

THE NATIONAL FASD DATABASE

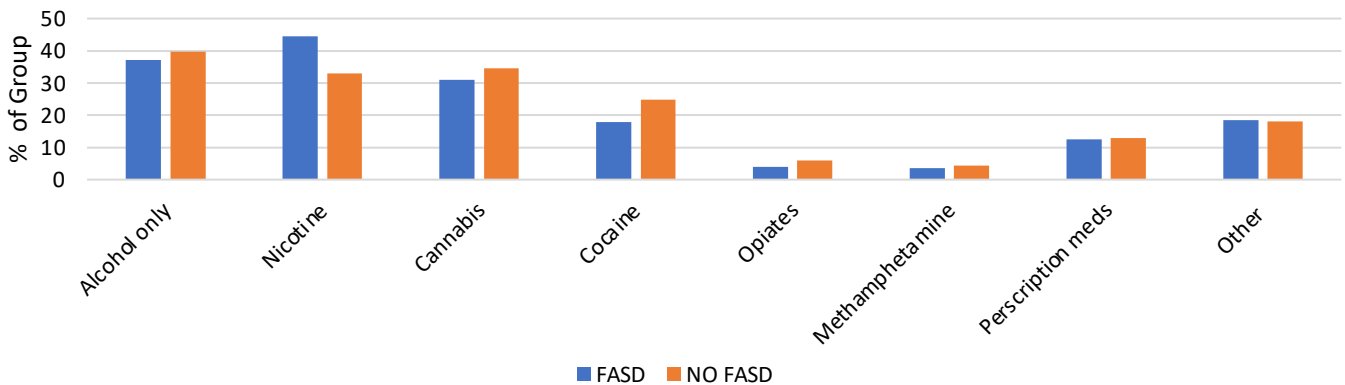
NEWSLETTER

Winter Newsletter / December 2022

PROJECT UPDATE

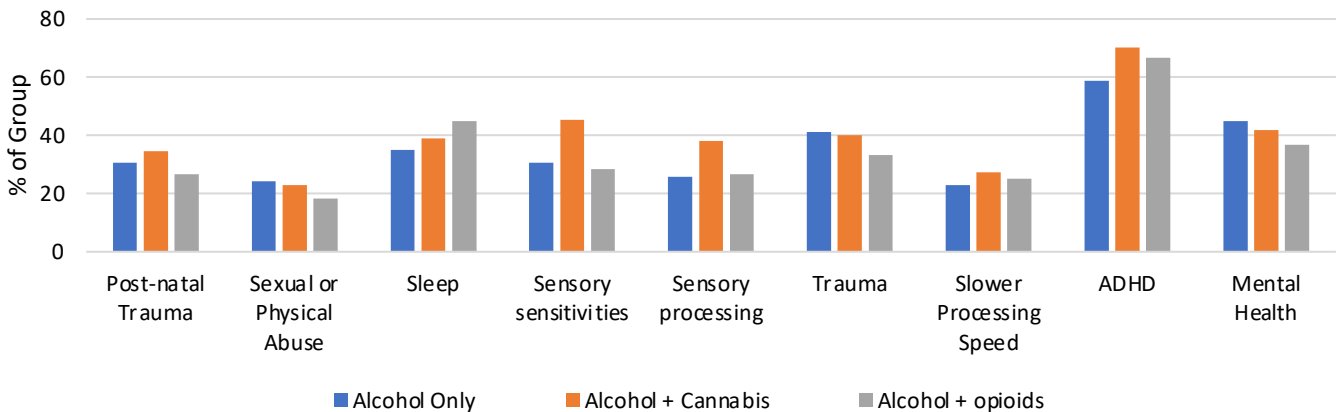
- 4,318 records as of December 14th, 2022
- WELCOME to the database Alvin Buckwold Child Development Program in Saskatoon!
- CanFASD is currently working on a project with the Public Health Agency of Canada (PHAC) which is informed by data from the National Database and the knowledge of clinic operations – a lot of which has come from database clinics! We are very excited that PHAC has engaged with CanFASD to develop a better understanding of FASD assessment and diagnosis in Canada. A portion of this project involves writing a report on the National FASD Database and what it captures.

Prenatal Exposures



Our data show that more than 60% of individuals with FASD and those without FASD have at least one additional prenatal exposure in addition to alcohol. The most common additional exposures include nicotine, cannabis, and cocaine.

