

Caseworker assigned

16. On what date were you assigned a caseworker to handle your request for Child Focused Services?

Provide your best guess. If you are not certain you can select the 15th of the month. This provides us with the number of days families have been waiting.

Example: January 7, 2019

Skip to question 17

Request for Child Focused Services

17. Where are you at in the process of requesting Child Focused Services? *

Mark only one oval.

I have not yet been assigned a caseworker to discuss my request Skip to question 32

I am still waiting for request for my Child Focused Services to be submitted
Skip to question 32

I am still waiting for a decision on my request Skip to question 23

I requested Child Focused Services and received a denial Skip to question 18

Skip to question 32

Denied Child Focused Services

18. When did you request Child Focused Services?

This request may have been verbal or by email. Provide your best guess. If you are not certain you can select the 15th of the month. This provides us with the number of days families have been waiting.

Example: January 7, 2019

19. When did you receive a decision denying your request for Child Focused Services?

Provide your best guess. If you are not certain you can select the 15th of the month. This provides us with the number of days families have been waiting.

Example: January 7, 2019

20. What reason was given for denying your request for Child Focused Services?

21. Did your caseworker tell you about Specialized Services?

One of the areas that can be funded within Child Focused Services is Specialized Services. These services from speech-language pathologists (SLP), occupational therapists (OT), physical therapists (PT) and psychologists can be provided when there is a need in 2 or more of the following areas:

1. behaviour
2. communication and social skills
3. cognitive abilities
4. physical and motor development
5. self-help and adaptive functioning

More information about Specialized Services is [here](#)

Mark only one oval.

yes

no

22. Did your request for Child Focused Services include a request for Specialized Services?

Mark only one oval.

Yes

No

Skip to question 32

Waiting for Child Focused Services decision

23. On approximately what date did you request Child Focused Services?

This request may have been verbal or by email. Provide your best guess. If you are not certain you can select the 15th of the month. This provides us with the number of days families have been waiting.

Example: January 7, 2019

24. Did your caseworker tell you about Specialized Services?

One of the areas that can be funded within Child Focused Services is Specialized Services. These services from speech-language pathologists (SLP), occupational therapists (OT), physical therapists (PT) and psychologists can be provided when there is a need in 2 or more of the following areas:

1. behaviour
2. communication and social skills
3. cognitive abilities
4. physical and motor development
5. self-help and adaptive functioning

Find information about Specialized Services [here](#).

Mark only one oval.

yes

no

25. Did your request for Child Focused Services include a request for Specialized Services?

Mark only one oval.

yes

no

Skip to question 32

Child Focused Services in your agreement

We want to know about the Child Focused Services offered in your agreement. One of the areas that can be funded within Child Focused Services is Specialized Services. These services from speech-language pathologists (SLP), occupational therapists (OT), physical therapists (PT) and psychologists can be provided when there is a need in 2 or more of the following areas:

1. behaviour
2. communication and social skills
3. cognitive abilities
4. physical and motor development
5. self-help and adaptive functioning

More information about Specialized Services is [here](#)

26. Did your caseworker tell you about Specialized Services?

Mark only one oval.

yes

no

27. Does your current FSCD agreement include Specialized Services?

Mark only one oval.

yes *Skip to question 28*

no *Skip to question 30*

Skip to question 30

Specialized Services term

28. How many years have you had Specialized Services for?

Mark only one oval.

This is our 1st year

This is our 2nd year

This is our 3rd year

This is our 4th or higher year

29. Have you been told that this is your final year with Specialized Services?

FSCD staff may have use the term transition year to state that Specialized Services will end at the end this agreement's term.

Mark only one oval.

Yes

No

Skip to question 30

FSCD Agreement funding level

30. Did your FSCD funding increase or decrease when your agreement was last renewed? *

Mark only one oval.

- funding increased *Skip to question 32*
- funding decreased *Skip to question 31*
- funding stayed the same *Skip to question 31*
- This was my first agreement for either FSS or CFS *Skip to question 32*

Skip to question 32

Did you request an increase?

31. Did you request an increase and it was denied?

Mark only one oval.

- yes
- no

Skip to question 32

Funding, Supports and Services Provided by FSCD

The purpose of the FSCD legislation, which includes the [FSCD Act](#) and [Regulation](#), is to:

- provide a spectrum of proactive family-centred supports and services that support the development and inclusion of children with disabilities and strengthen the family's ability to promote their child's healthy growth and development
- build on the family's strengths and abilities as well as their existing supports and resources to help increase their capacity to promote their child's development
- address the unique needs of children with disabilities and their families throughout the stages of childhood and as they prepare for becoming an adult
- enable families to continue to care for their child in the family home and community
- provide integrated and coordinated supports and services to children with disabilities and their families
- promote greater consistency in access to required supports and services

32. Does your agreement provide the funding, supports and services your child and family requires?

Mark only one oval.

yes *Skip to question 34*

no *Skip to question 33*

Skip to question 33

Supports required

[This chart](#) outlines the supports and services that FSCD can provide.

33. How does FSCD funding, services and support differ from what your family requires?

Skip to question 37

Positive outcomes from FSCD services

34. Please describe the importance of the FSCD program to your family, and positive outcomes and supports for your family.

Skip to question 38

Families whose agreements have ended

35. Why do you no longer receive FSCD services?

36. If your FSS Agreement or FSCD Agreement was terminated without your consent, please share the reasons given for termination:

Skip to question 37

Impact of going without needed funding, services or support

37. Describe the impact on your family of not receiving the funding, services or support you require from FSCD. This could include specific effects on your child's development, their inclusion in early learning and child care, their community, your employment, and the wellbeing of your family.

