


A decorative arch of purple circles and crescents frames the central text. The arch starts with two solid circles on the left and right, followed by several crescents and circles of varying sizes, culminating in a solid circle on the right.

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CREATING INTERSECTIONS

**A SYSTEMATIC AND PERSON-CENTERED
HARMONIZING FRAMEWORK FOR HOUSING
INDIVIDUALS WITH FETAL ALCOHOL
SPECTRUM DISORDER**

October 2018

A black silhouette of a mountain range spans the bottom of the page.

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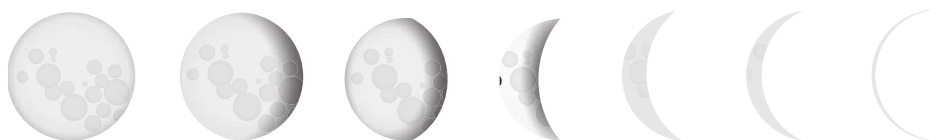


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*We are starting from a “strong foundation on
which to build together.”*

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AN INTRODUCTION TO THIS DOCUMENT

THE CATALYST

This project was catalyzed by service providers and individuals with fetal alcohol spectrum disorder (FASD), as well as their caregivers, all of whom described challenges navigating conventional housing support systems. In particular, current housing models were described as not yet meeting the unique and ever-changing needs of individuals with FASD—we can do better. Our community partners spoke of the need to find fitting models of service delivery for individuals with FASD who are unhoused so that they may experience opportunities to build upon their strengths, and successful achievement of their goals. Together with this community, we have developed a harmonizing housing framework that offers a more responsive, complexity-sensitive way of meeting the ever-changing needs of individuals with FASD who are unhoused, with the ultimate goal of engaging and supporting these individuals in housing tenure in ways that promote individual success and goal attainment.

THE DIFFERENCE

We enact a translational, systems-informed, process-oriented, relational, and person-centred approach to housing by embedding fluidity in our responses to changing circumstances and providing guiding lights for those who are supporting individuals towards their successes. Specifically the framework we developed offers alternatives to conventional categorical housing practices, in a movement towards recognizing the unique needs of each individual within interacting systems. In essence, with the support of many community partners, we are attempting to harmonize processes for service providers and tenants as they navigate changing circumstances. In the end, we've come away with a resounding focus on making intersections.

*“The problem is complex, but
there is a will to change things.”*

THE DOCUMENT

We have organized this document into five parts. First, we situate the reader in our work. Second, we provide background information to acknowledge the complexities involved in housing. In the third section, we describe the responsive harmonizing framework. That is followed by a section on implementing the framework. In the fifth section, we suggest that harmonization and responsivity will light the way forward to ensure we are meeting the housing needs of individuals with FASD. Finally, we offer the appendices which contain the underpinning evidence for the framework and implementation suggestions. The voices of our community members are embedded in all models and messages and are made explicit in the accompanying quotes. Throughout the document we provide italicized quotes in various colours and black capitalized summary statements that highlight key themes.

THE HOPE

This project marks the first step of many in the implementation and maintenance of meaningful housing service delivery and supports to better understand how to meet the needs of individuals with FASD. Our hope for the framework described in this document is twofold. First, that it empowers service providers in their efforts to support individuals in meaningful ways, and second, that it reflects the voices of individuals struggling to be housed. We hope that through the use of this framework we can begin to recognize current practices, celebrate successes, and

adapt programming to better meet the needs of individuals with FASD.



“It will take time and hard work, but it is possible.”



■ SECTION 1: CONTEXT FOR OUR WORK

Although there are city, provincial, and federal initiatives to “end homelessness,” thousands of individuals remain unhoused in Alberta (Gaetz, Dej, Richter, & Redman, 2016). Recognizing the challenges associated with housing, researchers and community agencies have sought to both understand, and then respond to this complex social issue—providing a rich foundation of learnings to inform future initiatives. Therefore, capturing and organizing both research and community knowledge was essential in order to move forward with a more cohesive understanding of how best to support individuals with FASD in their housing pursuits. Our end goal is to amalgamate all of this valuable information to create an evolving harmonizing framework that reflects current understandings and that provides a guiding light forward for individuals with FASD, their family members, and those who work closely with them. In subsequent sections, we introduce key language used throughout the document and describe our approach and the philosophies underlying the development of this framework.

Thank you to Mitts
for sharing
an image
of your
home.



LANGUAGE

To help readers understand this document, here are definitions for key terms used throughout:

HOUSING TENURE:

this term is used rather than the term housing success or housing maintenance, as we take the perspective that housing success can mean a variety of things to a variety of people. By moving away from vague conceptualization of success towards concrete outcomes (e.g., days housed, establishment of relationships) we facilitate a more comprehensive and fine-tuned understanding of the outcomes associated with housing individuals with FASD.

INDIVIDUAL WITH FASD:

person-centred language placing the individual first and recognizing that FASD is only one part of their being.

INDIVIDUAL WHO IS UNHOUSED:

person-centred language placing the individual first and recognizing that being unhoused is a circumstance and not an integral piece of an individual's being (Park, 2016). In the context of the person-centred language movement, we have chosen to use the term unhoused rather than homeless, with the recognition that home has a variety of meanings that go beyond the description of a physical dwelling. Individuals living unhoused may describe the streets or a city as their home—a place where they may have a chosen family and a sense of familiarity and how to keep themselves safe (Lee, 2014). Choosing the descriptor unhoused rather than homeless also depicts an experience of being without a house and does not use deficit-based trait language (home-less) to describe the individual, resulting in a more precise use of terminology (Park, 2016). Indeed, individuals living unhoused and their supports have called for a change in language, with one man living without a house stating “I have a home. It’s Palo Alto. I’m unhoused” (Park, 2016). By using this terminology we ensure not to negate anyone’s experience of home.



“Humanize the system!”