Impacts of Alcohol Only, Alcohol and Cannabis, and Alcohol and Opioid Prenatal Exposures in Individuals with FASD



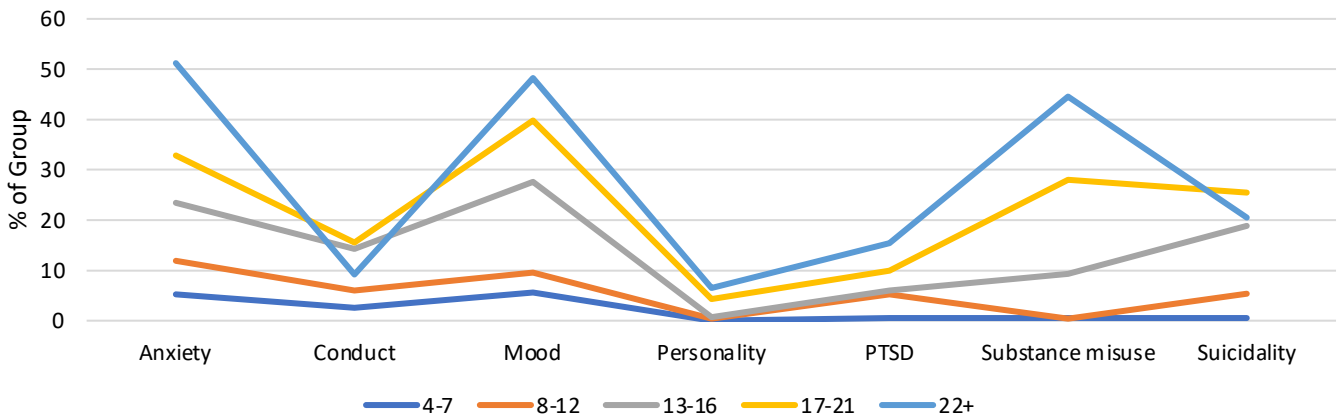
Alcohol-only, alcohol+cannabis, and alcohol+opioid exposures may have different impacts on different the experiences and health of individuals with FASD. While it is easy to assume that prenatal exposure to substances would have a negative impact on the exposed individual, it is also important to investigate if any substances are protective against adverse outcomes. Dr. Mela will be working on a paper examining the outcomes of various prenatal exposures, particularly which substances may exacerbate impairments and challenges as well as those that may have protective factors. This data will have to be interpreted and reported with caution but will provide a more accurate clinic picture of individuals with PAE and additional exposures.

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DATA HIGHLIGHTS

- Adults with FASD are significantly more likely to be diagnosed with some mental health disorders and experience substance abuse compared to the general Canadian population.
 - Anxiety disorder - **3.5x** more likely
 - Mood disorder - **4.3x** more likely
 - PTSD - **4.9x** more likely
 - Substance misuse - **17.4x** more likely
 - Suicidality - **19.9x** more likely
 - ADHD - **55x** more likely