Skip to question 38

Administrative review

38. Did you participate in an administrative review?

The review of an FSCD program decision (informally called an administrative review) is one of the concern resolution options available to parents and guardians. It provides an opportunity to have a decision made by the FSCD program reviewed by Delivery Managers who were not part of the decision making process.

Mark only one oval.

yes *Skip to question 39*

no *Skip to question 42*

Skip to question 42

Administrative review

39. Were you successful in your administrative review?

Mark only one oval.

yes *Skip to question 47*

no

40. Did you find the administrative review process to be fair?

Mark only one oval.

yes

no

41. Any comments you'd like to share regarding your administrative review?

Skip to question 42

Appeal Panel

Parents and guardians can request to have a decision reviewed by a committee that is independent and separate from the FSCD program to ensure an objective appeal process.

42. Were you advised of your right to appeal a FSCD decision?

Mark only one oval.

yes

no

43. Did you participate in an Appeal?

Mark only one oval.

yes *Skip to question 44*

no *Skip to question 47*

Skip to question 47

Appeal process

44. Were you successful in your Appeal?

Mark only one oval.

yes

no

45. Did you find the Appeal process to be fair?

Mark only one oval.

yes

no

46. Any comments you would like to share regarding your Appeal process?

Skip to question 47

Additional comments

47. Please share any additional comments that would help us understand your FSCD experience and how you feel FSCD could be improved:

48. Which provincial electoral district do you live in? *

This information enables us to communicate with MLAs in the provincial government how FSCD impacts families in their own district. Look up your electoral district [by address](#), by [postal code](#), or [by map](#).

Mark only one oval.

- Airdrie-Cochrane
- Airdrie-East
- Athabasca-Barrhead-Westlock
- Banff-Kananaskis
- Bonnyville-Cold Lake-St. Paul
- Brooks-Medicine Hat
- Calgary-Acadia
- Calgary-Beddington
- Calgary-Bhullar-McCall
- Calgary-Bow
- Calgary-Buffalo
- Calgary-Cross
- Calgary-Currie
- Calgary-East
- Calgary-Edgemont
- Calgary-Elbow

- Calgary-Falconridge
- Calgary-Fish Creek
- Calgary-Foothills
- Calgary-Glenmore
- Calgary-Hays
- Calgary-Klein
- Calgary-Lougheed
- Calgary-Mountain View
- Calgary-North
- Calgary-North East
- Calgary-North West
- Calgary-Peigan
- Calgary-Shaw
- Calgary-South East
- Calgary-Varsity
- Calgary-West
- Camrose
- Cardston-Siksika
- Central Peace-Notley
- Chestermere-Strathmore
- Cypress-Medicine Hat
- Drayton Valley-Devon
- Drumheller-Stettler
- Edmonton-Beverly-Clareview
- Edmonton-Castle Downs
- Edmonton-City Centre
- Edmonton-Decore
- Edmonton-Ellerslie
- Edmonton-Glenora
- Edmonton-Gold Bar
- Edmonton-Highlands-Norwood
- Edmonton-Manning

- Edmonton-McClung
- Edmonton-Meadows
- Edmonton-Mill Woods
- Edmonton-North West
- Edmonton-Riverview
- Edmonton-Rutherford
- Edmonton-South
- Edmonton-South West
- Edmonton-Strathcona
- Edmonton-West Henday
- Edmonton-Whitemud
- Fort McMurray-Lac La Biche
- Fort McMurray-Wood Buffalo
- Fort Saskatchewan-Vegreville
- Grande Prairie
- Grande Prairie-Wapiti
- Highwood
- Innisfail-Sylvan Lake
- Lac Ste. Anne-Parkland
- Lacombe-Ponoka
- Leduc-Beaumont
- Lesser Slave Lake
- Lethbridge-East
- Lethbridge-West
- Livingstone-Macleod
- Maskwacis-Wetaskiwin
- Morinville-St. Albert
- Olds-Didsbury-Three Hills
- Peace River
- Red Deer-North
- Red Deer-South
- Rimbey-Rocky Mountain House-Sundre

- Sherwood Park
- Spruce Grove-Stony Plain
- St. Albert
- Strathcona-Sherwood Park
- Taber-Warner
- Vermilion-Lloydminster-Wainwright
- West Yellowhead
- I don't know

49. Which category best describes you? Check all that apply:

Though not based in science, [these terms](#) may influence the way we are treated by individuals and institutions. We are trying to understand how access to PDD varies across the population.

Check all that apply.

- Black
- East Asian
- Indigenous (First Nations, Inuk/Inuit, Métis)
- Latin American
- South Asian
- Southeast Asian
- White
- Do not know
- Prefer not to answer
- Other: _____

50. What is your total household income?

We are trying to understand how access to PDD varies across the population.

Mark only one oval.

- Less than \$25,000
- \$25,000 to \$50,000
- \$50,000 to \$75,000
- \$75,000 to \$100,000
- \$100,000 to \$125,000
- \$125,000 to \$150,000
- Prefer not to answer

51. I consent to receive more information from Inclusion Alberta about work being done to ensure government understands how FSCD is working for families, and where improvements can be made.

Mark only one oval.

- yes
- no

52. I am providing my email address so that Inclusion Alberta can contact me about my story. Inclusion Alberta is collecting stories to to raise awareness about how FSCD can better support families. Before using your story, Inclusion Alberta will contact you and get your explicit consent.

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