**UNDERLYING
PHILOSOPHIES
AND
PERSPECTIVES:
OUR GUIDING
LIGHTS**

*“What’s it like
being you?”*

This project was influenced and shaped by our underlying philosophies and perspectives: our guiding lights. These lights may be viewed as powerful systemic, teaching, and guiding forces as we move through the phases of life. Recognizing that we all operate from a foundation that influences all actions and products, we choose to explicitly state our foundation.

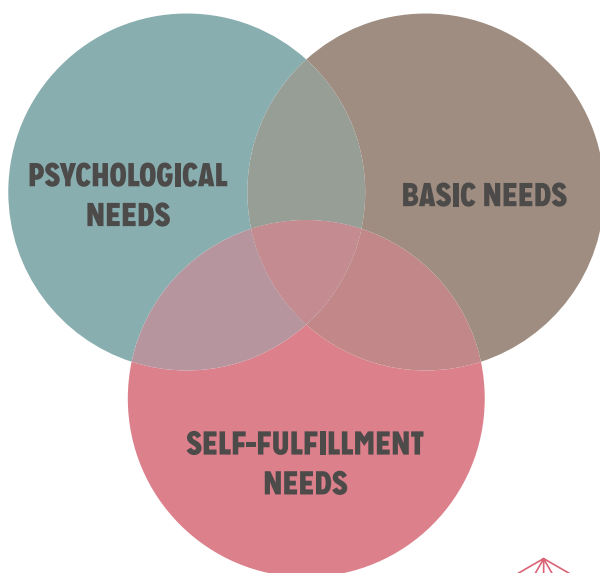
A SYSTEMS FRAMEWORK

We write this report from a systems framework, with the understanding that individuals can only be understood as existing within a complex interplay of individual, environmental, social, cultural, and historical factors (Bronfenbrenner, 1977). To even begin to understand the complexities of housing some of our most vulnerable citizens face, many factors need to be explored with the understanding that there are no simple solutions. Thus, we have moved away from a categorical, depersonalized approach and towards understanding tenants’ experiences, strengths, and needs.



PERSON-FOCUSED

Similar to this layered view of an individual's being, we take a comprehensive approach to understanding individuals' needs. Our second guiding light illuminated the need for us to bring the individual to the forefront. A comprehensive approach to understanding an individual's needs moved us away from a focus on housing alone, to a focus on tenants' basic, psychological, and self-fulfillment needs. This focus follows from traditional Blackfoot (Lincoln Michel, 2014) and developmental psychology teachings (Maslow, 1943). These teachings illuminate the fact that housing meets only one of many individual needs, and that we can better shape services through responsive practice.



Throughout this document, you will see the conceptualization of **Person-Centred Needs** (see visual). Some may recognize the needs as part of the hierarchy of self-actualization often credited to Maslow (1943); however, this hierarchy is thought to originate from Blackfoot teachings (Lincoln Michel, 2014). Traditional theory and teachings have hierarchically ordered individuals' needs, wherein it's assumed that certain needs must first be met before the individual can progress to meet their higher order needs. The hierarchical representation of needs was not a good fit for our person-centred philosophy, from which we understand that individuals have unique needs and that they will not progress through the stages in a similar manner. We recognize that individuals enter into the housing process with diverse needs in the basic, psychological, and self-fulfillment domains. Basic needs include physiological and safety needs such as shelter, food, and water, and developing a sense of security and safety. Psychological needs include the experience of relationship building, mental well-being, adaptive coping, and connection through culture, spirituality, and community. Self-fulfillment needs include the experience of a sense of belonging, finding purpose, meaningful contribution, and giving back.



WATCH FOR OUR
CONCEPTUALIZATION OF
PERSON-CENTERED NEEDS TO
REFLECT THE EMBEDDED ROLE
OF THE INDIVIDUAL WITH FASD
IN MEETING THEIR HOUSING
NEEDS.

RELATIONAL APPROACH

When working from a person-centred, systems lens, the importance of relational practice emerges. Through communication, we are better able to understand each other's needs. Through intersections of ideas from multiple perspectives, we are better able to work towards our goals from a foundation of understanding

and trust, preventing barriers from surfacing due to misunderstandings or lack of communication. Our final guiding light encourages us to be open to learning from one another, no matter one's station in life, and shines the light on the value of interconnectedness.

*“BEING HEARD
- listened to - [is]
so key. [I] heard
this and [it]
excited me there is
change to come.”*



OUR PROCESS

We provide you with a brief overview of the collaborative development of this provincial working framework on housing options and supports for individuals with FASD. The hopes for this project were that it integrate both research and community knowledge, with the involvement of individuals with FASD, their caregivers, experts from the realms of housing and FASD, and researchers. **Our Process** is depicted and described in this section (see visual).



EMPIRICAL LITERATURE REVIEW

(June to December, 2017)

Familiarity with existing literature was important so that the framework development occurred from an informed space. Our team reviewed 5771 search results, reviewed 304 abstracts, and read 128 peer-reviewed articles regarding the housing of individuals with intellectual disability, mental illness, and substance abuse. We restricted our search to English publications from 2007 to 2017.

HOUSING INITIATIVES MEETINGS

(November 21 & 22, 2017)

An essential aspect of this project was to hear the perspectives of those who are directly involved in housing individuals with FASD. Our team contacted 66 experts in the areas of housing and FASD from across Canada. Over 40 people joined us to discuss our research findings, mostly surrounding Housing First, a housing program centred upon housing individuals without the demands of sobriety and treatment compliance, in relation to their experience with housing as individuals with FASD, as caregivers of children with FASD, and as service providers. At these meetings, attendees shared their thoughts and we took notes. Attendees completed surveys, provided us with their written thoughts, and told us what they thought of the meetings. This mine of information was analysed in the months following.

