Fetal Alcohol Spectrum Disorder and Best Practices for Supportive Housing Options

Includes:

Final Report, Sample of Interview Questions, List of Contacted Housing Agencies

By: Leili Esken

Completed for: Moms FASD Advocacy Group

Supervising Professor: Joel Cahn

Trent Community Research Centre Project Coordinator: Brittany Finigan

Course Code: FRSSC 4890

Course Name: Forensic Community-Based Research Project

Completion Date: April, 2023

Project ID: 5065

Suite 3.10, Trent University Student Centre

1600 West Bank Drive

Peterborough, ON K9L 0G2

Phone: (705) 748-1093

Email: tcrc@trentu.ca

Website: trentu.ca/tcrc

Fetal Alcohol Spectrum Disorder and Best Practices for Supportive Housing Options

Report

By

Leili Esken

Host Organization: Moms FASD Advocacy Group

Faculty Supervisor: Joel Cahn

FRSC 4890

2022 – 2023

Acknowledgements

I want to thank the members of the Moms FASD Advocacy Group, Kathy Dracup-Harris, Barbara Hnatiak, Janet Van Camp and Ellen Wilson for bringing this project forward and allowing me to contribute to your advocacy work. It has been wonderful working with you all on this project.

Table of Contents

1 Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong disability that affects the brain and body. It is caused by prenatal alcohol exposure and affects approximately 1 in 20 Canadians. Individuals with FASD often exhibit below average executive and adaptive functioning skills, and struggle with communicating complex feelings. It is not uncommon for someone with FASD to experience homelessness at some point in their lives. Due to these complexities and many more, individuals with FASD often have difficulty finding housing that is safe, supportive, and sustainable. Two sets of semi-structured interviews were conducted in order to identify the needs and common challenges of someone with FASD and how to support their housing requirements. A list of best practices and components of supportive housing models was developed. Most individuals with FASD were found to struggle with living independently; so, two models supporting semi-independence were outlined. The “check-in model” and “live-in model” are two viable supportive and sustainable housing options for individuals with FASD.

2 Introduction

Fetal Alcohol Spectrum Disorder (FASD) is caused by prenatal alcohol exposure. FASD affects the brain and the body for the entire lifetime [1]. Individuals with FASD often need lifelong special supportssupport to help them succeed in different aspects of their lives [1]. FASD, being a spectrum disorder, presents itself differently in everyone, but common struggles include mental health problems, depression, anxiety, ADHD, and other learning disabilities [2]. Individuals with FASD struggle with an array of primary and secondary disabilities. They are often affected by learning disabilities and developmental immaturity. Their social, adaptive, and executive functioning skills are also normally below average [2]. Secondary disabilities, challenges which result from dealing with primary disabilities, often include having trouble with the law and being involved in the legal system as well as drug and alcohol problems [3]. The varying intensities of these challenges and disabilities are unique to each person with FASD.

Individuals with FASD also often struggle with their planning abilities, memory skills, and communicating complex feelings and ideas [3, 4]. These barriers often impact their ability to live independently as adults and they often struggle with obtaining and maintaining employment. Support is needed throughout adulthood, and it often comes from family members, parents,

caregivers, or social workers [2, 5]. The supports specifically designed for individuals with FASD in Canada are frighteningly scarce, as acknowledged in literature and by The Governments of Ontario and Alberta [5,6,7].

Drug and alcohol problems, a criminal record, emotional instability, poor communication skills, and below average executive and adaptive functioning skills are many reasons why individuals with FASD struggle to find housing. Flannigan et al. discovered that individuals with FASD tend to learn better and perform better when their environment endures minimal changes [5]. This is one of the reasons why housing instability greatly affects these individuals. The inability to acquire stable housing, constantly moving, changing roommates, or being evicted are additional barriers faced by these individuals.

The purpose of this project is to identify the components and best practices of current housing models specifically made for individuals with FASD. This project will be conducted for the Moms FASD Advocacy group. This is a group of parents, all of whom have adult children with FASD, and who are passionate about advocating for support for individuals with FASD.

First, a review on the current available housing options for individuals with FASD was conducted. Secondly, interviews of individuals involved with current and past housing options were conducted, and questions aimed to determine what the components and best practices of housing options are for individuals with FASD.

There has been extensive research done on disabilities experienced by individuals with FASD. One experiment focused on adaptive behaviour and adaptive functioning skills [8]. Specific adaptive functioning skills that are generally impaired in individuals with FASD include socialization skills, communication, and daily living skills. Researchers discovered low levels of adaptive functioning skills through semi-structured interviews with caregivers. Based on experiences from caregivers, this research also discovered a cessation in individuals' development as they aged and that there was a general lack of improvement with age in the realm of socialization and communication [8]. It is important to understand deficits in behavior and communication skills as they are prominent reasons why individuals with FASD struggle to live independently and without support. Subpar communication skills can cause strained landlord-tenant relationships and could be a cause of evictions.

A study done at the University of Calgary [9] performed a quantitative analysis of the Homeless Management Information System (HMIS) specifically focusing on FASD data. It

determined that 93% reported addiction issues; 68% reported involvement in the criminal justice system; and 63% reported mental health issues [9]. The length of homelessness among participants ranged from one to twenty-four years with a median of thirteen years. These types of challenges highlight the importance of specific housing for individuals with FASD because finding independent housing with a criminal record and addiction issues can be difficult.

It is well known that the needs of individuals with FASD can be extensive. Pepper, Watson and Coons-Harding [10] focused on the needs of individuals during their emergent adulthood; the phase of life after school and before full independence, usually eighteen to twenty-five years of age. Researchers surveyed parents of children with FASD, some adoptive, some biological, and all the families were living in Ontario at the time. With respect to housing needs, the survey results amplified the need for supportive housing in Ontario. Much of the feedback consisted of not knowing where to send their adult children to live, and that standard subsidized housing in Ontario was not supportive enough for their kid's needs. Many parents called for a structured living environment for their kids where there was enough independence for them to feel like self-sustaining adults, but also enough support to keep their kids on the right track. Parents feel that social workers in this environment would be required around the clock [10]. This work is important to this research because understanding the needs of the adults with FASD by their family members who have lived with them their whole lives and raised them, gives insight into the need for supportive housing options from a perspective that would be unachievable from purely an academic perspective.

In 2005, Brownstone [11] made a call for permanent supportive housing for individuals with FASD. They outlined recommendations for a facility to be built based on results from interviews and focus groups with people with FASD, parents of people with FASD, government officials, and community-based agencies. Brownstone outlined a strong need to assist individuals aged sixteen to twenty-four, an important transitional age, as they shift from family homes, foster care or incarceration into a more independent lifestyle. In addition to more independence, there was a recognized need for intensive specialized support as well [11]. Since 2005, there has been some permanent supportive housing built for individuals with FASD. Although the call from Brownstone has been answered by a few, there is still a long way to go, which is where this project fits in. It is important to recognize this almost two-decades-old work and compare the recommendations to the current housing options that have been developed since its publishing.