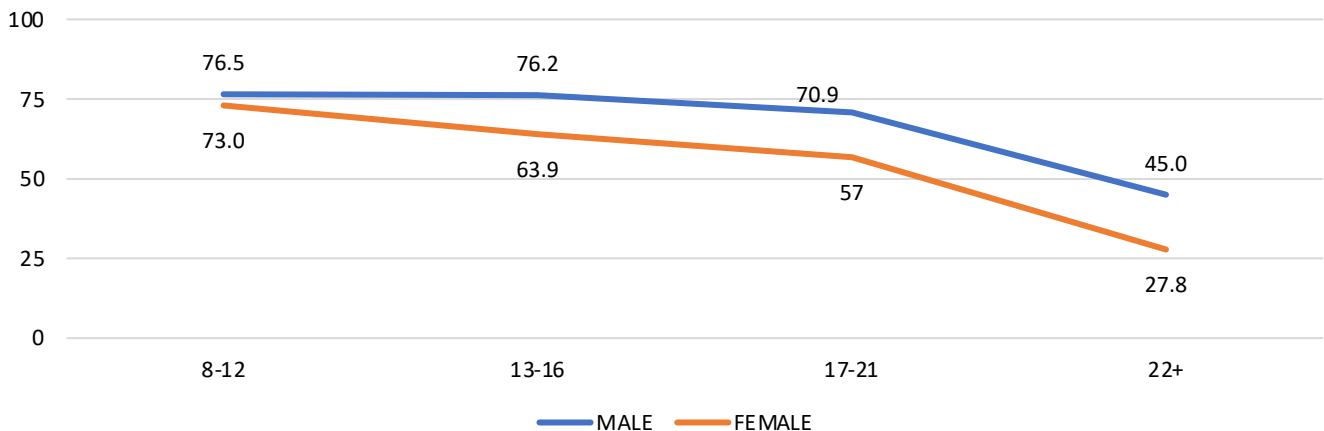
Mental Health Across Ages in FASD



The prevalence of certain mental health disorders experienced by individuals with FASD appears to vary with age. Trends in this data indicate that the prevalence of mental health conditions in individuals with FASD increases over the lifespan. This means that individuals with FASD, particularly those who are diagnosed in childhood and adolescence when mental health concerns are less frequent, should routinely have their mental health assessed.

Given the high prevalence of ADHD among individuals with FASD, we are beginning to dive deeper into the details of this relationship. This work will continue in various ways, but here is a brief snapshot of ADHD over the lifespan.

ADHD Diagnosis in Males and Females with FASD Across the Lifespan



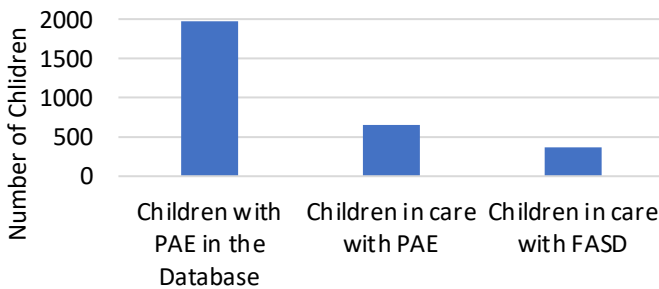
ADHD is most prevalent in individuals with FASD who are 8-12 years old. One explanation for this may be that the attention deficits, hyperactivity, and impulsivity associated with ADHD are more noticeable in school-aged children. Relatedly, there is a decline in diagnosed ADHD over the lifespan. This may be explained by the fact that ADHD symptom severity declines with age and may be less noticeable to others. While this observation of change over the lifespan occurs in both males and females with FASD, the decline in ADHD diagnosis is more noticeable for females than males by 22 years old.

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Digging even Deeper into the Data!

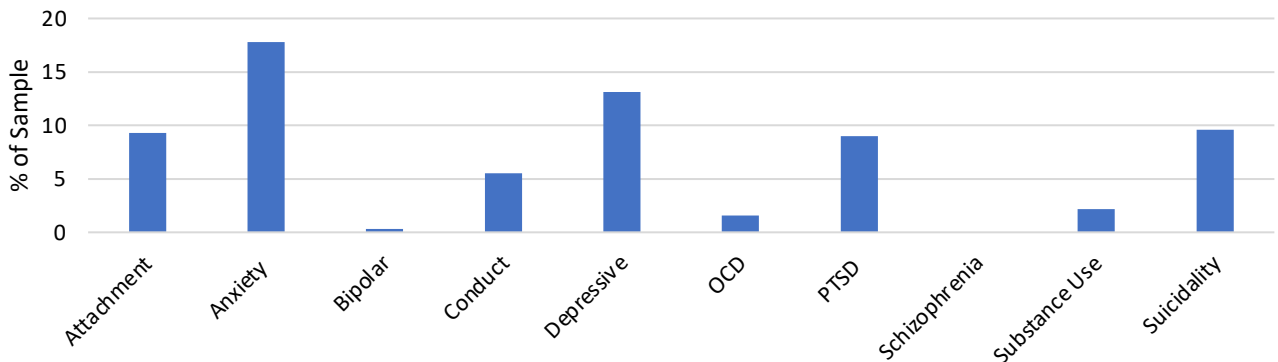
Below are just some of the descriptive statistics that highlight the experiences and features of **children with FASD in the database** who are in the child welfare system. It is **important to note**, that while these data are from individuals <18 years old in the database, many adults in the database are likely to have gone through the child welfare system and may have had the same difficulties and experiences as the children that contributed this data.