NETWORKING AND SYNERGIES

(Winter/Spring 2018)

As a part of the project, we prioritized collaboration and, in doing so, made connections with other project leaders. Our goal was to ensure the creation of a strategic plan that was meaningful, feasible within the community, and synergistic with related ongoing initiatives. Specific activities in support of this collaborative practice have included meeting with Alberta Health Services (AHS) staff to explore the synergies between the work occurring in our project and their Integrated Housing and Health Services Strategy (IHSS) and Action Plan (January, March, and May, 2018). This synergistic collaboration led to a visit at Hope Terrace, a permanent

supportive housing program specific to individuals with FASD. Following the Hope Terrace meeting, we connected with a team from Lethbridge who were creating a business case for housing individuals with FASD. We also had the opportunity to make contact with groups who are considering individuals' housing needs through different lenses. For instance, we connected with Cermak Rhoades Architects, a firm collaborating with the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS) to create visual spatial housing designs for programs working with individuals with FASD.

MAKING SENSE OF IT ALL

(Throughout 2018)

A key aspect of any work is to delve deep into interpretation—a full exploration of “what does this all mean?” The data collected from the literature review was entered into databases in an attempt to make sense of it all. We then scoured the internet for information about housing programs in Alberta to learn more about what was happening in our communities. Thematic analysis was used to sift through the written data provided by the Housing Initiatives meeting attendees. We derived themes from the data, and sent an overview of these themes back to the attendees for their review and feedback. Finally, we pulled all the information and our learnings together to create the framework offered in this report.



Thank you to our friends at Homeward Trust and Hope Terrace for sharing an image of the residents' home.



■ SECTION 2: ACKNOWLEDGING THE COMPLEXITIES OF HOUSING SERVICE

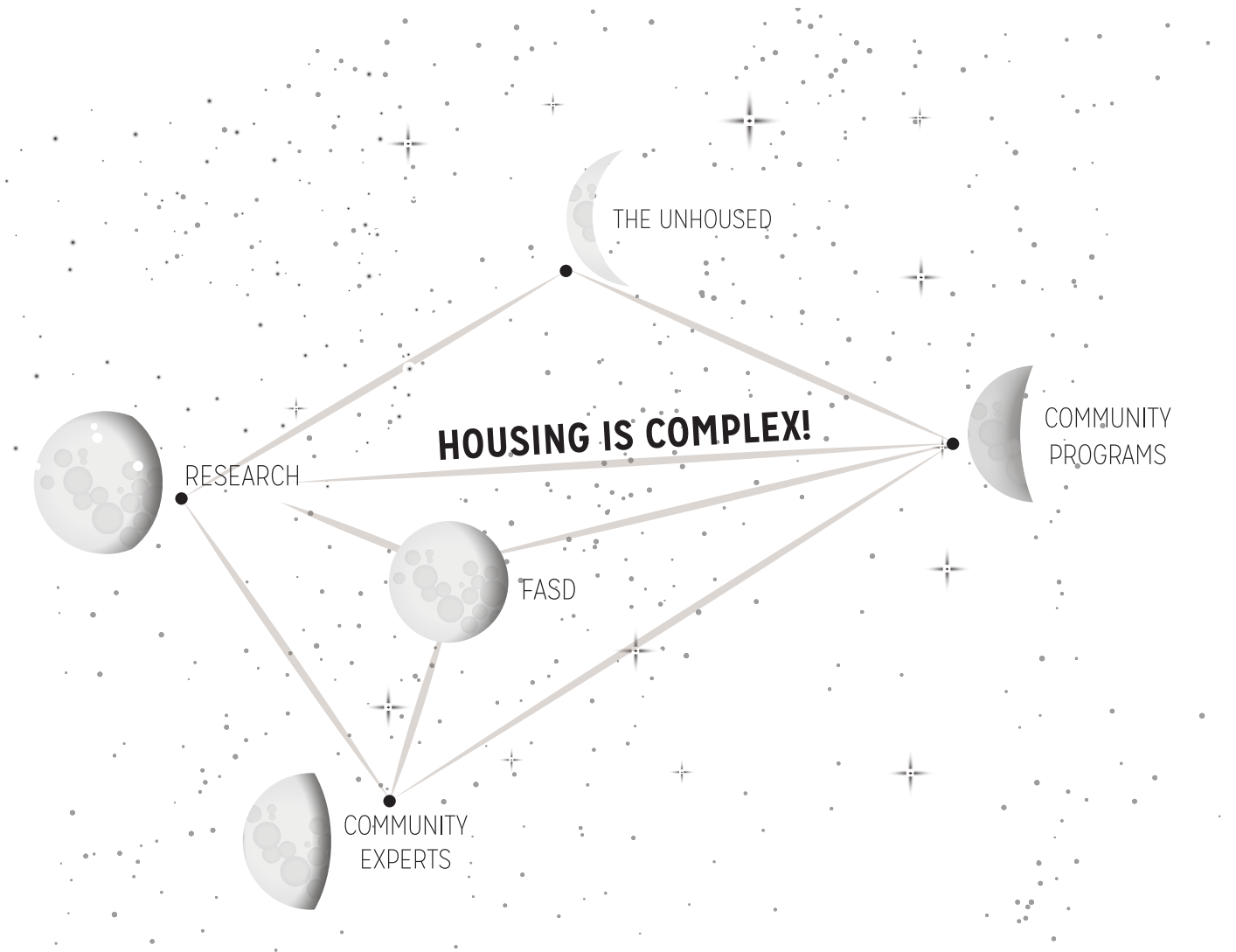
Over the past year, we explored a vast amount of research regarding individuals' experiences of living unhoused. Specifically, we sought information about individuals with FASD's experiences of living unhoused. As we worked through this abundance of information, one thing became clear: there is no simple answer to housing individuals with complex needs, such as those with FASD. In the end, we understood that we needed to establish a framework that was both responsive and structured.