A roadblock that individuals with FASD face is that accessing financial support in Ontario is terribly difficult. Many individuals with FASD do not present with enough serious features of their disability to qualify for support programs such as Ontario Disability Support Program (ODSP). The Ontario Disability Support Program Act [12] also states that someone can become ineligible for support if "the person is dependent on or addicted to alcohol, a drug or some other chemically active substance." which is something that 45% of individuals with FASD struggle with [3]. The requirements of ODSP also require that the individual to have a substantial physical or mental impairment and have a diagnosis or verification by a person with prescribed qualifications [12]. Obtaining a diagnosis of FASD can be a long process and difficult without proof of prenatal alcohol exposure [10], a challenge for adopted children with unknown parentage. Understanding how difficult accessing support in Ontario is for individuals with FASD is important to the current research as it explains the need for more support options for these individuals.

In Canada, there are currently only a few permanent supportive housing options specifically for individuals with FASD. The first is Hope Terrace. First opened in 2016 by the Bissell Centre, Hope Terrace currently provides permanent, supportive housing for just over twenty adult individuals with FASD [13, 14]. At Hope Terrace in Alberta, there is staff present around the clock to provide support, stability, and care. When this facility opened, residents were able to consume alcohol or use drugs without the fear of eviction; this is the model still in use. The staff is trained to help these individuals get further treatment if needed. Staff also help residents with attending medical appointments, court appearances, goal-setting, and mental health support [13, 14]. This housing model appears to be a successful one. Learning from their experiences for this project could prove invaluable.

Another supported housing option is the non-profit known as Options for Independence, a semi-independent apartment complex specifically for individuals with FASD [15]. Located in Yukon, this residence offers safe and supportive housing for diagnosed individuals or those highly suspected of having FASD. Around-the-clock support is available, and programs provided to residents include learning money management, household maintenance, food preparation, relationship planning and navigation and more. Support for navigating medical and legal appointments is also available here. Options for Independence follows a "residents first" approach, partnering each resident with a staff member so that each resident's strengths and

challenges are understood in depth [15]. This housing model is another that appears to be a success story and was further investigated in this project.

One other housing option is in Platteville, Wisconsin [16]. This community is composed of five residents all of whom have an FASD diagnosis. It is operated by volunteers and a not-for-profit organization. The house is situated on an expansive farm property that encourages collaboration between residents as well as garden and farm maintenance as an activity. This home has been running successfully for almost five years and claims to have a “replicable model” [16] which was examined by speaking to the person who designed it. This space provides residents access to communal spaces, a private bedroom, and many activities that place residents directly in the community.

3 Research Questions

1. Are there current housing models for individuals with FASD that are successful and sustainable?
2. What are the components and best practices of current housing models for individuals with FASD?

4 Methodology

Two sets of semi-structured interviews were conducted in order to identify needs and common challenges of someone with FASD and how to support their housing requirements.

The first section of the research involved interviews with caregivers and/or adoptive parents of people with FASD. Eight parents were interviewed; they were conducted via phone or video call and took anywhere from 45-90 minutes. With the consent of participants, interviews were recorded and transcribed. The goal of these interviews was to gain an understanding of what individuals with FASD struggle with daily and types of support they need. Questions were meant to focus on challenges and provide information on what their kids need in day-to-day life, in terms of support (emotional, mental, financial, organizational etc.). Parents were also asked about their kid’s housing history, drug and alcohol use, and their income source. Parents were also asked about their personal experiences raising and living with someone with FASD as well

as how FASD impacts their housing situations and why it can be so unstable. Questions asked of participants can be found in Table A1 of the appendix.

The second section of the research was conducted by interviewing housing professionals who have been involved in designing, implementing and/or running housing models for people with FASD. There are currently only a few permanent supportive housing options for individuals with FASD in North America, and the people who run them or were involved in their implementation were interviewed. The list of organizations of where the housing professionals were from can be found in Table A3 of the appendix. Six interviews were conducted via phone or video call. With the consent of participants, interviews were recorded and transcribed. Questions aimed to gain an understanding of the funding models, room style and set up, eviction rates, implemented rules, and available addiction and mental health support, as well as available support for executive functioning skills. Housing professionals were asked about the staff employed at their housing units and how they support these individuals and how they were trained on FASD. They were also asked about their experience supporting people with FASD and how they currently serve that population, what they do well, and what they would do in the future. Questions asked of participants can be found in Table A2 of the appendix.

Interviews were transcribed and condensed. Data from both sets of interviews was coded and organized by. Common themes were then extracted. If a theme appeared more than once from the parent interviews, it was included in the list of challenges and housing issues. Information gained was also used to expand and explain the list of challenges faced and supports required. The second set of interviews was explored by themes such as tenant characteristics, funding, physical setup services, supports and more.

The information gained from the first set of interviews was compared to the information gained from the housing professionals in order to develop a list of best practices for two main supportive housing options.

To address potential biases in gathered data, any extreme outliers were removed. This was implemented in the analysis of data from both part one and two of the interviews. Themes from the parent interviews were included in the results if they appeared more than once. Best practices and components of housing units were listed if they were mentioned more than once. This was done to counteract extreme positive or negative data and develop a balanced list.

4.1 Ethical and Safety Considerations

This project dealt with the feelings and needs of a vulnerable population, individuals with FASD. In order to protect sensitive and confidential information, interviewees were asked not to disclose any names or identifying information of any vulnerable individuals. Names or any sensitive information that was willingly or inadvertently given in the interview was omitted from the final report. Sensitive information was identified by the researcher. Nobody from the vulnerable population was directly contacted or interviewed. A formal ethics application was submitted and approved by the Trent University, Forensic Science Department Board of Ethics prior to interviews occurring.

5 Results

5.1 Parent interview results

The results from the interviewed parents provided a great deal of insight into the FASD brain and experience. It was discovered that even though FASD is a spectrum disorder and there are a variety of different experiences, there are some commonalities in terms of supports required to succeed in daily life. Housing was the focus of this study. It was explored in depth as to why it is needed and what is needed.

"…but now we have these kids and they're adults and where do they go because it is difficult for them to finish school and maintain a job, keep an apartment, handle their emotions, and handle their finances like the just can't do it, the brain is damaged. They need the supports." – Interviewed Parent on why supportive housing is needed for people with FASD.

The results of the parent interviews outlined many similar challenges and needs of their kids with FASD. The interview results are summarized in Table 1.

Table 1: Summarized results of parent interviews organized into challenges and needs. Ages of kids spoken about ranged from 19-28 years old.

Results of Parent Interviews		
	Challenges	Needs
Most Common (Mentioned by more than 4 parents)	- Below average executive functioning skills. - Aggressive behaviour was a main reason for leaving the family home in the first place. - Outbursts and aggressive behaviour. - Struggles with other mental health issues (depression, anxiety, PTSD). - Struggle with drug and alcohol use and abuse. - Cannot follow strict rules all the time. - Supports are not easy to access, and parents often have to piece resources together for their adult kids. - Financial and budgeting challenges, money is often spent very soon after receiving. - Primary source of income is ODSP or other government funding. - Holding a job is difficult.	- Personal, private space. - Cannot live completely independently. - Support worker who understands FASD. - Stable housing. - Daily reminders about basic life skills (hygiene, cleaning room, laundry, dishes etc.). - Help identifying social services and applying/ managing them. - Help with scheduling and attending appointments. - Flexible rules and understanding staff members who enforce and explain the rules.
Somewhat Common (Mentioned by 2-4 parents)	- Run ins with police, been to jail, known within the system or criminal record. - Available housing is often so expensive and hard to pay for. - Primary source of income is their job, part-time, full time or seasonal. - Social and makes friends quickly although they are not always the safest friends. - Understanding social boundaries and appropriate behaviours.	- Would do well in a permanent supportive housing unit that is specific for FASD. - Would do well living independently with support check ins. - Trauma informed staff. - Needs help identifying healthy relationships or friendships vs unsafe ones.