Prevalence of PAE and FASD in Children in Care



At the time data were analyzed, there were n=1,972 children with PAE in the database. 33% of children in the database who have confirmed PAE were in care (n=652). Of the children with PAE who are in care, 56% had an FASD diagnosis (n=366).

Mental Health Diagnoses of Children in Care with FASD

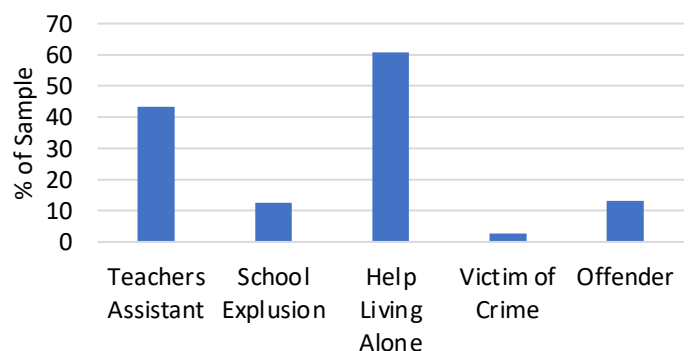


Children in care experience a variety of mental health disorders. On average, children in care have two diagnosed mental health disorders. Clinicians should be particularly vigilant in assessing for mental health conditions in children involved with the child welfare system. Children who are struggling should be referred to mental health support and their caregivers educated on what signs and symptoms to watch for. Separation from caregivers in the first 18 years of life is an adverse childhood experience that can have lasting implications on a person's mental health and attachment.

Children in care experience difficulties with daily living. Over 40% of children in care have a teachers assistant. While this indicates that school is a common struggle for these individuals, it also means that an intervention has been put in place to support these children. What is harder to determine is how many children would benefit from a teachers assistant but do not currently have one.

One particularly interesting statistic is that over 13% of children in care are involved in the justice system as an offender and nearly 3% are victims of crime.

Difficulties with Daily Living of Children in Care with FASD



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WHAT'S NEXT FOR THE NATIONAL FASD DATABASE?

Over the past few months, led by Dr. Cook, the team began thinking about improvements that can be made to the database. This has included thinking about current limitations in the database, variables that require more detail or clarification, and what missing information would be helpful to collect. This thought process has been guided by what the team feels and has heard what clinics need to know more about. Through consultation with clinics, we will be determining the next steps for the database and plan to implement these changes soon.

CO-CREATING HOUSING SOLUTIONS: ENACTING OPPORTUNITIES FOR INDIVIDUALS WITH FETAL ALCOHOL SPECTRUM DISORDER (CHOoSE)

The Canadian government has made it a priority to house its most vulnerable citizens, citing access to housing as a basic human right. As many as 80% of youth and young adults with FASD have had difficulty sustaining independent living, and more than 30% have been unhoused at some point in their lives.

Youth with FASD are particularly vulnerable to housing instability when they 'age out' of services (e.g., foster care, school) or when their caregiver(s) pass away and they do not have strong pre-established housing and social supports. Many individuals with FASD also experience co-occurring mental health and substance use challenges which may create further barriers to acquiring and maintaining safe and supported housing. Service providers, individuals with FASD, and caregivers have described challenges navigating conventional housing support systems which often fail to meet their unique needs.

CanFASD, in partnership with Overlap Solutions, has received funding from the Canadian Mortgage and Housing Corporation's Solutions Lab that will provide a unique opportunity to unite Canadian housing providers, youth with FASD, caregivers, researchers, and policymakers to be innovative. Together, we will co-design an implementation approach in response to needs-based and strengths-based housing for individuals with FASD and to do this we need your help. Please see the **three** attached recruitment posters and please forward them within your Networks.

THE DATABASE IN ACTION

- Dr. Cook has been very busy presenting on the database. Presentations have included:
 - "Using the National FASD Database to Better Understand Developmental Origins of Health and Disease (DOHaD)" – DOHaD Conference 2022, Vancouver, BC
 - "FASD and ADHD" – Canadian ADHD Resource Alliance (CADDRA) Conference, St. John's NL
 - "Prenatal Exposure to Alcohol and Other Substances: Effects on Physical and Mental Health Trajectories" – Society of Obstetricians and Gynaecologists of Canada Scientific Conference, Quebec City & European Conference on FASD, Arendal, Norway
 - "Canada's National Database on FASD" – The Royal College of Obstetricians and Gynaecologists' World Congress, London, UK & European Conference on FASD, Arendal, Norway.
 - "Building Capacity for Prevention, Diagnosis, and Interventions" – The Natalie Davison Honourary Lecture, London FASD Conference, London, ON, Canada (virtual)

CLINIC AND DATABASE REPORTS

This year, we will prepare and distribute the national and clinic database reports by the end of March. Our hope is that these documents will support your end-of-fiscal year reports for funders and assist in advocating for sustained or increased funding and support for your clinic.

