Building Better Pathways to FASD Care:
Preliminary Findings on ***Frontline*** Provider Readiness and Barriers to Early Identification in Canada

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Clinical Neuropsychology MA Candidates

Supervised by **Dr. Mary Desrocher**

York University | The Desrocher Lab

POSITIONALITY STATEMENT

MARGAUX BOUILLARD (She/her)

I am a biracial (Black and White) woman of French and Canadian background. As a master's student in clinical developmental neuropsychology, my research interests lie in children's neurodevelopmental disorders, with a particular focus on FASD.

As a researcher, I recognize that my academic background and prior experiences shape how I interpret healthcare providers' perspectives and practices. I aim to approach this study with openness, reflexivity, and respect for the diverse expertise and experiences of healthcare providers working with individuals living with FASD.

POSITIONALITY STATEMENT

MARWA IBRAHIM (she/her)

I am a graduate student in Clinical Developmental Neuropsychology at York University. I was born in Egypt, raised in the United Arab Emirates, and immigrated to Canada in 2008.

My training in neuropsychology influences how I approach research on Fetal Alcohol Spectrum Disorder, particularly in relation to assessment, diagnosis, and service access. I am mindful that academic and clinical frameworks do not always reflect the realities families and community providers face. I approach this work with a commitment to respectful research that centers the lived experiences of individuals with FASD.

WHY FASD REMAINS UNDER-IDENTIFIED

FASD affects an estimated **2-4% of the Canadian population** (CanFASD, 2018)

~98% of individuals with FASD are **undiagnosed or misdiagnosed** (Popova et al., 2024)

Diagnostic services are concentrated in **specialized multidisciplinary clinics**

Access to services is **limited and unequal** (Dugas et al., 2022)

THE ONTARIO FOCUS

Significant gaps in:

Knowledge

Awareness

Services

Contributing factors:

Diagnostic challenges

Limited Professional training

Stigma

System-level barriers

WHAT WE DON'T KNOW

Frontline healthcare providers report (CAHS, 2025):

- Limited FASD training
- Discomfort discussing PAE

BUT:

- No data on how they
  - Screen
  - Refer
  - Intervene
  - Address stigma

Canadian Academy of Health Sciences
Académie canadienne des sciences de la santé

Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

June 2025

STUDY OBJECTIVE:

To examine how equipped healthcare providers are to identify, screen, refer individuals with suspected PAE, and what knowledge and system-level barriers shape early FASD identification and intervention.

PARTICIPANTS AND SURVEY DESIGN

SURVEY DEVELOPMENT:

- Canadian Academy of Health Sciences (2025) report
- Community partners

SURVEY STRUCTURE:

- Cross-sectional, mixed-methods online survey
- 95 questions
- Average completion time: 14 minutes

PARTICIPANTS

22 healthcare providers

Practicing in Canada (96% ON)

Working in the field of FASD for a minimum of **6 months**

89% female, 4% male

WHY THIS STUDY MATTERS

FASD workers are:

- First and consistent point of contact for families
- Underrepresented in research

Strong engagement:

- **86% participation rate**

Community & social service providers

- Play a key role in screening & support
- Yet are often overlooked

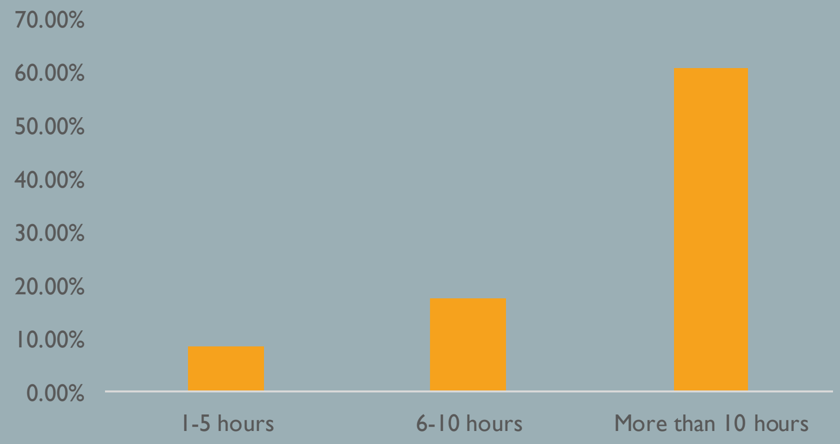
PREPAREDNESS AND TRAINING

Hours of FASD-specific education

more than 10 hours: 60.87%

6-10 hours: 17%

1-5 hours: 9%

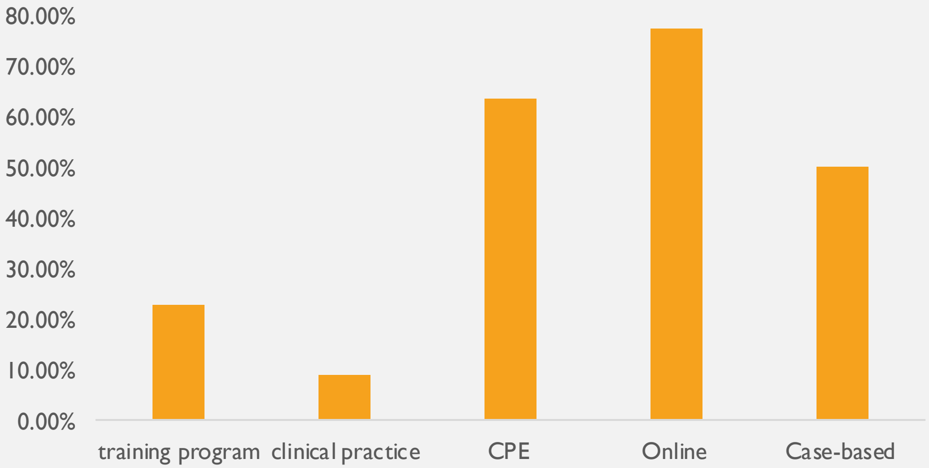


Where training occurred

Online modules/webinars: 77%

Professional development: 63%

Informal mentoring/ case-based learning: 50%

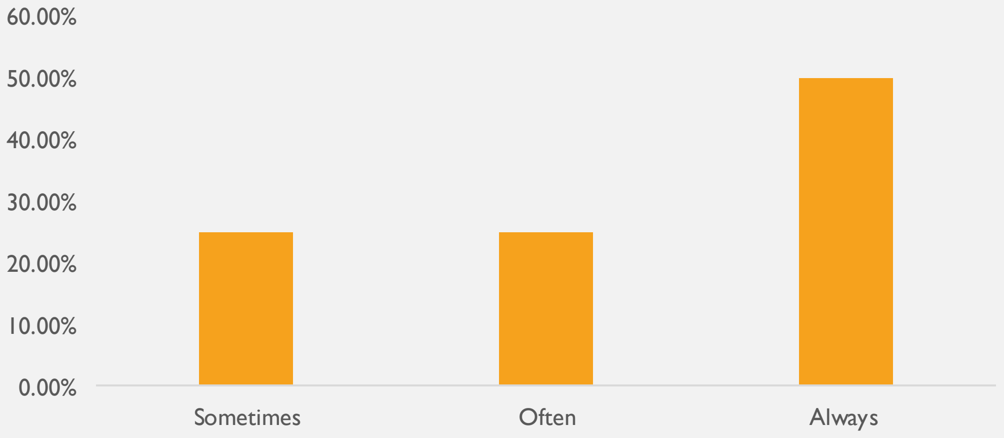


PRACTICE PATTERNS: WHEN IS FASD CONSIDERED?