5.2 Housing Options

The results of the interviews with the housing professionals were vast and informative. Once the raw data was thematically coded, it was organized into common themes. Utilizing the outcome of the housing professionals' interviews in combination with recommendations by parents, two housing options were outlined.

The parents shared an array of experiences raising their kids. Some expressed the need for their kid to live in a supported housing unit whereas others expressed that their kids could

live somewhat independently. The responses from the parents outlined common challenges and needs that the adult kids face. Responses from parents outlined two main housing options for their kids (Table 1). Responses such as their kids would do well in a permanent supportive housing unit that is specific for FASD, and their kids would do well living independently with support check-ins were both somewhat common answers.

Housing professionals that were interviewed most commonly had experience running permanent supportive housing options and some had experience with independent living with supportive check-ins. The various housing options discussed varied in rules, physical setup, and geographic location. Despite these differences, two common housing options were identified as viable.

The results of parent interviews identified two main needs for housing and the results of the housing professionals clearly outlined two possible housing options for individuals with FASD. Based on both sets of interviews, the two most sustainable, safe, and successful housing options for individuals with FASD are a "Check-in model" and a "Live-in model". These two options were discussed. Key concepts and best practices are outlined in Table 2.

Table 2: Results of the interviews explained by two housing options, check-in vs. live-in and the best practices for each.

Best Practices of Two Viable Housing Options		
	Live-In	Check-In
Tenant Qualities	- Have challenges living independently or in the family home. - Semi-independent/ interdependent.	- Able to live a more independent life but still require some check ins at their personal residence
Physical Space	- Private apartments or rooms in common building. - No roommates. - Open concept living area and kitchen. - Consider the geographic location – downtown can be convenient but maybe not the safest due to outside influences, rural can be safer but less convenient. - Ideal number 3-8 tenants.	- Smaller apartment, not too big. - If they have roommates, they must have their own room.
Financial	- Private funding model.	- Financially independent (often with the help of a trustee).

		- Pay worker per visit.
Services and Supports	- 24-hour staffed support. - Individual care plans. - Community and tenant centered – want to build community, friendship and peer support by utilizing common spaces. - Community activities are run – sports, cooking etc. - Help with financial planning, budgeting, and learning. - Mental health and substance abuse support. - Make sure they are connected to external supports as needed. - Help with getting to appointments, setting appointments.	- Individual care plans. - Financial planning, budgeting, and learning. - Mental health checks and connect them to resources if needed. - Make sure living space is in good condition, is clean and taken care of. - Check in on social relationships with family, friends, co-workers, and bosses or romantic partners. - Realistic goal setting and goal progress. - Work on building healthy relationships, setting boundaries and other social skills.
Staff	- Supportive and enthusiastic staff. - Ongoing staff FASD training.	- Trained on FASD and has ongoing training. - Case load not too big. - Serve all types of FASD.

6 Discussion

6.1 Parent Interviews vs. Housing Professional Interviews

Generally, housing professionals seemed to be informed and educated on how to support individuals with FASD. They often recognized common struggles and needs and had services in place to support them. The theme of trained staff members was well discussed. Housing professionals acknowledged emotional challenges and outbursts as not uncommon occurrences. They recognized the need to learn how to anticipate these episodes and how to handle them.

Housing professionals often had structures and programs in place in their housing model to aid with social skills, behaviour, and other executive functioning limitations. These were common challenges outlined by the parents interviewed. Thus, it is a positive trend that housing professionals are aware of common challenges and seemed to be FASD informed.

One common practice that all housing professionals understood and tried to implement was avoiding black and white rules. They understood that someone with FASD struggles to adhere to a strict set of rules such as a curfew. This was mentioned by all the parents in the interviews.

Based on the similarities between the challenges and needs of someone with FASD as outlined by the parents and how well the housing professionals seemed to be equipped to handle FASD, it is reasonable to examine their housing models. The list of best practices and qualities of the two housing options will be examined. About half of the parents expressed that their adult child would do well in a permanent supportive housing unit that is specific for FASD, and the other half thought that they would do well living independently with support check-ins.

6.2 Check-In model

Many individuals with FASD that are high functioning often want to live independently. Most of the time though, they still need some supports, even if they are not daily. About half of the parents interviewed express the need for support workers to check in on the kids living independently, as often as needed. Supports would include social support, financial planning and organization, accompaniment to medical or legal appointments, cleaning, household chores, and more. When people get referred to, or join, this program it could also help them find and secure an apartment in which to live, if they do not have one already. One of the barriers people with FASD face when acquiring housing is knowing how to fill out the necessary paperwork that comes with applying for an apartment. It was also noted during the interviews that sometimes the individuals experienced a bad day, and simply needed a couple of hours, secluded in their safe and private room to recuperate. Having a support worker who understands that and can help work on tenant-landlord relationships could be key to keeping them housed.

Supports such as these exist already in some areas, but due to limited resources and large caseloads, services are not abundant. There is also the issue of some individuals with FASD not being eligible for this type of regular check-in service. In the Peterborough area, (other areas were not explored for this option) these supports are only offered to individuals with FASD who also have a diagnosed intellectual disability. This excludes a huge population of those with FASD without a diagnosed intellectual disability.

There are two ways this issue could be addressed. The first is to advocate for extra funding and support for the system already in place, including extra funding for more FASD workers. In order to best serve the FASD population, the requirements about who benefits would need to become broader and more robust, in order to include those who are currently excluded by the criteria, yet still need support.

The second way this could be implemented could be an attachment to the live-in unit. The client who is affiliated with the live-in unit or charity that runs it would live on their own but have support and services from the permanent housing unit. Preferably, they would live near the main building and have access to supports and services offered by the staff, be able to partake in the group activities and community meals as well as have a safe, social place to be. The unit will be discussed in further detail in the following section.

Check-ins would have certain goals such as checks on the person's mental health, and working on building healthy relationships with friends, family, landlords, neighbours etc. Financially, support workers can also help with ODSP applications, setting up automatic rent deposits, setting up a financial trustee and some budgeting assistance.

Individuals with FASD are vulnerable and easily influenced by outside sources. Neighbours or people they meet sometimes do not have their best interests at heart. Having a support worker come in person can show neighbours or people around them that the individuals have a support network. It demonstrates they are not on their own, and that there is someone watching out for them. This helps lower the risk of their vulnerability being exploited.

Check-ins would be scheduled as often as needed and can range from a few times per week to a few times per month, but no less than once per month. This is a viable option for those who want to live on their own but are not able to live fully independently.

6.3 Live-In Model

6.3.1 Tenant Qualities

A permanent supportive housing unit that is designed to serve those with FASD should serve only people with FASD. Although not extremely popular, there are past, current, and future models that are designed solely for adults with FASD to live in throughout Canada and the United States. One of the reasons that traditional housing for people with intellectual disabilities do not work for individuals with FASD is because they are not served properly, and staff are overwhelmed trying to learn how to serve such a variety of people with a variety of disabilities. FASD is such a diverse disorder, and it affects 1 in 20 Canadians. Such a prevalent disorder should have specific support.