We acknowledge the **Complexities of Housing Service** by sharing our learnings in several domains (see visual). We have condensed the information in the main document to make it accessible and easy to work through; however, several appendices containing more in-depth information are referenced throughout the document for the interested reader.

“One size cannot fit all.”



COMPLEXITIES OF HOUSING SERVICE



WE MUST CAREFULLY CONSIDER THE UNIQUENESS
OF INDIVIDUALS' EXPERIENCES OF BEING
UNHOUSED.

The circumstances that lead an individual to become or remain unhoused are varied and complex. In the following sections, we aim to provide a brief overview of the factors associated with this experience at both an individual and a systemic level. Although we have chosen to use the term unhoused as much as possible throughout this document, we use the term homeless when necessary to ensure the clarity of other authors' statements and thoughts.

DIVERSE PERSPECTIVES ON "HOMELESSNESS."

The Canadian Observatory on Homelessness (COH) defines homelessness as "the situation of an individual or family without stable, permanent, appropriate housing, or the immediate prospect, means, and ability of acquiring it" (Gaetz et al., 2012, p. 1). According to this definition, approximately 35,000 Canadians are homeless on any given night, and at least 235,000 experience homelessness each year (Gaetz, et al., 2016).

However, when viewed through an Indigenous¹ lens, these statistics may not capture the full picture of our nation's homeless. The Aboriginal Standing Committee on Housing and Homelessness

describes a homeless individual not as one who lacks a physical dwelling, but as one who is "isolated from their relationships to land, water, place, family, kin, each other, animals, cultures, languages and identities" (Thistle, 2012, p. 6).

THE UNHOUSED: A BRIEF HISTORY AND OVERVIEW

Given the systematic dismemberment of Indigenous views, beliefs, and practices that occurred throughout Canada's history under such destructive assimilation

policies as the Sixties Scoop and the residential schooling system, it is no wonder that Indigenous peoples are overrepresented in the population of individuals who are unhoused. Although official statistics indicate that less than 5% of the Canadian population is Indigenous, it is estimated that 28–34% of the shelter population identifies as Indigenous (Gaetz et al., 2016). As colonial practices shaped the very conditions that continue to contribute to homelessness amongst Indigenous peoples, it is now imperative that, in keeping with the Truth and Reconciliation Commission's (2015) call for action, strategies are developed and implemented to house individuals with this Indigenous definition of homelessness in mind (Gaetz et al., 2016).

WE NEED SHARED UNDERSTANDING THAT INFORMS ACTION.

¹ Indigenous: the term Indigenous is used to describe the diverse First Nations, Metis, and Inuit peoples of North America.



INDIVIDUALS' UNIQUENESS MUST BE CENTRAL IN HOUSING CONSIDERATIONS AND, IN TURN, APPROACHES TO HOUSING SHOULD MEET THOSE UNIQUE NEEDS.

WHAT DO WE THINK WE KNOW ABOUT INDIVIDUALS WHO ARE UNHOUSED?

The experience of trauma that has echoed—and continues to echo—through generations of Indigenous peoples is all too common amongst the broader unhoused community as well. Many individuals who are unhoused grew up in unstable homes and experienced trauma from a young age (Martijn & Sharp, 2006; Raising the Roof, 2009), and they continue to experience trauma and victimization while unhoused (Calgary Recovery Services Task Force, 2016). The population of individuals who are unhoused is diverse: 27.3% are female, 18.7% are youth, 2.2% are veterans, and the number of older adults and seniors who are unhoused is increasing (Gaetz et al., 2016). A considerable proportion of individuals who are unhoused have mental illness, physical disabilities, and substance use disorders (Gaetz et al., 2016; Goering et al., 2014). Although it is widely known that many individuals who are unhoused have mental illness,

physical disabilities, and substance use disorders, considerably less information is available around the prevalence of FASD within this population. For those who are unhoused, their physical and mental health conditions are often exacerbated by their living situation, making it difficult for them to engage in the activities that would benefit their physical and mental health, quality of life, and community functioning most (Goering et al., 2014). Unfortunately, these factors are also associated with the significantly reduced life expectancy of unhoused individuals (Goering et al., 2014). Understanding the characteristics and commonalities of the population of individuals who are unhoused is important to ensure housing services can be tailored to meet these individuals' basic, psychological, and self-fulfillment needs; however, we must also examine the systemic factors that contribute to the circumstances that lead an individual to become or remain unhoused.

ALTHOUGH IT IS WIDELY KNOWN THAT MANY
INDIVIDUALS WHO ARE UNHOUSED HAVE
MENTAL ILLNESS, PHYSICAL DISABILITIES,
AND SUBSTANCE USE DISORDERS, WE NEED
TO BETTER UNDERSTAND THE UNHOUSED
POPULATION WITH FASD.

BEYOND THE INDIVIDUAL: HISTORY, POLICY, AND GOVERNANCE

From the late 1980s to the mid-2000s, there was a dramatic rise in rates of individuals who were unhoused in Canada (Gaetz et al., 2016). Gaetz noted that this dramatic rise was associated with the disinvestment in affordable housing coupled with economic shifts that negatively impacted the job market. More emergency services, such as shelters, were built in response to this growing issue, though this approach was largely reactive and did little to prevent elevations in the rates of individuals being unhoused (Gaetz et al., 2016).

In 2008, the response to the rates of individuals who were unhoused shifted from crisis-management to the development of large-scale plans to “end homelessness” at various levels of government (Gaetz et al., 2016). A number of provinces and municipalities began constructing their own strategies to address the issue and, notably, the federal government invested \$110 million into a five-year study on the effectiveness of a housing intervention model known as Housing First (Goering et al., 2014). Titled the At Home/Chez Soi project, the study examined the impact of the intervention in five major cities across Canada in what was the world’s largest trial of its kind.