Providers reported asking about prenatal alcohol exposure when:

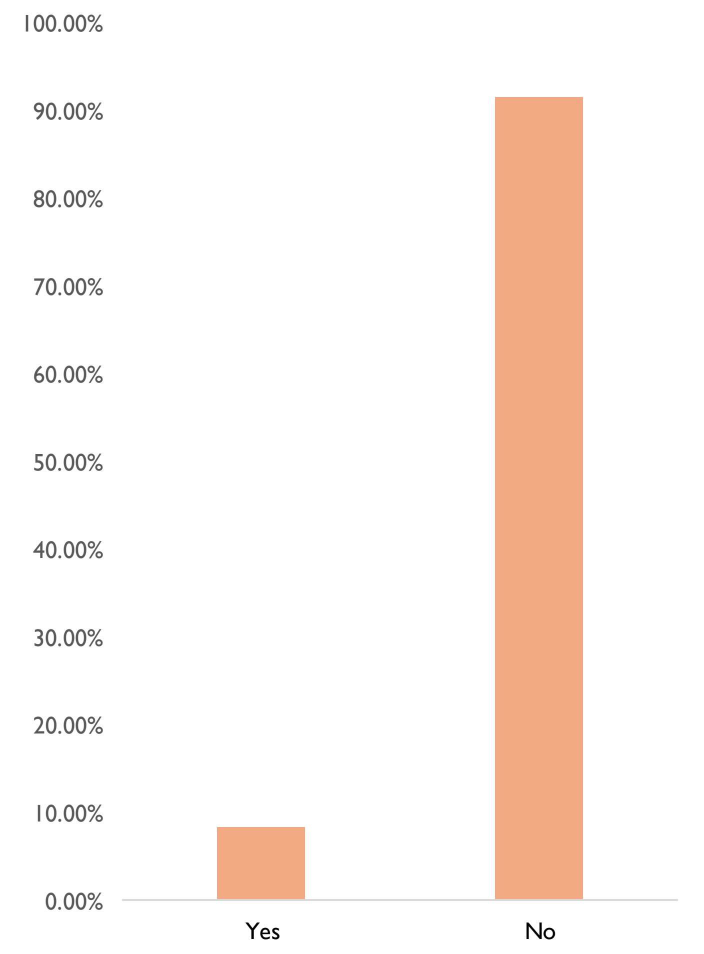
- prior diagnoses did not fully explain difficulties (76.9%)
- attention or impulsivity concerns were present (61.5%)
- emotional or behavioral regulation difficulties (61.5%)
- learning difficulties (46.1%)