Age

The programs investigated in this report revealed housing options for 18 years or older. This has to do with youth housing regulations and the complications of housing people who are not legally adults. No programs had a cap on the age, and some served people from the ages of 18-50. Most commonly, tenants were close in age, usually within 10 years of each other, which meant they often had similar lifestyles, interests and needs, contributing to a more successful living arrangement.

Size of housing unit

Based on the experience of the interviewed housing professionals, it was found that the ideal number of tenants with FASD in one living unit is three to eight. Less than three and there will not be enough funding brought in by rent to cover the costs of the house. More than eight can cause more internal friction than necessary. Some supportive housing units discussed had 15-25 tenants, but they were in a larger building with more complete apartments; not just in a house or duplex. This number can work if it is staffed properly but to serve this population the best way possible, there should not be more tenants than students in a school classroom.

Monthly Cost

In order to live in a supportive housing unit or house, a monthly rent must be paid. This amount varies drastically based on the number of staff employed, whether financial support for food is public or private, and the geographic area of the home. The interviews with housing professionals did not provide a clear, all-around rent that should be charged, and it varied significantly. One commonality was that there was a fair amount (more than 50%) of tenants that received provincial disability support (in Ontario this is ODSP). This proportion was mirrored by parents in interviews. More than half of the kids discussed were receiving ODSP as their primary source of income. As such, monthly charges should not exceed or max out the amount received monthly by someone receiving this financial support. This housing option usually costs as much or slightly more than a typical apartment in the geographic area. While this is not a cheaper option for some, it is a safer, more supportive, and sustainable option.

Application and Intake

Criminal records should not be a deal breaker for a potential client. They should be examined on a case-by-case basis when assessing clients for intake. The parent interviews revealed that criminal records or involvement in the justice system was not uncommon. If a hard rule is in place for "no criminal records," a large portion of the population that needs this support will be excluded. A petty theft charge for something like shoplifting is much less serious than sexual assault. This distinction is why it needs to be assessed based on the individual.

A recommendation to help develop an individual care plan for tenants would be to have a lengthy listening session with the parents or caregivers of the tenants before they move in. Each person with FASD faces individual and unique challenges and they require different support. The people who know these areas best are the people with whom they spend the most time and those who raised them. It is important that staff are open and receptive to the advice and recommendations parents provide for the care and support of their kids. Staff should be prepared to handle each person as they move into the house because change is often difficult for people with FASD and knowing more about them beforehand can better help them deal with situations that arise, making tenants more comfortable.

The attitude of the potential tenant is a very important factor. They must want to be there and live there. This type of permanent supportive housing is meant to be just that, permanent. Group homes are often temporary, unstable and can be unsafe and understaffed. This type of model is not meant to be like this. When the tenant is there of their own volition or as a suggestion of a close friend or family member, they are more likely to be happy there. When they actively participate in community projects and group activities, they are more supported by their peers and staff. Goal setting is also something that can be encouraged and supported. Goals such as holding a part-time job, keeping a tidy room or saving for a cell phone have all been goals mentioned in the interviews.

Five out of six housing professionals recommended housing a single gender and not having a co-ed space. As expressed by almost all the parents, individuals with FASD often have trouble with interpersonal relationships and boundaries. CanFASD has expressed that some individuals with FASD are overrepresented whether being involved in, or being the victim of, problematic sexual behaviour [17], which has been confirmed by parents as well. Creating a co-ed space introduces a variable that can complicate feelings, relationships, and stir emotional

responses that could cause stress in their lives. This variable is best dealt with before it is encountered by not creating a co-ed living space.

Rules

The three main goals of building this type of housing project are that it be safe, sustainable, and supportive. The safe and sustainable aspects are heavily impacted by the rules in place. Most interview participants, parents and housing professionals agreed that people with FASD have a difficult time adhering to black and white rules. One of the issues with traditional housing options such as residential programs, group homes and even shelters is that the rules are hard and fast and if broken you could be evicted. This contributes to the high proportion of individuals with FASD struggling with housing in the past.

"We can't have this black white rule that says if you're late for curfew you get kicked out, like in all of the shelters, foster homes, group homes if you're late for curfew X number of times or you steal X number of times or lie X number of times eventually you get kicked out… we're asking people to do things that they can't" – Parent describing FASD

Housing professionals were divided on whether curfews should be implemented. A strategy to combat this is to have the staff monitor the comings and goings, and to enforce the rules if needed with respect to any guests that may enter the house or building. This encourages a safer environment and fewer people who do not live there flowing through the home.

To encourage a smooth and sustainable living option, there must be some rules in place regarding guests, times that the kitchen cannot be used (such as in the middle of the night) and drugs and alcohol. To ensure that the rules are fair and reasonable almost all the housing professionals interviewed encouraged tenants to be involved in the rule development process. This helps with self-reflection and community building. Staff must understand that rules cannot be enforced through a black and white lens.

It is well known that individuals with FASD are at a higher risk for developing substance addictions [3]. Housing professionals were divided on whether alcohol and drugs should be allowed in the home. Some expressed that this encourages their use and could be dangerous to other tenants. Others have a safe injection and use area on site. It is recommended that this is

discussed with the tenants, parents, and board of directors to determine what will work best for that specific group.

6.3.2 Physical Space/Setup

The recommendations in this section are primarily focused on a house that would be converted into individual apartments or bedrooms with common areas.

Location of house

There was a difference in opinions among the professionals interviewed. Some suggested that living in a more downtown area is beneficial to their clients because it could be within walking distance to grocery stores, doctors' offices, banks, and other social services. While this could be good for convenience there is a hesitancy among parents who were interviewed. Many parents describe downtown locations as "dangerous" for their kids. Someone with FASD does not always have well-developed reasoning skills and because of this they are often vulnerable and can be taken advantage of in many ways. In a downtown area, some individuals can make friends quite quickly and might not realize if the friends are using them for money, somewhere to sleep, drugs or something else. The vulnerability exhibited by someone with FASD can lead to exploitation in a variety of areas and can be dangerous for them. Living in a highly populated area exposes them to a variety of influences, some of which might not be the safest or most appropriate for them because of their brains and the immaturity that is often present. Other professionals have the same concerns as the parents and recommend a more rural setting. One house in particular is set on a farm. They have had great success with the individuals living there, as living in the country allows them the opportunity to perform farm chores as a fun group activity. A new permanent supportive house for individuals with FASD is being developed, and they purposefully chose a rural area so as to avoid some of the negative influences that can be present in a downtown area. If it is feasible, the official recommendation would be to obtain a house in a rural area, as avoiding a downtown metropolitan area can reduce negative outside forces and stressors.

Bedroom

One of the most important points made by 100% of people interviewed was that each person living in the house needs their own bedroom. No roommates. The stress involved in sharing a space with someone else is too much for someone with FASD. The people living in this type of home would also be adults and as such, deserve their own personal space. Parents expressed that it is not uncommon for someone with FASD to need a few quiet hours in the morning to be alone and get ready for the day, and they need their own private room to be able to do this.

It is highly recommended by many parents and housing professionals that the rooms/apartments are not too big because they can become very messy, very quickly. Spaces becoming unorganized and messy is a common theme expressed by most parents. One professional had a few specific recommendations for bedroom content and cleanliness that may be very helpful. She recommended only having one set of cutlery, one plate, one bowl, one cup, one mug etc. so that the dishes cannot stack up and become overwhelming. In addition, they recommended having open storage spaces, open shelving units, and no closet doors. Open storage limits the mess that is hidden and limits the number of things that can accumulate. Limiting this can be good for daily functioning and stress. Another recommendation in terms of maintaining cleanliness is providing a laundry basket that is not too big. Many parents mentioned laundry as an issue they experience with their kids whether it be letting it pile up, not doing it, or not changing the load etc. Limiting the laundry load can make the task more manageable.