The results were extremely promising (Goering et al., 2014), and at the study’s conclusion in 2013, the federal government announced a renewed commitment to “ending homelessness” with a focus on the chronically unhoused and the Housing First approach (Gaetz et al., 2016).

GOVERNMENTS ARE INCREASINGLY INVESTING IN HOUSING INITIATIVES TO BETTER UNDERSTAND WHAT MAKES HOUSING STRATEGIES WORK.



CURRENT STATE OF HOUSING

In 2017, Canada’s federal budget saw over \$11.2 billion earmarked to help “end homelessness” by 2028 (Raising the Roof, 2017). Despite increased federal investments in housing initiatives, establishing community buy-in for social housing programs is not always easy. In particular, the “not in my back yard” (NIMBY) perspective can be a significant barrier to successfully accommodating individuals who are unhoused. NIMBY is the fear that introducing a program to a neighbourhood will increase criminal activity, reduce property values, and otherwise negatively impact community members (Dolan et al., 2012). However, recent studies (Armstrong, Been, Ellen, Gedal, & Voicu, 2008; De Wolff, 2008) have found no support for these beliefs when it comes to housing programs. Instead, a combination of transparency, community collaboration, and education have been suggested as effective ways to combat the NIMBY perspective (Dolan et al., 2012). Overall, we see the need for broadened understanding of the terms homelessness and unhoused that include consideration of both individual and systemic factors associated with the experience of being unhoused. Very little is known about the needs of specific sub-groups of the population of individuals who are unhoused, including individuals with FASD. In order to ensure housing services best meet the needs of individuals with FASD who are unhoused, existing knowledge about FASD and individuals’ experiences of being unhoused must be translated into practice.



INCREASING OUR
UNDERSTANDING HELPS
US TO REFRAME OUR
PERCEPTIONS.

HOUSING FOR INDIVIDUALS WITH FASD

One of the groups that has been described as particularly at risk of being unhoused are individuals with FASD. The term fetal alcohol spectrum disorder (FASD) is a diagnostic term that refers to a broad spectrum of presentations and disabilities caused by prenatal alcohol exposure (Cook et al., 2016) and injury to the developing brain. FASD is a lifelong disability (Brownstone, 2005) that can look and present differently across individuals. Roughly 4% of Canadians are diagnosed with FASD (FASD Research Network, 2018), but the condition often goes undetected, leaving many individuals without the necessary supports in place for them to thrive in the community. Those who are assessed and diagnosed also face challenges around accessing effective services, partly due to a lack of resources designed specifically for individuals with FASD. In addition, many community members and stakeholders do not fully understand the complexity of FASD and the range of challenges that are associated with the diagnosis. For a full overview of FASD and its impact on affected individuals and society, see Appendix I.

Broadly, individuals with FASD may present with deficits that impact their mental health and adaptive functioning (Astley, 2004). Overall functioning (e.g., low overall cognitive ability) or specific aspects of functioning (e.g., weak verbal skills existing alongside well-developed non-verbal skills) may be affected. To complicate matters further, the deficits that are believed to be a direct result of prenatal alcohol exposure are often worsened by other adverse exposures and events in one's life, such as physical or emotional trauma. For example, many individuals with FASD are born with increased sensitivity and vulnerability to life stress (Hellemans et al., 2010) due to abnormalities in their central stress response system. When exposed to stressors during childhood and adolescence, they show increased vulnerability towards developing depression, anxiety (Hellemans et al., 2010), substance use, behavioural difficulties (Doyle et al., 2017), and other mental health issues.

CURRENT HOUSING MODELS MAY NOT PROVIDE GUIDANCE TO MATCH THE NEEDS OF UNIQUE POPULATIONS SUCH AS THOSE WITH FASD.

Increasingly, researchers are using information translation to convey scientific information, such as that related to FASD, in an easily understandable, memorable, and relevant manner (Kaslow, 2015). Service providers and other relevant stakeholders working with individuals with FASD may benefit from information translation, specifically around the unique needs of individuals with FASD. An increased understanding of FASD can help give service providers meaning to the everyday challenges that individuals with FASD face and also provide valuable insight into more complex problems, such as being unhoused. In turn, information translation facilitates action through well-informed service providers who are better-equipped to problem-solve and create more effective solutions for tenants with FASD. Because FASD is a lifelong disability, individuals with FASD require ongoing support from well-informed service providers who understand that each individual is unique.



Unfortunately, a lack of FASD-informed practice across systems leads to individuals with FASD facing challenges with housing (Badry, Walsh, Bell, & Ramage, 2015). We encourage community members to take an FASD-informed approach, one that is grounded in an understanding of the complexity of FASD and the experiences

of being unhoused that emphasizes responsiveness to the physical, cognitive, and adaptive strengths and vulnerabilities of this population. An FASD-informed approach provides the context for a shared understanding of individuals with FASD, helping people to make sense of what they may see through an FASD-informed lens. To assist service providers with taking an FASD-informed approach, we have developed three **FASD-Informed Tables** to help them understand the range of physical, cognitive, mental health,

and adaptive aspects of FASD, and how to problem-solve when working with individuals who are unhoused. See Appendix II to access these translational tables and see their use illustrated through a case example.

“Is Housing First an ethical response for everyone with FASD?”

We promote the use of an FASD-informed approach by encouraging service providers to refer to the **FASD-Informed Tables** throughout all stages of the housing journey. During intake, individuals who are unhoused are first identified and then placed on a waiting list. We encourage housing case managers to listen to each individual’s story and ask relevant questions to gain a thorough understanding around what led to each individual becoming unhoused. The Service Prioritization Decision Assistance Tool (SPDAT) for Single Adults (OrgCode Consulting Inc., 2015), Vulnerability Assessment Tool (VAT)—Canadian Version (Canadian Observatory on Homelessness, 2016), and the Life History Screen are great starting tools to collect information during intake, but we encourage providers to go beyond them to also consider how possible aspects of FASD may have impacted the individual. During the search for housing, housing case managers should work collaboratively with the unhoused individuals and exercise responsiveness to their housing needs, that is, it “must be a team approach.” Once suitable housing is found, case managers can continue to work collaboratively with individuals, setting goals around the individual’s basic, psychological, and self-fulfillment needs. Together, they can evaluate progress towards these goals and problem-solve to overcome barriers. If individuals become unhoused again, case managers are encouraged to reflect on the factors that led to this lapse, including any vulnerabilities related to trauma and FASD, and individual strengths that may not have been fully drawn upon.

