

# Exploring the Transition into Adulthood For Adults with Fetal Alcohol Spectrum Disorder

## *Summary Report*

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## INTRODUCTION

### About FASD

Fetal alcohol spectrum disorder (FASD) is a lifelong condition that affects the brain and body of a person who was exposed to alcohol before birth (Cook et al., 2016; Mattson et al., 2019).

FASD affects each person differently, so individuals with FASD can have different symptoms (Cook et al., 2016; Mattson et al., 2019). Some of the most common symptoms of FASD include difficulties with memory, decision-making, picking up on social cues, attention, and managing emotions. These differences can be mild or severe and affect how they do everyday tasks.

Each person with FASD has their own set of strengths and challenges, and it is important to appreciate them because many of their strengths and challenges can offer valuable insights into the support they need as they transition into adulthood (McLachlan et al., 2020; Olson & Sparrow, 2021).

### Transitioning into Adulthood

For people with FASD, moving from being a child to an adult can be a combination of positive and negative experiences, depending on the people, supports, and circumstances in their life. For some people, positive transitions to adulthood include having consistent social support and relationships, the opportunity for self-expression, and participating in activities centred around their strengths (Gault et al., 2024a; Gault et al., 2024b; McLachlan et al., 2020; Olson et al., 2021; Skorka et al., 2022). However, some of the challenges adults with FASD might face are

difficulties meeting the expectations of adult life, such as dealing with money and living alone, due to heightened support needs, not having support services after turning 18 years of age, and systemic barriers like not having adequate supports, and stigmas surrounding FASD (Dunbar Winsor, 2021; McLachlan et al., 2020; Pepper et al., 2019).

Adults with FASD can do well in adulthood when they can build on their strengths and when supportive people, support services and strategies, and environments help them succeed (Skorka et al., 2022; Gault et al., 2023; McLachlan et al., 2020; Pei et al., 2024). However, **there are still areas that we need research to address:**

1. We need to include both adults with FASD and caregivers in research that talks about their own first-hand experiences instead of relying solely on caregivers and service providers to share those (Bashista, 2022; Shelton et al., 2018).
2. We need more information on what strategies and supports could help adults with FASD thrive in adulthood and what barriers need to be addressed (Anderson et al., 2019; McLachlan et al., 2020; Pepper et al., 2019).
3. There are not enough support services and strategies to help adults with FASD transition into adulthood successfully (McLachlan et al., 2020; Pepper et al., 2019).

This study wanted to find answers to these knowledge gaps by talking directly to adults with FASD and their support people. We wanted to learn what it was like for adults with FASD as they became adults and figure out what helped or made things harder for them.




## **RESEARCH OBJECTIVES**

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**1) Learn more about the experiences of adults with FASD and their support people during the transition into adulthood.**

**2) Find out what things helped them in the transition or what made it harder during this time.**

## METHODOLOGY

	<p><b>RECRUITMENT</b></p> <p>Lauren Gnat (master’s student) asked people and organizations that support individuals with FASD to send out my recruitment materials. Lauren was looking to speak with:</p> <ul style="list-style-type: none"><li>● Adults <u>with</u> an FASD diagnosis who were living in Canada and were 19 years old or older.</li></ul> <p><b>AND</b></p> <ul style="list-style-type: none"><li>● People <u>who support</u> an adult with an FASD diagnosis (ages 19+) and who were living in Canada.</li></ul>
	<p><b>RESEARCH DESIGN</b></p> <p>We did 24 online interviews using Zoom. Before the interviews, we explained the study and got their consent to participate. Lauren then asked each participant about their experiences with the transition to adulthood, either for themselves or for the adult they support.</p> <p>The interviews with adults lasted between 33 to 75 minutes, and those with support people lasted 42 to 105 minutes. We compensated each person \$50 for their time.</p>
	<p><b>DATA ANALYSIS</b></p> <p>After completing all of the interviews, Lauren created a transcript of what was said and sent it to the participants for them to review.</p> <p>After that, Lauren organized the information into themes with the help of my supervisor, Dr. Morton Ninomiya, and my collaborator, Dr. Catherine White. Each person independently organized information into themes about the adult’s experiences of becoming an adult. We discussed and compared themes based on what people said worked well, problems and challenges they faced, and what could be made better in the future.</p>

*Note.* The term “support person” was used instead of “caregiver” because it allowed us to include a wide range of people who support adults with FASD. A support person is someone who regularly tends to the needs of a person with FASD and has many insights into the person’s daily living, well-being, transition experiences, and transition-related strengths and needs.