A common theme that parents spoke about was hygiene reminders. They often found themselves having to remind their adult children to shower, brush their teeth and do their laundry. They often had to be reminded multiple times daily. One solution would be to hang a whiteboard on the back of the bedroom door. This way, private reminders can be noted which may help with memory and the completion of tasks.

Common areas

An open-concept design is recommended if possible. Open dining rooms, living rooms and kitchens make it easier for staff looking out for tenants and for them to attend to problems or escalations before they happen. Creating accessible, safe, common spaces for tenants is imperative for building community, friendships and trust among the people who live there.

Living room

Many parents described their kids as very social and able to chat up a room. If this is a strength that someone has, it should be given a space to be appreciated and explored. Some parents described their kids as less social but still wanting friends, as most people do. When common spaces are set up to be welcoming with comfortable couches, available snacks, and familiar faces, the tenants are able to have a space to mingle and spend their time outside of their rooms when they wish. Private rooms are there for personal space and private time but there should be no expectation to stay there all the time. One of the main philosophies echoed by almost all of the housing professionals interviewed was to create a home, not just a place to live.

Peer support was the most successful component of one of the housing options. The individual who ran that specific housing program described how using common spaces for group conversations led to fewer interpersonal conflicts and allowed for safe, facilitated discussion with all tenants to express what they were feeling. Creating a space large enough for these conversations and activities to happen will greatly contribute to the personal relationships between tenants.

Kitchen

Even if the building is built with kitchens in the individuals' apartments, a common kitchen is a necessity for a few reasons. Some of the tenants with FASD may not be able to cook for themselves. The common kitchen allows for staff-tenant interaction and aids with cooking. Some professionals also had experience with tenants sharing meals and cooking for each other. It all depended on the strengths and weaknesses of the tenants in the specific building. Another reason, similar to the need for common living room spaces, is that common kitchens provide an area to build community and a home. Community dinners and cooking together are ways to build trust, work on interpersonal relationships, build friendships, and have a community feeling. Housing units that provided community meals, even just once a week, saw an uptick in engagement from tenants. The use of community meals will depend on what kind of setup is chosen for food, whether the food is shared or not shared.

There are also some recommendations for the setup of the kitchen. Similar to the bedroom, open shelving units are preferable as the smaller number of cupboard doors results in fewer doors having to be repaired. One housing professional suggested that when storing cooking

utensils or cleaning supplies such as a broom, to have them hanging up, with an outline of the shape painted on the wall where they hang. This helps tenants put things back in the proper spot as they are clearly labelled with shapes. Appliances should have pictures and graphics with reminders to turn them off. Stoves should have clearly marked “high, medium, low” options. If possible, buy stoves that turn off automatically by timer. Expect to spend money on repairs of sink faucets, stove knobs, and other small items, as people with FASD often do not recognize their own strength and these items often end up broken.

6.3.3 Financial Considerations

The results from the interviews of housing professionals presented two funding model options; government funded or privately funded. Both have pros and cons associated with them.

Government Model

When a permanent supportive housing unit is primarily government funded, there are a few benefits. Government-funded (use a hyphen when connecting compound modifiers that appear before the noun modified) PSH often allows for the building to charge tenants rent geared to income. This is a positive thing because the monthly charge for tenants is no more than they can afford comfortably; usually around 30% of their monthly income, whether it be a provincial disability or earned income. This puts less strain on the tenants who often do not have a strong financial understanding nor an ability to save money.

Something to consider when exploring a government-funded option is that most of the clients will come through the system via other services. This is called “coordinated access”. Most of the time clients are not able to walk up to the building and apply to live there. They must already be supported by another government agency that puts their name forth for the application and interview process. While this can take the strain off building management to fill the rooms and apartments themselves, it can be discriminatory towards individuals with FASD who have not been able to seek help through an agency beforehand. This often happens to people who are homeless, do not have a proper FASD diagnosis, or whose FASD is not paired with a diagnosed intellectual disability.

Private Model

Private models are often run by a charity or non-profit organization. This, like the government model has pros and cons, mainly adding more work for board members, however, more inclusive and individualized.

The first step in creating a permanent supportive housing unit using a private model is creating a charity. This involves numerous licensing applications, filling the board member seats and fundraising. It should be noted that not a lot of research into the charity/non-profit licensing application process was conducted for the purposes of this project. One major recommendation by a housing professional working under this model is to make sure board members are FASD informed and educated. This allows for better discussion and service implementation when everyone making the decisions understands for whom the decisions are made.

One major component of the private model that differs from the government model is the tenant-intake process. It was recommended by a housing professional working under this model to fill the rooms by reaching out to local disability support services or local agencies who support individuals with FASD as they might have clients in mind who could be a good fit for the house. Although this could be a good way to start, intake is not limited to this as it is in the government model. Anyone with FASD in the area (or their caregiver or support person) could put their name in to live here. The intake does not have to be limited to coordinated access.

Something to consider is how much more work it is for an individual to run a house using the private model. Even though, often there are board members to provide help, the main tasks will fall on the leader. There is also the need for fundraising in the community, applying for government grants and maintaining the building and staff. Another consideration is the rent charged to tenants. Since this model is not being subsidized by the government directly, a higher rent is charged to tenants and rent geared to income is often not an option. If the client is on ODSP, as many are, the full rent allotment plus some of the other payment is often required in order to keep the house running. The private model is usually more expensive for the clients but because the building/house is often smaller than the government-funded models, there is more individualised service, support, and care. Smaller numbers and spaces for tenants can also lead to a less stressful living situation.

Although both the government and private models have validity and can work, the private model is often better for tenants in the long run because of the quality of support and smaller groups. Although there is often more work for the director and board members, the sustainability and support that can be offered in a smaller space is better for the clients in the long term.

Costs

Main Expenses

Interviewed professionals all cited staff salaries as their number one cost of running a permanent supportive housing option. Not only is paying staff a proper wage important, but hiring enough staff for a proper staff-to-client ratio is imperative to the success of the program.

Another important consideration of cost is material items, such as appliances. Individuals with FASD often do not have good proprioception, so a common theme among almost all interviewees is the damage to appliances. Knobs on stoves, microwave and fridge doors, along with sink faucets have been found to be broken many times. Replacements for these types of things is an important budget consideration. A similar consideration is with bedroom furniture. One parent who was interviewed recalled not being able to remember the number of mattresses that they had to buy their son because of mold growth due to hidden food, picking at the mattress and sometimes bedwetting. Another parent described broken dresser drawers because of their son being hard on them. A recommendation for furnishing a house or building for individuals with FASD, would be to buy inexpensive but sturdy furniture. Kitchen cupboards with open shelves might be a good consideration as well.

Building maintenance is another cost consideration. Things such as snow shoveling and grass cutting can be completed in a few different ways, as suggested by housing professionals. The first way is to contract an outside company to come in and take care of this regular maintenance. This is more expensive and can sometimes be difficult to organize but it puts less stress on the staff. The other option is to place this responsibility on the staff. This is the cheaper option because they are already being paid for the hours they are at the house. Depending on the situation, however, it could take away from staff-client facetime and support. Professionals in the field recommend hiring a building maintenance company to take care of these tasks if it is feasible in the operating budget. If it is not possible then it should be included in staff contracts as a part of their duties. Sometimes, depending on the clients in the house and their physical

abilities, some tenants want to participate in these tasks and take care of their home. It should not be forced upon them but if someone is wanting to shovel the driveway, for instance, it can be encouraged.