This process will help case managers to build on their existing understanding of individuals and better equip them for success through increased responsiveness to their needs during the rehousing stage. Once individuals have demonstrated a period of tenure in their housing and successful progress towards meeting other identified goals, they may move towards graduation. Graduated programs may not be a good fit for all tenants, as some will require lifelong supports. In order to make appropriate housing decisions, realistic discussions need to occur between all parties around the necessity of continued supports to ensure that the housing is sustainable and progress towards other goals is maintained.

A variety of community housing programs exist, some of which are tailored to the needs of individuals with FASD. However, not much is known about the connection between housing models and housing tenure for individuals with FASD. With recognition that individuals’ unique needs should guide housing program decisions, we proceed to explore what is known about community programs.

“How are we defining success in housing?”

WHAT'S HAPPENING ON THE GROUND? COMMUNITY HOUSING PROGRAMS

Over the past decade, researchers have undertaken few initiatives to better understand and address the pressing housing needs of individuals with FASD, and attempts to estimate the prevalence of FASD amongst the unhoused population remain limited. Thirteen years ago, Brownstone (2005) innovatively began to explore the housing experiences and needs of individuals with FASD. Since that time, few have carried on that line of research. According to the demographics researchers provide in current empirical literature, it appears that few service providers or researchers collect FASD diagnostic information from the individuals they house. In practical contexts, few housing programs are identified as FASD-specific. In all likelihood, many individuals with FASD may be accessing services without knowing or disclosing their diagnostic status.

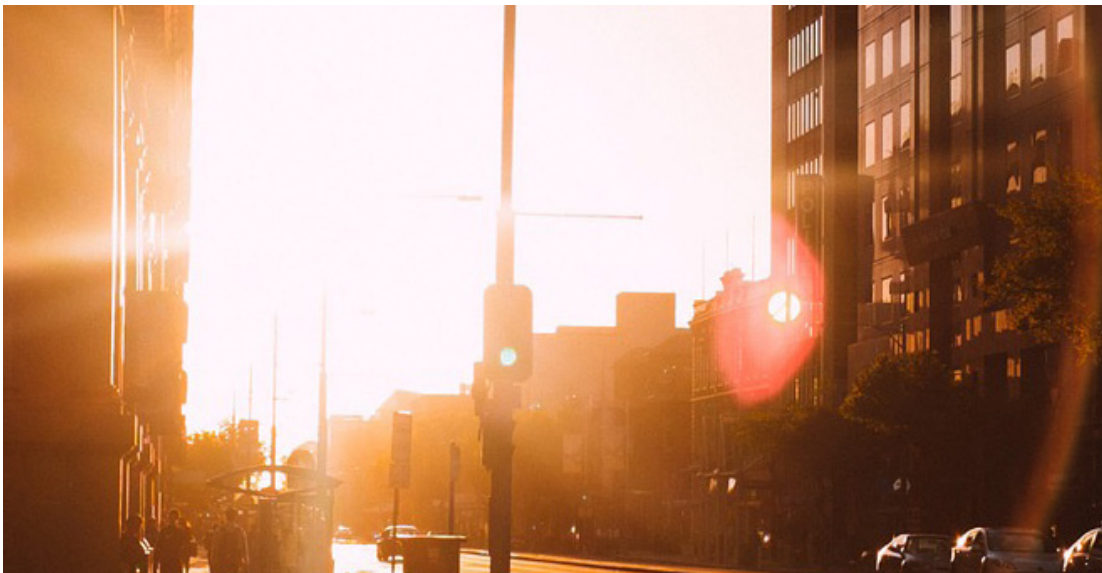
Through her research, Brownstone (2005) discovered that all individuals with FASD whom she interviewed had been relatively unhoused, and 93% had been absolutely unhoused. Those who are relatively unhoused may couch surf or reside in temporary or substandard shelter, and those who are absolutely unhoused live on the streets and may access shelter services (Chan, D'Addario, & Sherell, 2005). Parents of individuals with FASD expressed concern about their children's quality of life and housing, and a general misunderstanding of their children's diagnoses. They urged, "We need a place where 'FASD' belongs... without it, our children will never get the help they need." (Brownstone, 2005, p. 54). Brownstone's (2005) decade-old call for FASD-informed and -specific housing programs fits just as well in today's social context. Exciting FASD-specific and non-FASD-specific housing initiatives are

occurring in Albertan and Canadian contexts, and we direct the interested reader to further explore these unique programs in Appendix III.

Our exploration of community FASD-specific housing initiatives led us to conclude that program evaluations of these initiatives are not easily accessed by the public. Thus, service providers are attempting to provide the best possible services to tenants with FASD with little evidence to guide the way. Going forward, administrators would benefit from a housing framework with embedded data-collection mechanisms that would provide evidence to support and inform housing decisions and policy. Evaluations may provide clarity regarding the feasibility of implementation and preservation of programs for this population, the ever-evolving needs of and impacts on the residents they serve, and the outcomes for the community as a whole.

Community experts will benefit from one another when they are able to share the successes and challenges associated with housing services for individuals with FASD. With such variation between programs, and limited evaluation evidence to identify programs' strengths and points for improvement, it is difficult to tell which programs work best for which tenants. In sum, there are many provincial programs geared towards meeting the needs of unhoused individuals in various ways. Little publicly accessible information exists regarding the effectiveness of these programs and their accompanying philosophies in meeting the needs of individuals who are chronically unhoused in Alberta.