Frequency of asking about PAE



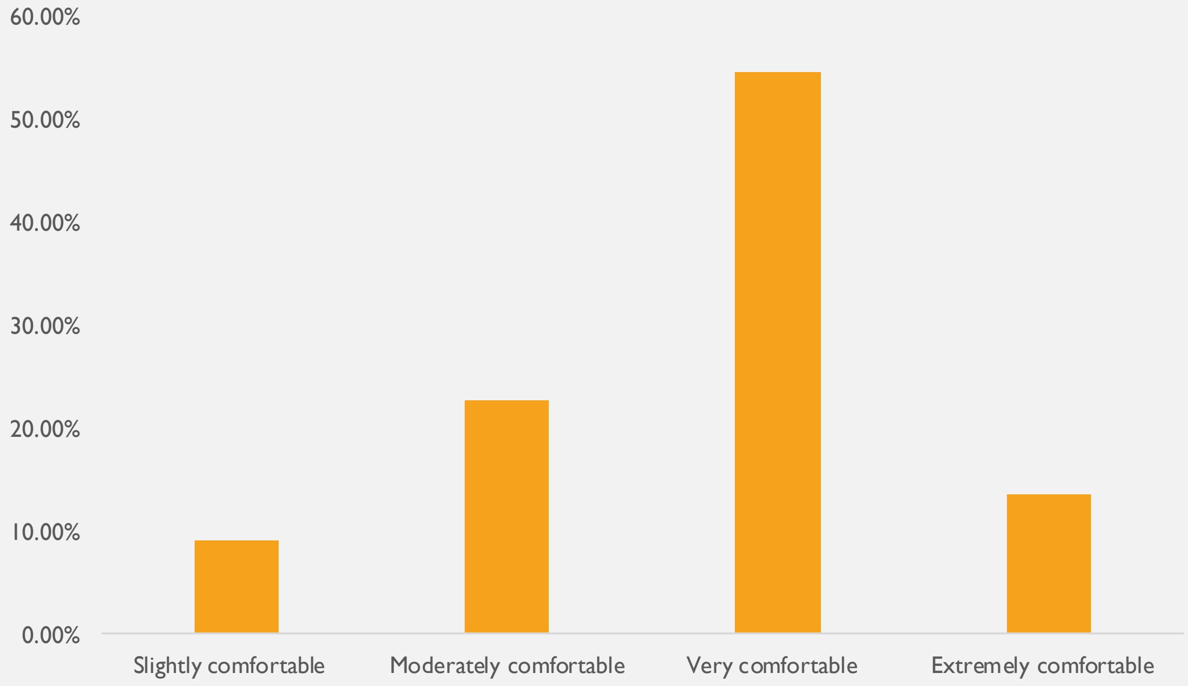
SCREENING PRACTICES

Use of screening tools for FASD or PAE risk



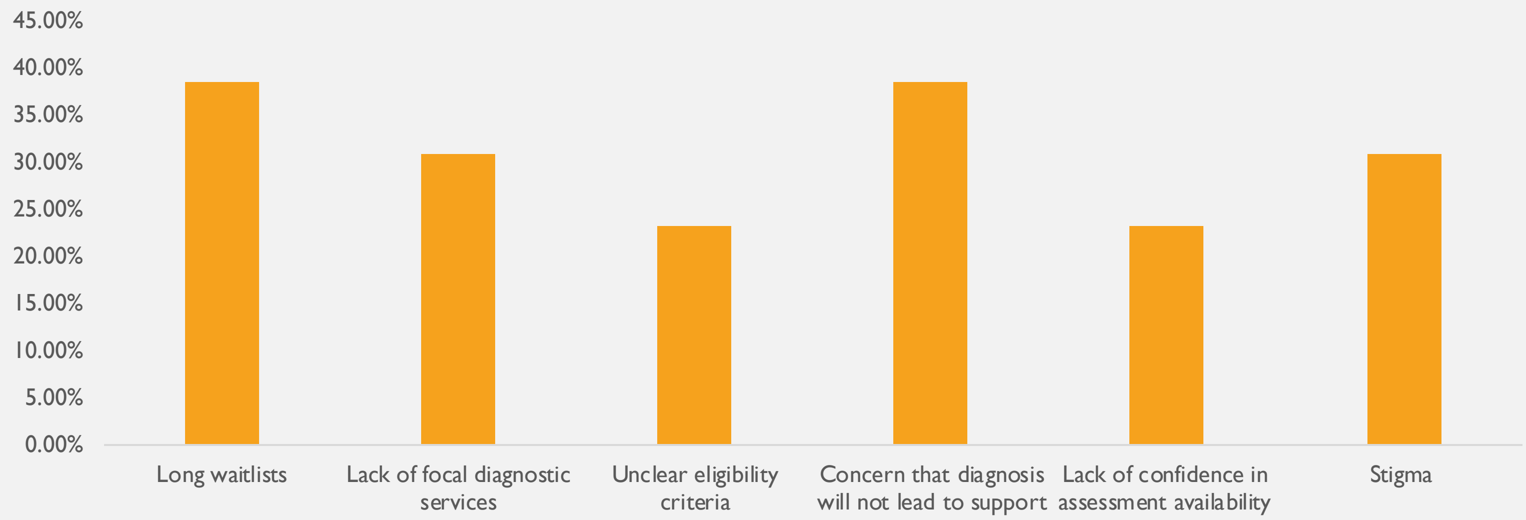
DISCUSSING PRENATAL ALCOHOL EXPOSURE

Comfort discussing PAE with families:



Challenges identified in open-ended responses

- stigma and fear of judgment
- incomplete prenatal histories
- need to build trust with families
- concern about causing harm



