

Autism Society of Alberta FSCD Program Review Town Hall

SUMMARY REPORT

February 11, 2021

PURPOSE

To discuss the government led Family Support for Children with Disabilities (FSCD) program review and provide the perspective of the lived experience of children and families from Alberta's united autism community (Autism Society Alberta, Autism Calgary, Autism Edmonton, Autism Society of the Regional Municipality of Wood Buffalo, Peace Autism Society, and Chinook Autism Society).

APPROACH

Parents of children with autism and service providers (a total of 40 participants) gathered for a Virtual Town Hall on Tuesday, January 26, 2021 to discuss the FSCD program review and recent parent survey. Seven key themes arose from the discussion:

SUSTAINABILITY

There is a clear understanding in the Autism Community that COVID-19 has placed extraordinary pressures on the Government of Alberta to manage its scarce resources effectively, efficiently and sustainably.

UNIVERSALITY

The Autism Community believes passionately that access to services must be based on need, not on ethnicity, years in Canada, family structure or family resources. Universality is paramount. If you qualify for FSCD you should be able to access it.

A sustainable system will also take a look at look at the unique circumstances in urban and rural areas. A one-size fits all system does not work and there is a tremendous opportunity to take a look into this issue at this moment in time.

Just like with the economy as a whole, a sustainable FSCD system will not be based on short-term cuts, but on optimizing the program over a longer horizon.

ON THE EDGE OF CRISIS

Most families live on the edge of crisis. Anxiety, fear, dismay, uncertainty, isolation, exhaustion and being overwhelmingly burdened are reported by most parents. A withdrawal of supports will push these families into crisis.

Limiting funding will force parents to withdraw from the workforce—the opposite macro-economic effect than what is desired.

LONG TERM PERSPECTIVE

The best evidence shows that comprehensive early intervention provides cost savings over the longer term—both within the FSCD program and as the children move to adult services. Cutting costs and reducing investments in services now will only increase costs for families and Alberta as a whole over the long term.

OPTIMIZATION – THE RIGHT WAY

How the system is optimized can have very damaging outcomes on the children. In the past, a “parent-driven” model has been used to put the burden of delivery of services on the shoulders of the parents. These parents frequently don’t have the expertise, capacity or resources to be the parent and the therapist. While funding dollars may not be spent—a savings on paper—the children do not receive the therapy they require and the families do not have the capacity to deal with the complexities of life, including meaningful employment.

COLLABORATION WITH FSCD

Transparency of needs and services is central to sustainability. Parents forced to “fight, fight, fight” for services are not nearly as collaborative as the system would like to see.

This is one of the sources of the historic tensions between FSCD and the families they are mandated to support. FSCD case workers are seen to be guardians at the gates of service tasked with the job of letting as few services through as possible. While unfair, this perception will only be exacerbated if the FSCD program funding is reduced or discriminately allocated.

CROSS-MINISTRY INTEGRATION

As the Autism Community looks to ways that the system could be made more sustainable, the answer is not in discriminatory funding, but in improving the integration with other government ministries. Today, social services, education, health care, justice, employment all touch the children and their families, yet there is little or no communication or shared service delivery. There is a huge opportunity for significant efficiencies if a “whole child, whole government, over a whole lifespan” approach could be taken.

THE PATH FORWARD

The Autism Community would like to see a more sustainable system. Their lived experience shows that the best path forward is to:

1. Start with what exists today, do not take a step backwards in funding or universality.
2. Manage services over the lifespan, investing early to benefit in the longer term.
3. Integrate and align services across government Ministries.
4. Recommit to the “supports” in Family Supports for Children with Disabilities.
5. Whole child, whole government, over a whole lifespan.

The participants greatest hope for the future was best articulated when they said:

“We would like to see the 5 C’s: **Consultation** with the experts and individuals in the field as well as those impacted like us parents; **Collaboration** between all agencies like education, AHS and FSCD—everyone working together; **Communication** between all agencies and parents with case workers; **Coordination** of all the above; **Caring**—by and for each other.”

Neuro-diverse children are just as intrinsically valuable and important as neuro-typical children. Parents are united in their desire for a sustainable system that works towards the best outcomes for children with disabilities which inevitably will lead to the best outcomes for the province as a whole.