

# Context

The Early Child Community of Practice was established in the Fall of 2022 with assistance from Autism Alberta's Alliance.

The Steering Committee developed a survey to:

- Develop a collective understanding of issues seen since funding and policy changes in 2018
- Generate experience-informed solutions

Community of Practice members were asked to forward the survey to clinicians at their agency and/or other service providers

The survey was active in March 2023

Here are some things we heard.

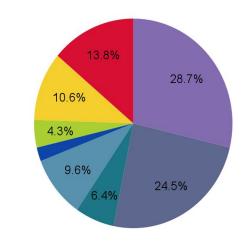
# Who Responded

#### Respondents



Average years of professional experience





- Speech Language Pathologist
- Occupational Therapist
- Psychologist
- Behaviour Consultant
- Physical Therapist
- Teacher
- Administrator
- Other

**Funding sources:** 61% Program Unit Funding (PUF through Alberta Education) & Family Supports for Children with Disabilities (FSCD), 19% PUF, 15% FSCD, 4% AHS, 1% other



How has early childhood service delivery changed?

How have the changes impacted children and families?

What are your experience-informed solutions?

# Main Themes:

## How has early childhood service delivery changed?

- 1. Delayed access
- 2. Insufficient services
- 3. Changing role of clinicians
- 4. Navigation and capacity issues
- 5. Less Inclusion
- 6. Red tape and redundancy
- 7. Less collaboration & integration of services
- 8. Lack of coordination & cooperation across ministries

# **Delayed Access**

#### Issues:

- AHS is no longer "assessing for programs" so families must explore other options
- Long waitlists for diagnostic and assessment services
- Long waitlists (up to one year) to access FSCD and be assigned a caseworker
  - Some children "age out" before they receive services
- Not enough Service Providers to meet needs
  - Weighted moving average a deterrent to capacity building
- Regional Collaborative Service Delivery model was eliminated (RCSD)
  - Less opportunity for regional assessments
  - Family liaisons eliminated

## Children and families are waiting too long to access FSCD funded services



agree or strongly agree



Longer wait time which then results in missed opportunities for early intervention

# **Insufficient Services**

#### Issues:

- "Cutting" 3rd year PUF
- FSCD expectation that families access less intensive Behavioural Development Supports
- Less hours for clinician in both PUF and FSCD programs
- Aides/assistants are less experienced or qualified and less clinician hours for training them
- Aide hours in FSCD program have decreased and are harder to access
- The children being served are often more complex than those of the past
- Less opportunity for parent engagement in PUF
  - Elimination of Family Oriented Programming Sessions (FOPS)

The current system is not meeting the needs of autistic children and their families



Somewhat agree, agree, or strongly agree



We had to stop parent feeding groups and well as other parent engagement opportunities

# Changing Role of Clinicians

#### Issues:

- Caseload have increased (less opportunity to make a difference) and hours have decreased
- Funding cuts/freezes have made it challenging to recruit and maintain qualified professionals
- Work is more consultative, less opportunity to individualize
- Changing expectations with respect to parent involvement/parent coaching
- Rates/wages have not kept pace with "market rate" or inflation
- More time being spend on training aides/EAs as it is increasingly difficult to recruit experienced staff

#### Clinicians considering leaving their field

37%

the burn out for staff expected to more with less is having many professionals leave early childhood services or the respective professions completely

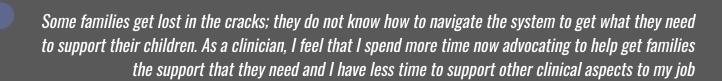
# **Navigation and Capacity**

#### ssues:

- Some programs have closed or halted expansion due to funding changes
- Limited options for very young children
- Accessing services requires more knowledge and advocacy

Report a waitlist for services at their agency or practice





# Less Inclusion

"Preschool PUF programs are essentially non-viable and beginning to close down in some large urban education divisions. For those that are still running, they can no longer be run as an inclusive model with neurotypical peers - again, funding issue"

# Red Tape & Redundancy

"Now the tired family has to go to underfunded, resource exhausted clinician or health professional to tell them what they already clearly stated with FSCD and request a *letter to tell the same story and say* that the child is STILL autistic? Where is the logic in this? This is why families walk away, this is why the areas of need significantly increase in adults. We are putting up roadblocks for families when they need it most!"

# Lost Opportunity

- Less opportunity for Common Approach (integrated FSCD and PUF services)
- Less opportunity for clinicians to collaborate with each other or others

"I have had to coordinate any form of communication with FSCD therapists on my own time to help the family who is completely overwhelmed"

# Lack of cooperation or coordination between ministries

"Ministries are not required to meet and collaborate on cases of significant needs as it used to be the case while the RCSD structure was in place. There is no connection of services and nobody knows about each other"

"HUGE gaps in coordinated care that often now fall to parents who are completely overwhelmed"

"Ministries are assuming that if a child has support in one area (e.g. education), that will be enough support in all areas of the child's functioning"



feel that services for young children with autism are integrated and coordinated across ministries

## Main Themes:

### How have the changes impacted children and families?

#### ssues:

- Children are waiting for assessments/services so the critical early intervention period is shortened
- Children are getting less intensive services (hours, duration of service)
- Families are frustrated/burned out,
- Families are paying out of pocket for services
- Parents are not receiving the same level of coaching and support they did previously
- Less opportunity for inclusion (move towards congregated programs)

"Children are not progressing on the same trajectory as we saw it in the past"

"Families are spending more time in 'crisis' or without support as they have to struggle and 'prove' that the level of support isn't enough before getting the level of support that is needed to help teach and support"

# **Experience-Informed Solutions**

In a fragmented system serving more complex kids with less resources, what can we do?

#### Reduce wait times

- For diagnostic, FSCD, specialized services, PUF
  & respite
- Decrease workloads by hiring appropriate levels of staff with realistic workloads

#### **Cross-ministerial cooperation**

- Streamline coordination between ministries
- "There needs to be an expectation that ministries collaborate on children with significant needs and follow a common approach, especially if a ministry knows that others are involved."

#### Provide needs-based services

- That is not code-based so that children can stay in their classrooms
- "Treatment recommendations should not be based on available funding - they should be based on research and best practice"

#### Eliminate redundancies

- Allow qualified clinical staff to decide what services are appropriate by accepting professional recommendations
- Reduce paperwork and increase length of FSCD contracts



"Those who may not have the voice, stamina or are simply exhausted get minimal and often feel 'shamed' or less deserving of services and settle for less"

# We can all play a part in building a system that best supports those in need