## DEMOGRAPHICS

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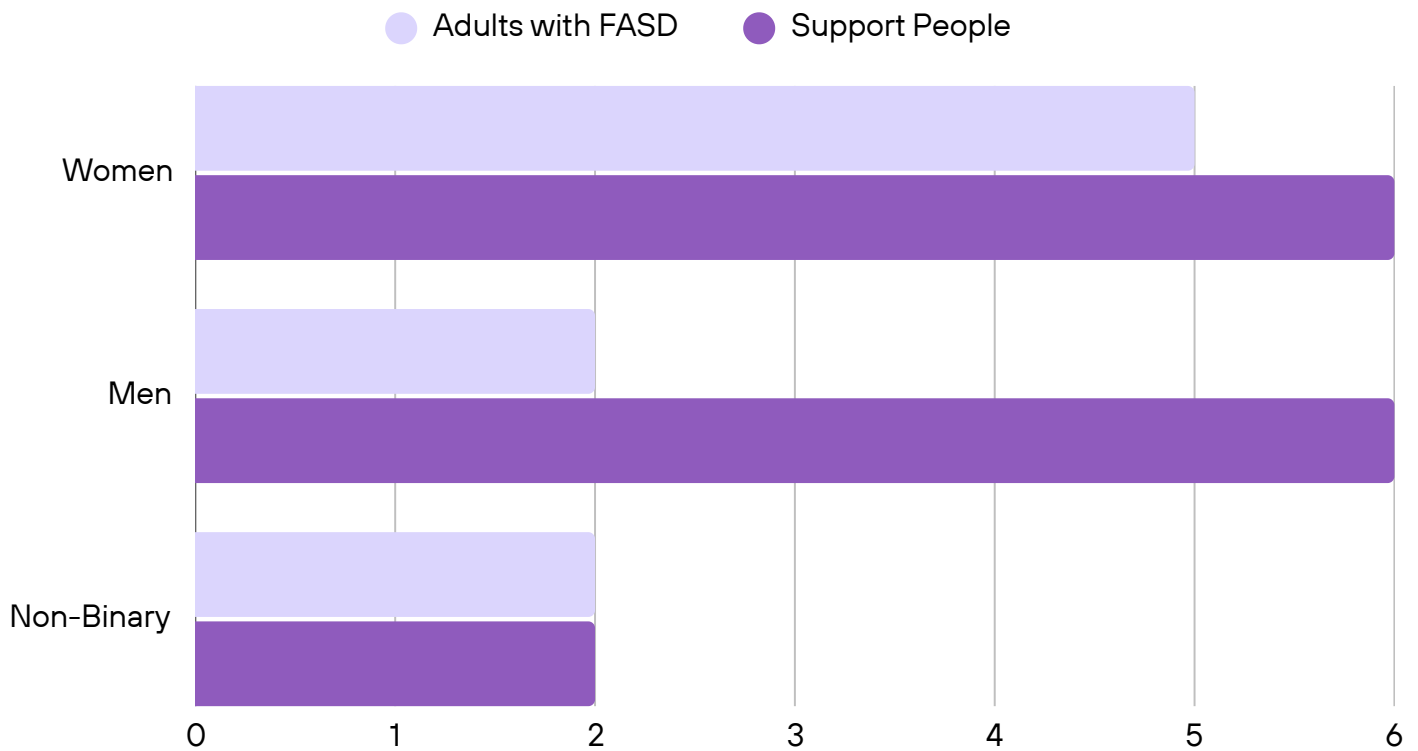
### Characteristics of Participants with FASD and Adults Described by the Support People

There were **nine adults with FASD** and **15 support people** that participated in the study.

One support person did not speak about a specific adult but worked as an FASD support worker with 10-12 adults with FASD, whose ages ranged from 14 to 22. Therefore, the categories for support people should total up to 14.

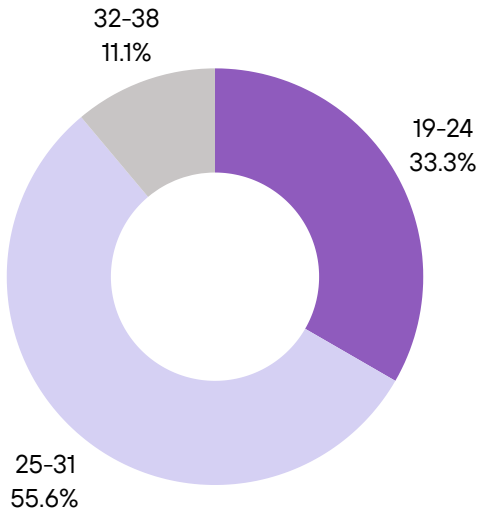
In addition, six participants with FASD and seven support people discussed the experiences of the same adult but were interviewed separately and analyzed as individuals.