Food

An element of daily life in permanent supportive housing that needs to be addressed in order for a house to run successfully is food. It must be decided, hopefully with input from the tenants, how much food will be common food for everyone or how much will be individual food. Professionals had differing opinions on this and some suggested that food should mainly be communal meals, cooked and eaten together almost all the time, with some individual food and snacks. Others found that mostly individual food works for them, so each tenant cooks their own meals with support if needed. Community meals would happen less often -- maybe once per week -- instead of every day. Either model could work, but it should be incorporated into the budget. For example, if community meals are being made and provided more regularly, a grocery fee should be charged to tenants each month. If community meals are happening less often, then the monthly rent/food fee should reflect that. Professionals agreed that community meals help build friendships, work on interpersonal relationships and create a feeling of "home." There was no common ground on how often this should happen. One suggestion that almost all professionals offered was to include snacks in the budget, so they are always available to tenants.

Transportation

Location, as was explained previously, is an important consideration when it comes to the budget of the home. If the house is in a rural area, and driving is required, it might be worth the consideration of buying a car for the house. When walking and public transportation are not options, a car can be useful for grocery trips, getting to doctor's appointments and other types of appointments that the clients might have to attend. Since it is less common for someone with FASD to drive, although some do, driving often falls on the staff to drive clients in their personal cars when accompanying them places. Some staff members are not comfortable with using their personal car for transportation so if in a rural area, homes should consider a car for staff use.

6.3.4 Services and Supports/Staff

Staff

"If I required [FASD trained staff] I wouldn't be able to find anybody." – Housing professional on whether previous training is a requirement for staff being hired.

Previous training is often not needed but requiring staff to be trained on FASD once hired, and repetitively throughout their employment, is important to the success of a program. Requiring them to attend seminars on FASD or completing online modules can all be implemented to help staff learn about FASD. An informed and understanding staff person is invaluable. Being able to recognize signs of stress and triggers and being able to step in and de-escalate a situation is an extremely valuable skill when working with people who have FASD. Many individuals in this population have experienced some sort of trauma in their lives, so having staff who are patient-centered and trauma-informed can make a world of difference when serving this population. Crisis resolution and trauma training should be part of the FASD training as well.

When designing, running, or working at a permanent supportive housing unit, it is important to be aware of the population that is being served. Understanding of, and knowledge about FASD can make such a difference in the success of the client-staff relationship. A staff member needs to understand how quickly emotions change. An interviewed parent expressed how volatile her son's emotions could be and how his anger levels would jump from zero to one hundred in a matter of minutes. Another parent shared how her son can often only handle one big task per day, whether it be going to get groceries, going to the doctor or any similar task. In between these days, he would need hours of alone, quiet time to recover. Staff need to be open to learning about the people they are helping, and they must understand the FASD brain. Informed, educated staff who are open to learning and helping are the best kind of staff to hire.

Care providers of some kind are best suited for these roles, and they may not need a formal education. No parent or professional thought that a formal education is required to help the population. Kindness, compassion, and the desire to help make a difference are some of the most important requirements for hiring staff.

"I don't want [my son] to be independent, I want him to be successfully dependent" – Interviewed parent.

Staff need to be involved in their clients' lives. They need to take the time to learn about them from their parents, and spend time with them, in order to best serve them. Staff are not there to just sit and watch the clients but should be engaged in activities like cooking dinner and cleaning up, travelling with clients to appointments and monitoring peer support sessions. They should be there to lend a hand and support the people, not just watch. These qualities are important for staff in both the permanent supportive housing option and the independent living with check-in option. Related to this, staff are encouraged to have regular meetings to discuss the tenants because staff may work on opposite shifts and experience different things. Having weekly meetings to discuss the clients and what is working for them or what needs to be changed creates common knowledge for all the staff and promotes individualization of support.

Services and Support

One hundred percent of housing professionals recommended around-the-clock staff on site. They recommended this because of the support that staff can provide such as emotional support in the middle of the night, or social support in the middle of the day. The housing professionals explained that having someone in the house can limit the number of emergency calls made by tenants in the middle of the night because in their experience having a support system in the house can be a screening tool for emergency vs non-emergency situations. They also explained that around-the-clock staff on site can be helpful to help diffuse emotionally tense situations which can arise at any time of day. This looked different through the various current and past models, but the common denominator was that there was staff there at all hours. If the house was smaller, with fewer tenants, it was more common for one staff member to be on-call where they would have their own bedroom, and tenants could receive help if they needed it. Larger units had someone working at the front desk throughout the night and some units had two staff members during the overnight. The proper setup for around-the-clock staffed support will depend on the size of the housing unit and the allotted budget for staff.

Common needs, as outlined by parents, include financial planning, daily planning, and hygiene reminders. Most of the housing professionals mentioned these needs as something they

support. People with FASD are often seen as more competent than they are based on their executive functioning. This often leads to repeated failures and many negative experiences.

"*Cloak of Competence"* – Interviewed parent describing her adult son's ability to appear more competent than he is.

Life and social skills were large areas of weakness that almost all parents expressed. Implementing programming to build these skills or working on them could be helpful for the tenants and their relationships with one another. Programming and education surrounding social skills, boundaries in a shared space, dating and sexuality could be quite beneficial. When designing and implementing these types of programs, it is important to consider how the FASD brain works. It is very common for someone to be able to understand a concept one day and not the next. Single-day or one-time programming would not work for them. Learning about boundaries and healthy relationships cannot be a one-day talk, it needs to be conversations had repeatedly and working through actual scenarios.

Financial planning and future planning are common areas of weakness for those with FASD. There was a very common theme in the parent interviews that individuals with FASD just always had a hole in their pocket. Paired with impulsivity and low-level planning skills, money often came and went very quickly. This sometimes left them not able to pay rent at the end of the month or have money for groceries when needed. Offering services that help build basic financial literacy skills can be very helpful. Services surrounding financial aid that staff can offer could be helping apply for ODSP, setting up automatic rent deposits if they do receive ODSP, or finding a financial trustee to help manage their money. A common result from the parent interviews was that money management skills were never learned and that it would be ideal for someone to manage their money for them. Supports such as these could help tenants become more financially literate and build everyday life skills.

Another service that could be offered by staff is goal setting. Working through goal setting can help build tenant-staff relationships and identify problem areas with which they may be struggling. Some examples that were given in the interview were: saving enough money for an Xbox, planning to move into a more independent life in a few years or even holding a part-time job for two months. These goals are extremely individualized and can range in timelines

based on the client's needs. Usually, one goal at a time is enough but it all depends on the individual's abilities.

Some common areas that need support in the life of someone with FASD include, booking and attending various types of appointments. Some individuals with FASD also have other conditions which require more care than a supportive housing unit can provide. Booking and attending doctors' appointments, therapy appointments or even legal appointments is not an area of strength for most with FASD. Having staff who understand the scheduling needs of their clients and helping them book and attend the right places at the right times is very helpful and should be considered a task for the staff.