BARRIERS TO REFERRAL FOR FASD ASSESSMENT

Themes from qualitative responses:

- limited services
- geographic inequities
- fragmented systems

INTERVENTIONS:
ACCESS & SUPPORTS

Access/Eligibility:

Flexible/Low-Barrier Eligibility (Diagnosis Not Required)

- *“We work from a suspected FASD and confirmed FASD.You do not need a dx [diagnosis] to received FASD support”*

Individual & Family-Centred Approach

- *“We look at the individual’s needs and provide recommendations – the family decides what they have capacity for”*

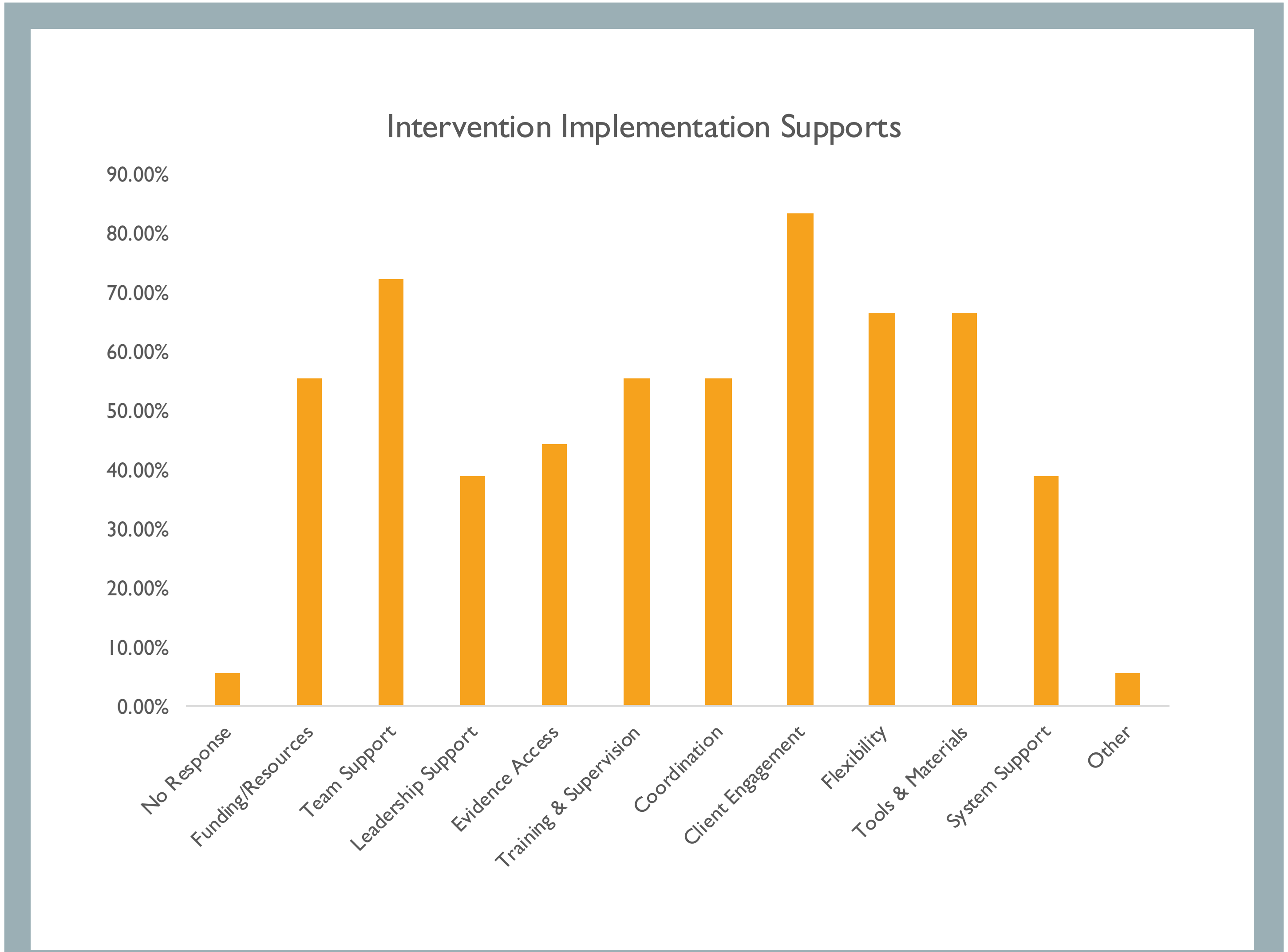
System Navigation & Referral-Based Access