### Gender Demographics of Participants

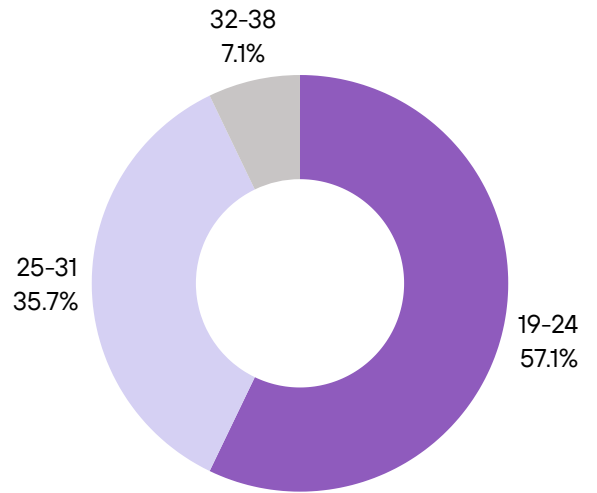


## Age Demographics of Participants

### Ages of Adults with FASD

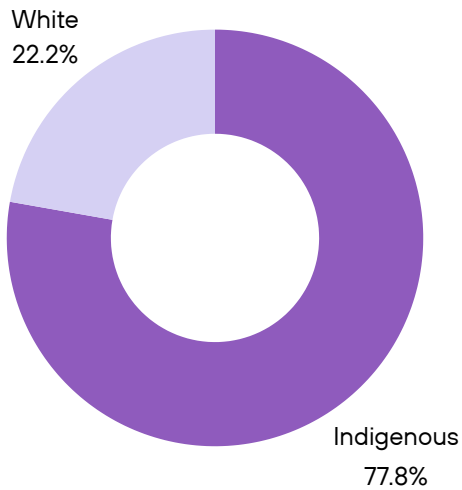


### Ages of Support People Describing Adults with FASD

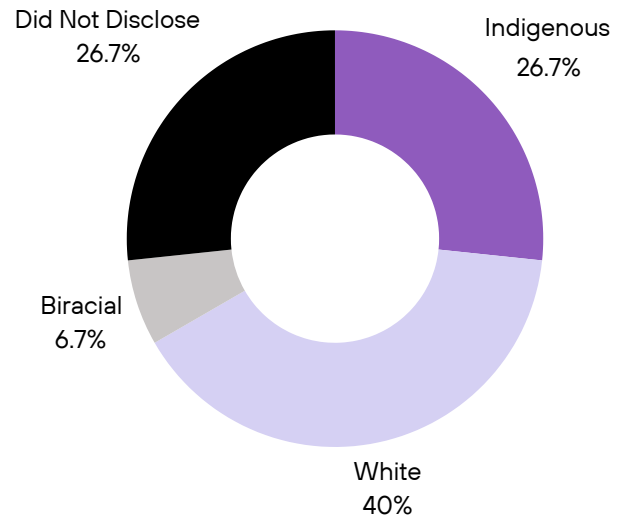


## Race or Ethnicity Demographics of Participants

### Race or Ethnicity of Adults with FASD

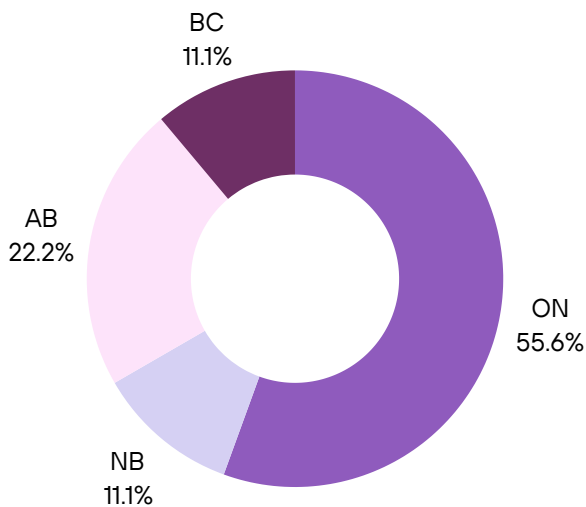


### Race or Ethnicity of Support People Describing Adults with FASD

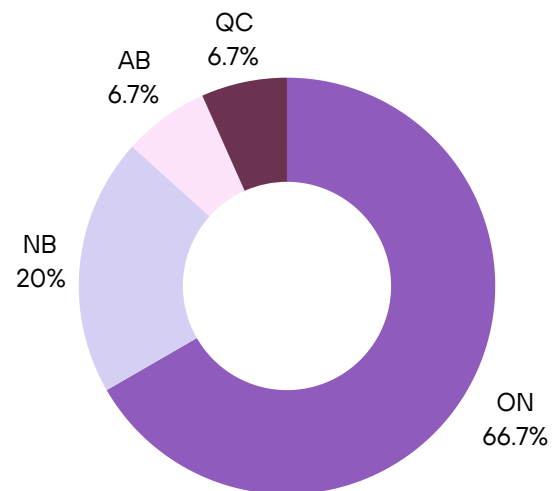


## Provincial Breakdowns

### Adults with FASD



### Support People Describing Adults with FASD



## FINDINGS

The themes were categorized into four major sections: 1) the early life experiences that influenced the transition to adulthood, 2) the perspectives from adults with FASD and support people regarding their daily living in adulthood (i.e., after turning 18/19), 3) the perspectives of adults with FASD and support people regarding their supports and support services in adulthood, and 4) the perspectives from adults and support people regarding the ideal supports, strategies, and recommendations for the transition planning and living in adulthood.

While many themes from this study are common experiences for adults with FASD, as described in other literature (i.e., D. Reid et al., 2022; Joly et al., 2022; McLachlan et al., 2020; Pei et al., 2024), it is important to note that these themes do not apply to every individual with FASD. Individuals with FASD, like everyone else, have unique strengths, challenges, and needs. Since FASD exists on a spectrum, the effects of it can be very different from one person to another. This means that everyone with FASD will have a different experience with adulthood, so different supports and strategies will help different people.

# 01. Early Life Experiences that Influenced the Transition to Adulthood (From Birth to 18 or 19 Years of Age)

## Early Childhood Experiences: Themes and Subthemes

### Theme 1: Positive Experiences

1. Supportive school environment with experience of success
2. Supportive parent(s)/guardian(s)
3. Access to helpful services (e.g. mental health, speech and language, physicians)

### Theme 2: Adverse Experiences

1. Mental health and trauma (e.g., suicidality, bullying)
2. Social and behavioural challenges (e.g., aggression, challenges with social cues)
3. Unsupportive School environment and challenging experiences
4. Unhelpful support services in childhood

The participants with FASD and support people described how some of their positive childhood experiences helped set them up for positive outcomes in adulthood. These experiences included having a supportive school environment, being successful in school, having a supportive parent or guardian, and having positive experiences with service providers and services, such as mental health and healthcare providers and services.