6.3.5 Building a Healthy Community

"We're not a group home, we're a family" – Housing professional quoting client.

This quote from one of the housing professional's clients was shared during the interview, and it perfectly encompasses the feeling and goals of the housing projects. The purpose of building a permanent supportive housing unit is just that, to make it a permanent home. Many parents wanted their kids to have a safe, supportive place that they can call home after having, in some cases, years of housing instability. There are a few recommendations from housing professionals which would need to be implemented in order to achieve this feeling of a healthy community and home.

"We want this to be a forever home" – Housing professional quoting parent of client.

Group activities were highly recommended. Having group activities encourages space for friendship building, working on interpersonal relationships and forming a common goal. It also creates space for building a community feeling and friendships with the people who were living together. Activities that were mentioned were but not limited to, basketball games, blanket making, running a stand at the local farmers market, attending a hockey game together and more. The group activities would vary in frequency but most commonly they were held weekly. It is important to recognize that not all tenants will want to participate every single time and this

should be respected as they are adults able to make their own decisions. That being said, staff should be highly encouraging of these types of events.

Similar to group activities, one housing model had great success relying on a peer support system. The whole house had a peer support system, they would help each other with tasks, going to the store, talking to workplace supervisors and more. This worked well with this specific group and could be successful in other groups as well. Encouraging open conversation in peer support meetings helped dissolve interpersonal relationship friction within the house and build trust and respectful relationships. Discussions could centre around what makes them feel safe in the house, how to feel more comfortable, and how they are feeling in general. The group would gather no less than weekly and create space for everyone to speak about anything they wished whether it be work, the house, their feelings, goals and more.

Some housing professionals also discussed community involvement. Organizing group volunteer opportunities or encouraging individual volunteering can be a great space for individuals with FASD. Some groups volunteer at local churches, soup kitchens, libraries, and seniors residences. This can be a great use of time in the day for those who do not have a job. Some tenants will need support from a worker when in these environments and some will not. Like everything with FASD, it will be individual.

6.3.5 Challenges

A challenge listed by almost all the housing professionals was cost. Running these types of permanent supportive housing options is not cheap. If the model chosen is primarily government funded, a lot of components of the model are at the mercy of the funder. They often have control of the people who live there, work there and more. If the funders are not FASD informed, the values they have may not align with the needs of the clients. Any model created needs to be tenant-focused and flexible; government bureaucracy often lacks these values.

> *"Bureaucracy is not inclined to be trauma informed; bureaucracy is not inclined to be client focused."* – Housing professional on pressures from government funders.

If working with a private model, creating the charity or non-profit that is going to fund the housing unit is not a short process. The creation of the charity, working through the licensing

process, fundraising, and finding competent and informed board members is a time-consuming endeavour.

Most housing professionals that were interviewed mentioned that their discharge and turnover rate was relatively low, but it still does happen. It is important to be reasonable and flexible when it comes to rules and enforcing them because of the way that the FASD brain is wired. Having said that, discharges can still happen and some reasons for them have included dangerous levels of drug and alcohol use that affect the other tenants or blatant disrespect for the rules over multiple occurrences. Another scenario could include recurring violence towards staff and other peers. As important as it is for staff to be FASD, crisis and trauma-informed, if a client becomes excessively violent, there is only so much that can be done for them.

If discharges need to occur, it is important to have a pathway out of the supportive living unit. If someone is discharged and left to their own devices to try and find new housing, the housing unit is just contributing to the housing problem they are working to solve. To avoid this possible problem, it is important to build connections with community resources that can be a part of the exit pathway. When someone is discharged, they should be connected with the supports that can help them navigate the change and build a plan of where to go next. There have been instances where someone was discharged from living in the house, but they were still a part of the support network and attended some of the group activities; they just were not living in the house anymore.

6.3.6 Implementation

The most feasible way to start a supportive housing unit or house for individuals with FASD would be to build a non-profit or charity. This is what the majority of housing professionals used as their model. The next step would be to purchase or rent a house, duplex, apartment building or a floor within an apartment building that suits the size recommendations outlined in this report. The third step would be to design the space appropriately for individuals with FASD, as physical space recommendations were discussed. Next, the hiring of staff should occur, keeping in mind they are key players in the success of a housing model. They must be willing to learn about FASD, and be kind and caring. After filling the house with tenants, if possible, conduct an intake interview with a close family member or parent. Parents and caregivers who

know the person well are the best sources of information when it comes to their kid's needs and triggers. Understanding the client through the eyes of someone who knows them well can make a world of difference when it comes to offering them support. It is also important to work closely with clients to develop their own set of rules and to make the space feel like home. After all, they are adults, and this is meant to be a safe space to call home.

7 Conclusion

Overall, it was somewhat reassuring to see that the past, current, and future housing projects that were examined through this research did understand the population they were serving. The housing professionals were in charge of FASD-specific housing, and it was quite clear that they had a thorough understanding of FASD and the brain as it was outlined by the parents. It is reasonable to rely upon the setups and supports that they offer due to the fact that they have been largely successful in helping the FASD population.

The results of the parent interviews were in line with the information from the literature that was available. The parents expressed similar challenges that their kids face such as difficulty with executive functioning skills, emotional regulation, money management and more. These were all themes outlined in the literature [2,3,4,8]. The previously researched models [13-17] were all discussed, and representatives of those organizations were interviewed. The various models were examined, and the data was compiled to create a list of best practices (Table 2).

Common concerns that the parents had, ranging from violent outbursts to cleanliness, were all taken into account when designing and running the currently available housing units. It is reassuring that the list of best practices, as provided in this report, was built from reliable, understanding, and informed sources. It is one thing to build a supportive housing unit or house for a group with intellectual disabilities, it is another all together to deeply understand this specific population, through the lens of the parents and people who raised them, and be able to provide competent, caring and informed service and support.

It is important to consider the feasibility of the implementation of a permanent supportive housing option. As explored through the differences between private and government funding options, the most feasible is the private model. It seems, based on the housing professionals' interviews, to be more realistic for a group of people to take matters into their own hands, to provide the support needed for housing individuals with FASD. With a private model, the board

of directors also has more control over the housing unit because they are not at the mercy of their funders.

The two research questions this project set out to answer were: Are there current housing models for individuals with FASD that are successful and sustainable? And secondly, what are the components and best practices of current housing models for individuals with FASD?

In summary, there are two main housing models and options for individuals with FASD. A permanent supportive housing unit specifically for people with FASD and a more independent living situation coupled with support check-ins on a regular basis. Both have the potential to be safe, successful, and sustainable. In terms of the components and best practices that make these two models sustainable, there are many puzzle pieces that attribute to success. A few of the most important are FASD-educated and informed staff members, a private space and bedroom for each individual client, and strong community building.

8 Limitations and Future Work

This research primarily addressed the population of individuals with FASD aged eighteen and over, but parents and caregivers expressed how challenges with their kids often arose in the tween to early teen years. Some of the kids who had been homeless experienced it in their teenage years. This was one of the starting points of housing instability, which in some cases, continued throughout their lifetime. The housing professionals interviewed in this study all designed or ran units that only allowed adults to live there, usually eighteen or older. This parameter leaves a portion of the population unserved.

There needs to be support in place for the transitional ages so as the kids grow, they are in touch with the supports and services they need to succeed; a large part of this would be housing. Future work could be conducted on alternative housing options for when individuals with FASD are between the ages of 13-18 and are unable to live within the family home. Work could also focus on why traditional housing options, such as group homes, are often unsuccessful for individuals with FASD.