- *“As a Program Facilitator, I refer to case workers who refer to other organizations – not sure there is any eligibility criteria currently”*

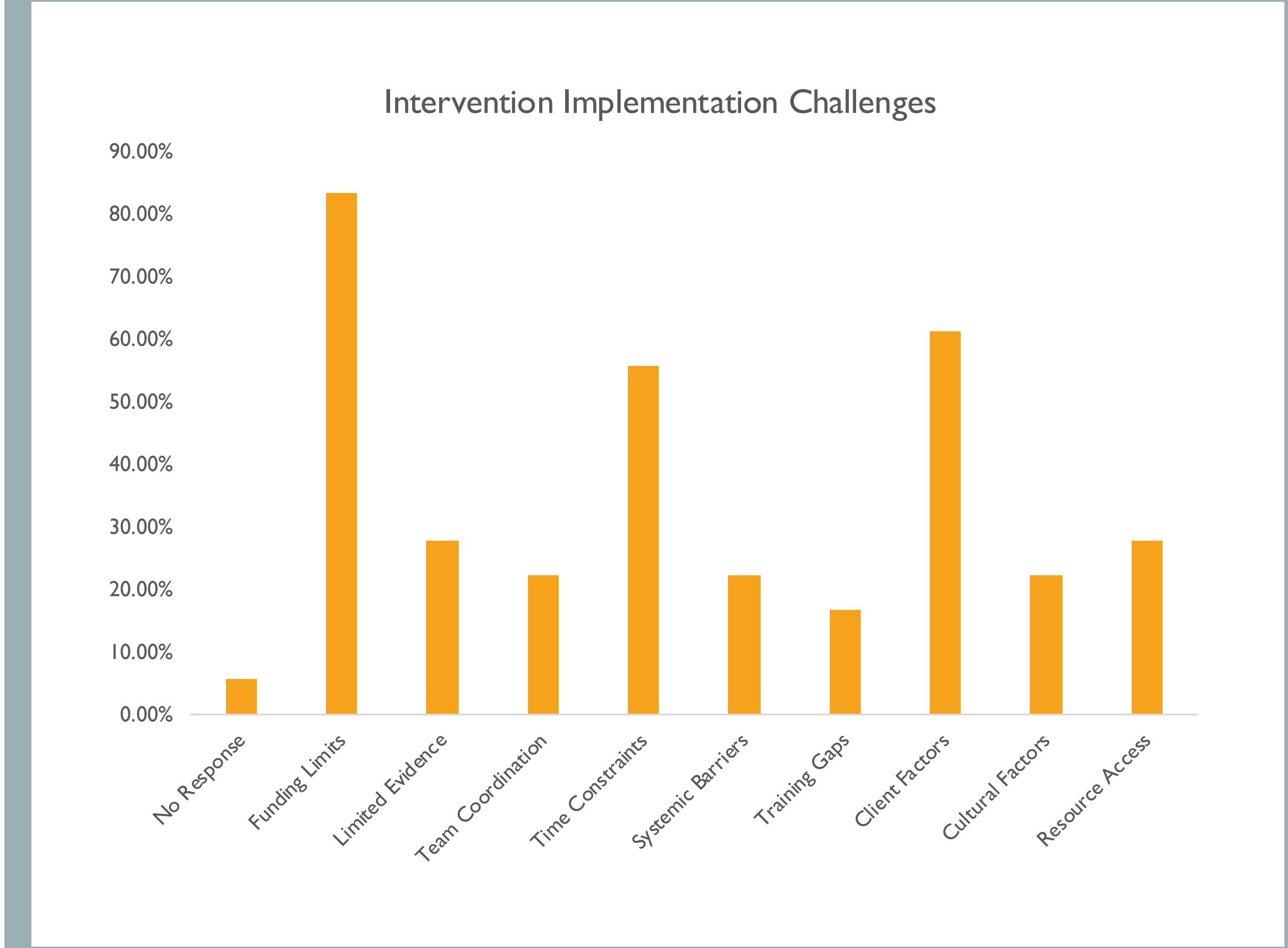
Contextual & Demographic Considerations

- *“Single versus dual-diagnoses, geographic region, mental health considerations, cultural background”*

INTERVENTIONS: ACCESS & SUPPORTS



INTERVENTIONS: PRACTITIONER-IDENTIFIED BARRIERS



INTERVENTIONS:
PRACTITIONER-IDENTIFIED BARRIERS

Services Access Barriers:

Limited Capacity & High Demand

- *"Limited – Too many waitlists, limited (if any) funding"*

Geographic Barriers

- *"It's really hard in the north to access anything"*

Lack of FASD-Informed Services

- *"Many services exclude FASD or do not have knowledge to support individuals with FASD"*

Cost & Resource Constraints

- *"Minimal supports… all come at a huge cost that families can't afford"*

Fragmented & Underdeveloped System

- ***"We know more about FASD than ever, but systems haven't caught up"***

FACILITATORS & PROMISING PRACTICES

1.Adapt Existing Evidence-Based Interventions

- *"CBT… needs heavy adaptation and DBT is a huge opportunity area… very skill-based (which aligns with FASD needs)"*
- *"ACT, PCIT, PEERS, TOPS"*

2. Relationship-Based & Trauma-Informed Approaches

- *"More important to use developmental, relational, and trauma-informed interventions… than to be limited to FASD-specific interventions"*

3. Individualized, FASD-Informed Care

- *"Tailoring treatment… through and FASD lens is extremely important"*

4. Community & Culturally Grounded Practices

- "Remote community find the lands healing and see the healthy way of good living"

5. Structural Supports & Service Models

- *"FASD-specific school classes, FASD-specific housing options"*

CONCLUSION

Preliminary findings suggest that frontline providers:

- frequently encounter potential indicators of prenatal alcohol exposure