If you have questions about how your reports can be leveraged to support your program – one of the main intents of providing the reports – please contact Andrew (andrew.wrath@canfasd.ca)

FALL & WINTER LEARNING!

COURSE ALERT: FASD for Community and Social Services Professionals Level II is now available on the CanFASD e-Learning platform: <https://estore.canfasd.ca/fasd-for-community-and-social-services-professionals-level-ii>. Watch for announcements about additional new courses coming soon!

Publication Updates

Wrath, Mela, Li, et al. recently published a paper on [psychotropic medication use in individuals with PAE](#). The main findings were that individuals with FASD had higher rates of psychiatric disorders and were prescribed significantly more antidepressants/anxiolytics and antipsychotics compared to those with No FASD or designated as At Risk. This is a thorough paper that discussed mental health and psychotropic medication use across the lifespan for individuals with PAE/FASD. [Please share this paper with your clinicians!](#)

Jessica Burns, a former Masters student of Dr. Kelly Harding, recently had a paper on FASD assessment and diagnosis in Northeastern Ontario accepted for publication in the Journal on Developmental Disabilities. This project used data from the database and will be shared on TEAMS once published.

A paper on sex and gender differences among people with PAE/FASD has been submitted for publication. We hope to know the status of that paper soon! If accepted, it will be shared on TEAMS.

CanFASD has released two Issue Papers this year. One is about FASD and [suicidality](#) and the other is on [psychotherapy for individuals with FASD](#). CanFASD hopes to release an issue paper on preschoolers with PAE/FASD before the end of the year.

In September, The Journal of Fetal Alcohol Spectrum Disorder published a CanFASD special issue titled "[Shifting Perspectives in FASD](#)". This special issue includes 10 articles spanning topics from child welfare to prevention and including the voices of those with lived experience in FASD research. This is a little something for everyone in this special issue. All articles are open access

NEW RESEARCH OPPORTUNITY FOR INDIVIDUALS WITH FASD

A Strengths-Based Study of Identity and Wellbeing in Adults with FASD

Dr. Katherine Flannigan, Dr. Jacqueline Pei, Dr. Kaitlyn McLachlan, Ms. Dorothy Reid, Ms. Marsha Wilson, CanFASD Adults FASD Expert Collaboration Team (AFECT)

This study is for adults with FASD. The study team is seeking to answer three primary research questions about adults with FASD: 1) How do adults with FASD see themselves? 2) What are adults with FASD good at? and 3) How do adults with FASD feel about their lives?

Please share within your clinics, with community partners, etc., to get the word out about this important and innovative study!



LOOKING FOR VOLUNTEERS

We are doing a study about **STRENGTHS IN ADULTS WITH FASD**

WHO CAN PARTICIPATE?

People with fetal alcohol spectrum disorder (FASD) who are 18 years or older.

WHAT WILL YOU DO?

Complete a private survey online. It will take about 1 hour. You can also create art and send it to us. If you don't have a computer, we can do it together over the phone.

WHAT DO WE WANT TO KNOW?

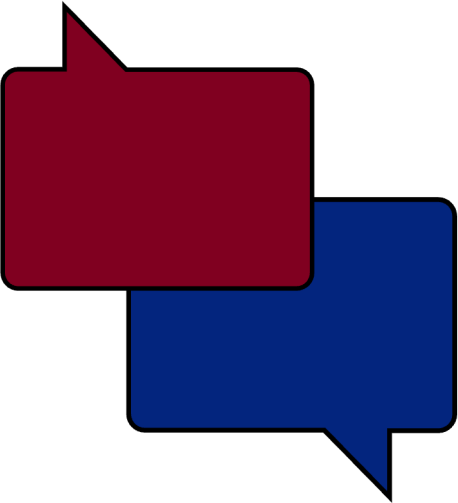
- How you see yourself
- What you're good at
- How you feel about your life

INTERESTED?