Future work could also be done in the area of aging and growth. As individuals with FASD age, their needs change. They might go through a period of wanting more independence so they might transition to the check-in model, they might age more and require more help on a

daily basis with something such as medication so they might transition out of the check-in model into the line-in model. Different levels of supports may be needed across the lifespan and the supports available should be able to accommodate these changes. Research could be done by following individuals with FASD throughout their lifetime and noting changes in needs which could be implemented into these systems.

In terms of the independent living with support option, or check-in model, there are currently supports offered to some individuals with FASD but not to all. In the future, work could be done to address the gaps in care in Ontario and what can be done to either connect people in this situation to permanent supportive housing units that could provide service, or to make the current, available services more robust and more heavily funded.

9 References

1. CanFASD. Canada FASD Research Network**.** https://canfasd.ca/what-is-fasd/. Accessed 2 Oct 2022.
2. Petrenko CLM, Alto ME, Hart AR, Freeze SM, Cole LL. "I'm doing my part, I just need help from the community": Intervention implications of foster and adoptive parents' experiences raising children and young adults with FASD. J Fam Nurs. 2019;25(2):314-47. doi: 10.1177/1074840719847185
3. Moore EM, Riley EP. What happens when children with fetal alcohol spectrum disorders become adults? Curr Dev Disord Rep. 2015;2(3):219-27. doi: 10.1007/s40474-015-0053-7
4. Aragon AS, Kalberg WO, Buckley D, Barela-Scott LM, Tabachnick BG, May PA. Neuropsychological study of FASD in a sample of American Indian children: Processing simple versus complex information. Alcohol Clin Exp Res. 2008 Dec;32(12):2136-48. doi: 10.1111/j.1530-0277.2008.00802.x
5. Flannigan K, Harding K, Pei J, McLachlan K, Mela M, Cook J, McFarlane A. The unique complexities of fetal alcohol spectrum disorder. Canada FASD Research Network. 2020. https://canfasd.ca/wp-content/uploads/publications/FASD-as-a-Unique-Disability-Issue-Paper-FINAL.pdf
6. Vincent D. Creating connections: Alberta's addiction and mental health strategy: addiction and mental health housing and supports framework. Gov Alberta. 2014 Jun. https://canfasd.ca/wp-content/uploads/2016/12/AMH-Strat_June13_Version10.pdf
7. Ontario Supportive Housing Policy Framework. Gov Ontatio. 2017 Mar. https://tdsa.ca/wp-content/uploads/2018/02/Ontario-Supportive-Housing-Framework-English.pdf
8. Crocker N, Vaurio L, Riley EP, Mattson SN. Comparison of adaptive behavior in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. Alcohol Clin Exp Res. 2009;33(11):2015-23. doi: 10.1111/j.1530-0277.2009.01040.x
9. Badry D, Walsh C, Bell M, Ramage K. Promising practice in delivering housing and support interventions to chronically and episodically homeless persons with FASD. University of Calgary; 2015 Jul.

10. Pepper J, Watson S, Coons-Harding KD. “Well where’s he supposed to live?” – Experiences of adoptive parents of emerging adult children with FASD in Ontario. J Dev Disabil. 2019 Nov;24(1):66-80.
11. Brownstone L. Feasibility study into housing for people with FASD. The Regina FASD community network. 2005. https://canfasd.ca/wp-content/uploads/2018/02/Feasibility-Study-in-Housing-for-People-with-FASD-Final-Report.pdf
12. Ontario Disability Support Program Act, 1997, S.O. 1997, c. 25, Sched. B. https://www.ontario.ca/laws/statute/97o25b Accessed Oct 12 2022.
13. Bissell: Permanent supportive housing for adults with FASD. https://bissellcentre.org/programs/individual/fasd-permanent-supportive-housing/. Accessed 13 Oct 2022.
14. PSH feature: Hope Terrace. https://interfaithhousinginitiative.wordpress.com/2018/04/03/psh-feature-hope-terrace/. Accessed 13 Oct 2022.
15. Options for Independence. https://ofiyukon.ca/index.php/about/about-ofi. Accessed 15 Oct 2022.
16. FASD Communities. https://fasdcommunities.org/about-fasd/. Accessed 19 Oct 2022.
17. CanFASD. Understanding FASD and sexual behaviour. https://canfasd.ca/2021/03/17/understanding-fasd-and-sexual-behaviour/ . Accessed 04 March 2023.

10 Appendix

Table A1: Interview questions and topic for parents and caregivers.

Questions for Parents/Caregivers
1. Can you first identify your relationship with the individual(s) with FASD in your life? 2. How old are they? 3. Can you describe some daily challenges you have seen and experienced with your adult child? 4. Can you describe some of the things you support your child with? (I understand this can be an extensive question, please list a few main themes such as: daily planning, money management, scheduling doctor's appointments, etc.) 5. If your child has ever moved out and lived on their own, were you still providing daily support? 6. Has your child ever struggled with drugs or alcohol? 7. What is their main source of income? 8. Have they ever been able to secure/qualify for any government support? If not, why not? 9. Do you know this person to have struggled with homelessness in their life? 10. Do you know this person to have struggled with securing housing in the past? 11. What are some barriers that they have faced when finding housing? 12. Would you care to share any other relevant stories or information about housing and the person you know? 13. Any additional comments?

Table A2: Interview questions and topic for housing professionals.

Questions for Housing Professionals
1. What organization do you work for? 2. Can you provide a quick explanation of how you have been involved with this housing project for individuals with FASD? 3. How long have you worked/ did you work for this housing project? 4. How many tenants are currently living in the house? 5. Is there an age limit or range that you allow to live in the compound?

6. Is there a maximum length of stay or is it a permanent option?
7. How do you screen applicants/how do you determine who is a priority for your housing
8. Do tenants live in single rooms, with roommates? Do you find that these individuals perform better in their daily lives when they live alone, with roommates, etc.
9. How does what you charge for rent compare to rent for an apartment in your city? (more expensive, cheaper?)
10. Where does your main source of funding come from?
11. Does your organization own the building or is it leased?
12. What amenities are available to the tenants? (shared kitchen, common spaces, gym etc.)
13. What staff do you employ? (social workers, nurses, occupational therapists etc.)
14. Do you provide or require staff members to have any type of specialized training about FASD?
15. What services do you provide to tenants? (24/7 on call support, financial planning, anything you can think of)
16. What feedback have you received from people in the program/house?
17. Do you have a high turnover rate and what are some reasons for eviction of tenants?
18. What has the reactions of the community been like since this housing model has been implemented? (are residents of the town happy to have this house there, are they hesitant? Please explain)
19. What barriers have you faced during your development, implementation or managing of the housing facility?
20. Why do you think this model has been successful? Or why do you think this model was not successful?
21. If you could change anything about your housing model – what would that be?
22. What recommendations or advice would you give to people working a role like yours in a new housing model.
23. Any additional comments?

Table A3: List of contacted housing agencies.

List of FASD specific housing agencies contacted	
Name of Organization	**Location**
Achieve Charity	Peterborough, Ontario
Whitecrow Village	Nanaimo, British Columbia
Bissel Centre	Edmonton, Alberta
Options for Independence	Whitehorse, Yukon Territory
FASD Communities	Wisconsin, United States
Canopy Services	Peterborough, Ontario