Little consensus exists, not only in the community but also in the empirical literature, regarding the long-term impacts of housing programs for individuals with severe mental illness. Further program evaluation is needed to determine how we are meeting the basic, psychological, and self-fulfillment needs, including housing outcomes, of individuals with mental illnesses such as FASD. To further understand current evidence around housing individuals with complex needs, we will now move beyond the exploration of community housing programs in Canada to explore international research on housing programs for individuals with complex needs.



**WE ALL BENEFIT FROM SHARED SUCCESSES MADE POSSIBLE
BY OUR HARMONIZING FRAMEWORK FOR HOUSING.**

WHAT ARE THE RESEARCHERS SAYING ABOUT HOUSING?

The next phase of our process was to immerse ourselves in the housing research. In order to do so, we conducted a comprehensive literature review. The focus of our literature review was on permanent supportive housing programs for individuals with mental illness, with substance use problems, and who are unhoused, and their connections to housing tenure. Interested readers may access Appendix IV for a more comprehensive overview of our process and findings. Out of 5,771 search results, we narrowed the list down to 126 articles to read in their entirety. Of those 126 articles, 77 met our inclusionary criteria.

HOUSING MODELS

The vast majority of articles we reviewed examined Housing First-based programming. Interested readers are directed to Appendix IV for an in-depth overview of the Housing First (HF) tenets, and variations of the HF service model. In the articles we read for this project, many concerns were raised regarding the vague descriptions of housing programs within the empirical literature (Benston, 2015; Dolan, et al., 2012; Leff, Chow, Pepin, Conley, Allen, & Seamen, 2009). As of yet, we do not have a firm understanding of what program components are necessary and for whom (Leff et al., 2009).

PARTICIPANTS

Researchers described housing research participants according to a variety of characteristics. We see a large amount of evidence supporting housing tenure for middle aged men. Concerning ethnicity, the majority of evidence supports housing programs for individuals of European and African descent, and to a lesser extent those of Indigenous ancestry. The evidence most strongly supports housing program tenure for unemployed, single, and chronically or absolutely unhoused

individuals with schizophrenia, bipolar, and depressive disorders, who may be veterans, and who struggle with substance use problems. None of the studies we read identified FASD amongst its participants. Thus, we were unable to access any empirical data that explored housing programs for individuals with FASD.

HOUSING TENURE

As has been mentioned in prior analyses and reviews (e.g., Benston, 2015; Dolan et al., 2012), we found that definitions of housing tenure varied throughout the publications. For instance some researchers reported housing outcomes by days housed, some by percentage of time housed, and others as percentage stably housed. Thus, comparability across studies is difficult, and the findings across studies cannot easily be combined.

REVIEWS OF HOUSING SUCCESS

A few researchers have attempted to amalgamate the evidence according to housing model types to provide an overarching view of housing success (please see Appendix IV for a comprehensive overview).

They found that housing models, regardless of the type, are superior to treatment as usual (TAU) in the prediction of housing tenure (Leff et al., 2009; Rog et al., 2014). In particular, much evidence supports the connection between HF and housing tenure (Adair et al., 2017; Woodhall Melnick & Dunn, 2016). However, many criticisms of the research are mentioned throughout, and most researchers acknowledge that more research needs to be conducted so that we may better understand if one size fits all, and “what models work best, in what ways, and for whom” before widespread implementation of a single mode of service (Leff et al., 2009).

PREDICTORS OF HOUSING TENURE

In our literature review, we included both quantitative and qualitative methodologies. In doing so, we hoped to capture a more holistic picture of both housing tenure and the potential reasons why some individual and program characteristics lead to housing tenure. Summaries of the quantitative and qualitative findings can be found in Appendix IV.

FACTORS: A variety of quantitative factors have been examined in relation to housing tenure and housing failure. Strong associations have been made between individuals’ long periods of being unhoused and housing failure (Adair et al., 2017; Burt, 2012; Van Straaten, et al., 2017; Volk et al., 2016). Please see Appendix IV for an in-depth overview of predictive factors.

At this time we do not have a consistent picture of who does well in permanent supportive housing programs and who struggles to maintain tenure. Some researchers have also used qualitative methodology to explore the factors staff and tenants associate with housing tenure.

EXPERIENCES: Researchers have used qualitative narrative explorations of staff and resident experiences to better understand reasons for tenants’ housing tenure and departure. Both tenants and staff connect many factors with housing tenure. Some researchers found that most every tenant they interviewed primarily connected their housing attainment and tenure to the absence of rules around sobriety (Collins, Clifasefi, Dana, et al., 2012). Tenants spoke of the importance of supports, subsidized rent, and guest management as key connections to housing tenure (Kirsh et al., 2011; Macnaughton et al., 2016). Tenants have expressed that both tangible features of housing such as privacy, laundry facilities, television, and meals, and less tangible features of housing such as feeling “at home,” being independent, having a social life, and choice have contributed to their satisfaction and retention of housing (Pearson et al., 2009). Housing staff have also identified factors of importance in relation to housing tenure. These include educating landlords about the strengths, difficulties, and illnesses their tenants may be facing (Kirsh et al., 2011). Staff and tenants have also provided narratives about factors connected to housing failure.

Nelson and colleagues (2015) found that tenants connected negative experiences in housing with substance use, hopelessness, negative social contacts, and isolation. Staff echoed the connection between lack of community integration and tenants' isolation with housing failure and stated the importance of facilitating community connections for their tenants (Kirsh et al., 2011). Iaquinta (2016) identified that tenants may require assistance to work out disputes with their landlords, and typically do not do well with rigid rules and regulations. Others have also found a connection between rules and housing failure, and mentioned violence as a reason for eviction (Anucha, 2010; Collins, Clifasefi, Andrasik, et al., 2012). Tenants especially voiced concerns about violence when residing in residences with communal living areas (Anucha, 2010).