- often rely on clinical judgement rather than screening tools
- face challenges discussing PAE due to stigma and incomplete histories
- experience barriers when attempting to refer individuals for assessment

WHAT’S NEXT?

Continue surveying provinces

Conduct interviews & focus groups with healthcare providers and families

Continue to collaborate with community partners and researchers

Develop a cognitive and social functioning screening tool for frontline service providers and teachers working with families/ individuals with FASD.

Develop a standardized measure of intervention outcomes

ACKNOWLEDGMENTS

Our participants!

Dr. Michelle Keightley

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Community Partner

Dr. Mary Motz

Ph.D., C. Psych | Clinical Psychologist

Community Partner

Dr. Mary Desrocher

Ph.D., C. Psych | Associate Professor at York University

Supervisor

HOW TO GET INVOLVED?

YORK U

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PRINCIPAL INVESTIGATOR POSITIONALITY STATEMENT

Mary Desrocher:

I am a White woman (European) from a working-class family, the first of my extended family to attain a PhD. I have lived experience with family members with substance use and mental health issue and have experienced trauma. I fully believe in the support that comes from anyone who genuinely cares about helping people, no matter the letters (or not) behind their name.

I am a faculty member at York University, doing research and clinical neuropsychology. My training is in assessment of neurocognitive function and neurorehabilitation. My degree means I worked hard but also means I do not know everything about other peoples' experiences. I acknowledge that I will make mistakes and am open to people talking about what would be better for me to know. I appreciate the opportunity to talk about our research and what is/ is not useful for those who learn about our work.