

June 2018

WHAT WE HEARD

Feedback from parents, families and advocates in the
Family Support for Children with Disabilities (FSCD) program

Introduction

Over the last months, parents, families and advocates have raised important concerns about how services are being delivered by the FSCD program. As a result of their advocacy, Community and Social Services hosted open listening sessions in Edmonton and Calgary to hear more about families' concerns and feedback. Over 110 parents and family members participated in these sessions and provided valuable insight about their experiences with the FSCD program.

Through the listening sessions, emails, phone calls and other feedback from families, it has become very clear that the FSCD program has become too focused on parents. We share the concern of parents and families about "parent training" and "parent coaching" and are taking action to shift Specialized Services policy and practice immediately.

Listening Session Themes

Listening Sessions for the FSCD program were held in Calgary, hosted by John Stinson, and Edmonton, hosted by Roxanne Gerbrandt, on May 11 and 12, 2018. 110 parents participated in the sessions, 34 in Edmonton and 76 in Calgary.

Key themes of the feedback received have been identified from the information compiled in the listening sessions, calls and emails. We want to thank everyone who has participated and advocated on behalf of their children and family members.

Parent Training versus direct services to children

- Parents want to be parents, not therapists
- Parents and families want access to direct therapy for their children
- Parents want the language of "parent coaching" or "parent training" eliminated
- Parents want reduced barriers for working parents
- Parents shouldn't have to give up work/careers to receive supports
- Parents cannot identify all the needs of the child
- Parents do not want to be judged by the program or made to feel guilty

Legislation

- Policies and procedures need to align with legislation and regulations
- Over time, policy and practice has shifted from the original intention of the legislation.
- There are differences between regions in the province and how policies are implemented

Service Providers

- There needs to be greater transparency and consistency in services
- Agencies need to be held accountable for quality of services delivered and how parents are treated
- Agencies need to listen to families
- How does FSCD approve or monitor service providers?
- Family agreements needs to specify what is direct therapy as well as support for parents/families

- There needs to be information about the direct services that are available, instead of forcing families to find out themselves

Supports/Workers: Access, training and consistency

- Concern about caseloads; need more time to meet with and support us, face to face time
- Concerns about worker turnover rate
- Workers are not financial gatekeepers, should be supportive navigators
- Need more training and supports for workers on program supports and policy, child development and options available
- Need workers that understand the challenges families are facing
- Need emergency planning for evenings and weekends from workers
- Support to direct services, rather than being told what to do

Information and Awareness

- Need clarity about services available
- Complex processes that are not clear
- Concern about needing to fight for services – not receiving information about available services
- Government of Alberta (GOA) website on FSCD is difficult to navigate
- Need for transparency of programs and services provided, parents should not have to research the policy manual to access supports
- Lack of clarity about options in service provision not just giving cookie cutter solutions
- Adversarial processes set up to make parents need to fight for services.

Next Steps

We value the feedback of parents, families and advocates and are committed to taking action to make immediate change.

The following immediate actions will be completed in July 2018:

- **Immediate end to all “parent training” or “parent coaching” language**
- **Immediate change to Specialized Services policy** to confirm parent involvement in specialized services is entirely optional . Parents are not expected to become therapists to their child, and they are not required to be in the room or participate when specialized services are being provided to their child.
- **Family Centred Supports and Services policy, FSCD Program Outcomes policy and Overarching Policies and Considerations Policy will be changed** to confirm support for direct services to children, and to ensure full alignment with FSCD legislation.
- **A FSCD tool kit will be provided to all families** to share information about the program, services that are available, and what parents can do if they have a concern or question about access to direct services.
- **We will share a transparent and accountable description of what specialized services are, what the criteria is and what services are available.**
- **New information resources, forms and website content** to improve access to information for parents and families about direct services to children. This includes changes to FSCD program brochures, Director’s Decision about Specialized Services

letter, Welcome to PDD letter and other resources.

In addition to these immediate changes, the following improvements will be made:

- **Multi-Disciplinary Team (MDT) process will be reviewed** to identify improvements to ensure this process is supportive for families by way of enhancing consistency, accountability and best practice (August 2018)
- **FSCD staff training is being updated and orientation training will be provided to staff** to support an immediate shift in practice to providing direct services to children in addition to supports for families. (Training modules completed by August 2018; implementation by September 2018.)
- **Full review of the entire FSCD policy manual** to ensure it follows the legislation and supports direct services to children. (September 2018)
- **Explore ways to increase service provider and FSCD program staff capacity to ensure better access to services.**

Additional listening sessions will be held with parents and families across the province to identify further improvements and hear additional feedback. The steps outlined above are first steps to make improvements for children and families. We will continue to work collaboratively and openly with families to explore additional actions and changes that can be made to ensure children are getting the best possible services.