Adults with FASD and support people also described the tough childhood experiences that they believe created challenges for the adults in childhood and continued to influence them into adulthood. The areas of difficulty included experiencing mental health issues and trauma in childhood, challenges in school environments, social and behavioural challenges (such as aggression and violence, challenges understanding social cues, and experiencing bullying), and unhelpful support services.

# 02. Perspectives Regarding Daily Living in Adulthood (After Turning 18/19)

## Daily Living Experiences: Themes and Subthemes

### Theme 1: Intrapersonal Daily Living Strategies and Successes

1. Working on one's mental health to achieve self-development
2. Building positive skills and habits

### Theme 2: Interpersonal Daily Living Strategies and Successes

1. Supportive parent(s)/guardian(s)
2. Social support and relationships (e.g., friends, significant others)
3. Sharing responsibilities (e.g., cleaning and shopping with others)

### Theme 3: Environmental Daily Living Strategies and Successes

1. Structured routine and consistency (e.g., scaffolding of support)
2. Housing successes (e.g., supervised housing, family managed housing)
3. Supportive work environments and bosses

### Theme 4: Daily Living Difficulties and Concerns

1. Difficulties navigating social settings and relationships
2. Being faced with unrealistic expectations for adults with FASD
3. Difficulties with housing, structure, and routine
4. Difficulties at work (e.g., unsupportive boss, struggles finding a job)
5. Difficulties with managing and maintaining finances

### Theme 5: Challenges with Societal Conditions

1. Dealing with stigmas and misunderstandings of FASD
2. Struggling with mental health and well-being difficulties
3. Impact of government decisions and policy

Adults with FASD and support people discussed the strategies and supports that help them in their transition to adulthood. Firstly, the participants discussed how adults with FASD found it helpful to focus on self-development and their mental health and build skills and habits when transitioning into adulthood. They also described how having parental and social support and sharing daily living responsibilities with others (e.g., sharing daily chores) helped them transition successfully into adulthood. Lastly, the participants noted that adults have been successful when they have structure



and routine, housing situations prioritizing safety and autonomy, and supportive work environments where their needs are understood and met.