To learn more or participate, [click here](#).
If you have questions, you can email Kary Flannigan at kary.flannigan@canfasd.ca

CanFASD
UNIVERSITY OF ALBERTA

THIS STUDY WAS APPROVED BY THE UNIVERSITY OF ALBERTA ETHICS BOARD (P100122299)



ARE YOU AN INDIVIDUAL WITH FETAL ALCOHOL SPECTRUM DISORDER OVER THE AGE OF 16 LIVING IN CANADA?

We are recruiting participants for a **qualitative interview study** to talk about your **lived experiences with housing**.



This interview will be conducted **virtually** and will take approximately **30-45 minutes** of your time.

We will ask you about:

- your current living situation
- your previous living situation(s)
- your strengths and challenges
- the supports you need to help you with housing



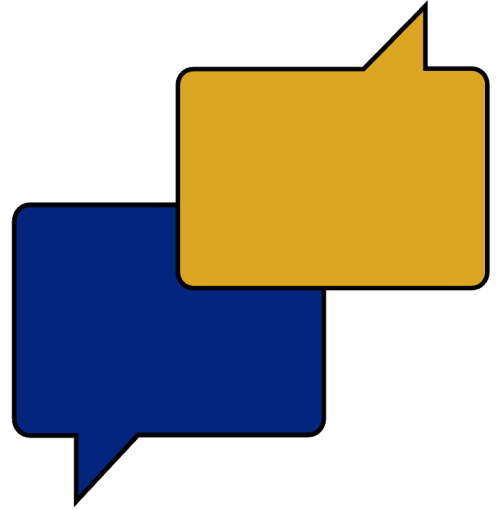
All participants will be compensated with a \$50 e-transfer for their time.

If you are interested in participating or would like more information, please contact:

housing@canfasd.ca
www.choose-fasdhousinglab.ca

This study has been approved by the University of Alberta Research Ethics Board: Pro00124005

ARE YOU A CAREGIVER, SPOUSE, PARTNER, CLOSE FRIEND, OR OTHER KEY SUPPORT PERSON OF AN INDIVIDUAL WITH FETAL ALCOHOL SPECTRUM DISORDER OVER THE AGE OF 16 LIVING IN CANADA?



We are recruiting participants for a **qualitative interview study** to talk about the lived experiences of **housing for individuals with FASD**.

This interview will be conducted **virtually** will take approximately **45-60 minutes** of your time.

We will ask you about:

- yourself and your family
- the individual with FASD that you support
- their experiences with housing
- your thoughts on housing needs in general for individuals with FASD



All participants will be compensated with a \$50 e-transfer for their time.

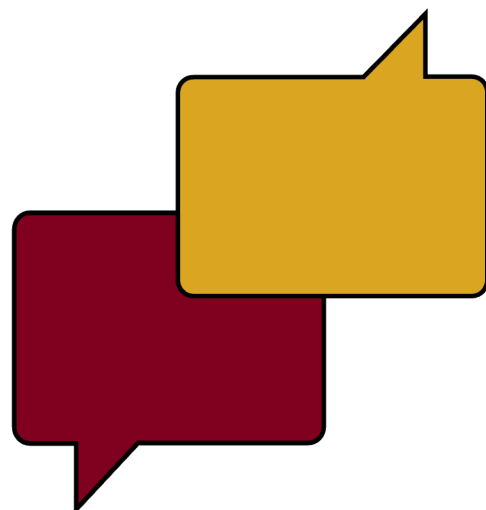


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www.choose-fasdhousinglab.ca

ARE YOU A HOUSING SERVICE PROVIDER OR AN EMPLOYEE OF A HOUSING PROGRAM IN CANADA?

(e.g., organizations that provide housing supports, private group homes, landlords, etc.)



We are recruiting participants for a **qualitative interview study** to talk about the lived experiences of housing for individuals with FASD.

This interview will be conducted **virtually** and will take approximately **30-45 minutes** of your time.

We will ask you about:

- your organization, program, and/or role
- how your organization interacts (or does not interact) with individuals with FASD
- your thoughts on the housing experiences of individuals with FASD
- your thoughts on supports needed for individuals with FASD



All participants will be compensated with a \$50 e-transfer for their time.



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