Participants with FASD and support people also discussed their difficulties with daily living, which included challenges navigating social situations and difficulties with mental health, housing situations, managing finances, maintaining employment, and establishing structure and routine. On a broader level, there were societal conditions that made daily living difficult for adults with FASD, according to those with FASD and their support people. These difficulties included stigmas about the condition, the challenges of living in a society that expects adults to transition like neurotypical adults, and the negative impacts of government policies and inadequate funding.

# 03. Perspectives Regarding Support Services in Adulthood

## Experiences with Support Services: Themes and Subthemes

### Theme 1: Support Related Successes

1. Supportive healthcare and mental health professionals
2. Attending support groups and helpful organizations
3. Promoting interdependence over independence (e.g., sharing daily living responsibilities)

### Theme 2: Support-Related Difficulties

1. Non-existent/ lack of services
2. Difficulties navigating services and accessing support
3. Challenges with existing supports and services (e.g., staff not listening to their needs)
4. Adult's unwillingness to receive supports

Participants with FASD and support people discussed some supports and strategies that made the transition easier for them, such as having supportive healthcare and mental health professionals, positive experiences with support groups and organizations, and living their lives interdependently instead of independently. Interdependence refers to seeing adulthood as something the adult and their supports move through together instead of aiming for independence because that can be an unrealistic expectation.

Although there are supports and strategies that benefit adults with FASD as they transition to adulthood, there are still notable barriers and difficulties that these adults face when it comes to receiving adequate support. Participants with FASD and support people discussed support-related factors that made the transition more difficult, such as the lack of available services, challenges with existing services, and difficulties in navigating and accessing support. Support people also mentioned having challenges getting the adults they support to engage in support services that they believed would be beneficial for the adult.

# 04. Proposed Supports and Strategies that Could be Beneficial in the Transition and Across the Lifespan

## Ideal Transition Supports and Strategies: Themes and Subthemes

### Theme 1: Ideal Strategies

1. Starting transitioning planning in childhood
2. Promoting education and awareness about FASD

### Theme 2: Support-Related Difficulties

1. Building a strong support system
2. Having a consistent primary support or companion
3. Personalizing housing supports (living with a support person, supported housing models)
4. Having support people who understand and support the adults' needs
5. Support for caregivers and support people (support groups)

Adults with FASD and support people provided ideas of what strategies could be beneficial for adults with FASD in the transition to adulthood. Participants described how ideal ways for successfully transitioning to adulthood included creating plans and strategies for preparing for the transition to adulthood while in childhood and providing education and awareness about FASD.

There were five proposed ideas for supports that could potentially benefit adults with FASD when they are transitioning to adulthood. Specifically, support people and adults with FASD highlighted the importance of building a strong support system and having a support companion. In addition, support people also provided examples of ideal housing support and support for caregivers and discussed the importance of understanding and supporting adults' needs.

## CONCLUSIONS

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The study was well done because it used a strengths-based approach, which meant it focused on what adults with FASD are good at and how they can be successful. While the study had some limitations, like most participants being from Ontario, it still provided valuable insights, and future researchers who ask about the transition can interview more people from other provinces. We should continue exploring how to better support adults with FASD because doing so can provide us with more ideas about how to help adults with FASD succeed in adulthood and increase the chances that they will find the right support.

The findings show that adults with FASD need personalized support and strategies throughout their lives. I am sharing these findings with people in the FASD community, including individuals with FASD, their support networks, organizations in the field, policymakers, and health professionals, to give them information that they can use to improve practices, policies, resources, and supports or develop new ones that help bring on a positive transition to adulthood.

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## RESOURCES

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1. [Life transitions for people with FASD: CARE Study Update](#)
2. [Transitioning into Adulthood with FASD \(webinar\)](#)
3. [Youth with FASD Transitioning Initiative Toolkit \(resource developed by Lakeland Centre for FASD\)](#)
4. [Lifespan Transitions](#)
5. [Article Summary – Review of Transition Planning Tools for Youth with FASD in Canada](#)
6. **Research articles**
  - a. [Towards Healthy Outcomes: A Framework for Integrated Community Intervention](#)
  - b. [State-of-the-Art Review of Transition Planning Tools for Youth With Fetal Alcohol Spectrum Disorder in Canada](#)
  - c. [Transitions into adulthood for people with fetal alcohol spectrum disorder: A scoping review of promising practices](#)
  - d. [System Kids: Transition-Aged Youth From Foster Care to Developmental Services](#)