Overall, we see that the evidence for housing programs, particularly HF, is compelling. Choice, non-abstinence-based housing, and consistent and long-term supports are mentioned as key factors related to housing tenure. However, the exploration of key tenets of housing models is in its early stages and much more research is needed before we know the key elements associated with tenants' housing tenure. In the current state of knowledge, we are not yet in a place to know with confidence who we are serving well and whose needs we have yet to meet.

For instance, what is missing from programming that would help house the 15–20% of individuals who do not remain housed under HF? Are those individuals more successful in treatment first programs? Do they benefit from entering a transitional program first? Some researchers have heard tenants express how difficult the transition from being on the street to being housed can be. This transition may be particularly salient amongst the FASD population, of whom many experience difficulty with change. We have much left to learn, a sentiment that was reflected in our Housing Initiatives meetings on November 20 & 21, 2017.



WE HAVE MUCH TO LEARN ABOUT PROGRAMS, INDIVIDUAL CHARACTERISTICS, AND HOUSING OUTCOMES.

WHAT ARE THE COMMUNITY EXPERTS SAYING ABOUT HOUSING?

On November 20 & 21, 2017 we had a large gathering that brought together researchers and experts in the areas of housing and FASD. Overall, everyone seemed hopeful about the future possibilities while acknowledging that “the problem is complex, but there is a will to change things.” Attendees expressed a readiness for action through sentiments such as “It will take time and hard work, but it is possible.” The collaborative event and the chance to be part of the creative process excited our community members and they expressed a desire to move beyond dialogue: “Enough talking, let’s make change!”

Community experts wanted to focus on what’s going right. Attendees expressed frustrations that discussions often centre upon challenges, as they believe that a deficit lens makes the issue of housing individuals with FASD seem hopeless. They wanted to start hearing more about successes, and “understand what our greatest strengths are and how we can leverage them moving forward.” The overall sentiment was that we need to understand the gaps in service, but that we can’t experience growth solely by examining the cracks in our system.

The meetings were a “great start to addressing the issue of housing and FASD” in collaborative action towards a framework. Community experts acknowledged that we are starting from a “strong foundation on which to build together.” Attendees appreciated that this meeting allowed for two sectors to come together, and they stated that “working on the operations level to develop a usable framework for housing is the best way forward.” In our feedback from the thematic content from these meetings, we learned about the desire to have even more people involved in these collaborative conversations including landlords and relevant members of government.

After a thorough analysis of the information collected at the Housing Initiatives meetings, we identified a number of themes. These themes are depicted visually in **Themes from Housing Initiatives Meeting** (see visual), and discussed comprehensively in Appendix V.

“[Let’s] understand what our greatest strengths are and how we can leverage them moving forward.”

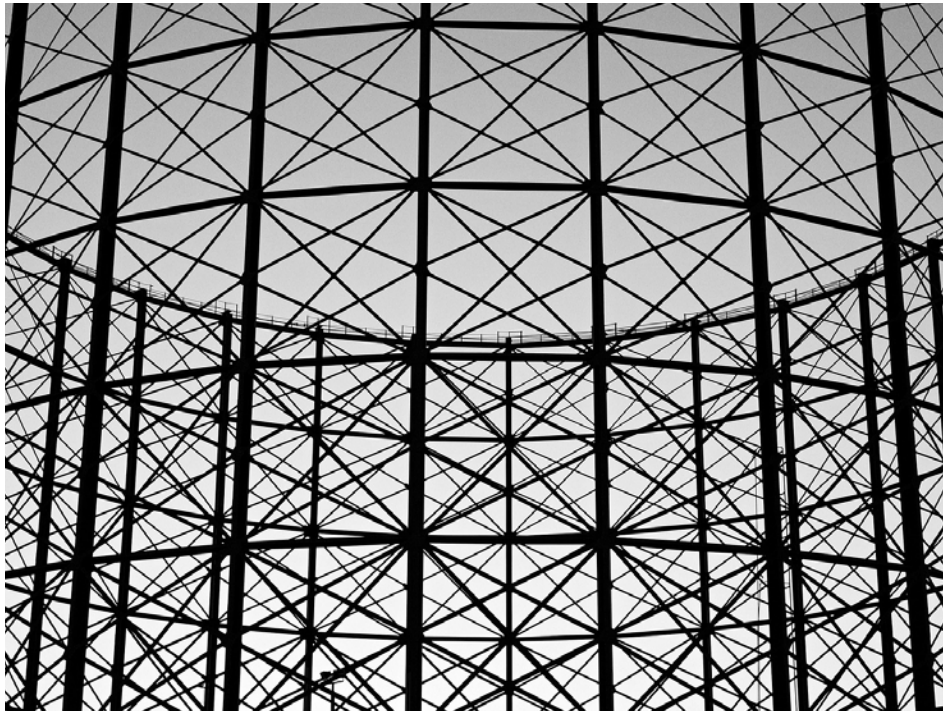
THEMES FROM HOUSING INITIATIVES MEETING

Service Provision— What’s Happening?	Service Provision— What’s Needed?	Proactive Problem Solving— Thinking Ahead	How Do We Provide These Services?
HF Alignment	Adaptability/flexibility	Problem solving/ tenant management	Listen to tenants/ those impacted
HF misalignment: research to practice gaps	Spectrum of housing	Hardest to serve, the “unhousable,” and the unserved	Collaboration, communication, and relationships
Practical considerations and barriers	Rural and cultural considerations	Why are people leaving?	Training and capacity
Assessment/decision making/ placement	Individual characteristics/ needs	Advocacy: landlord relations, dispute resolution	Language, shared understanding
	Move from a system to an individual focus	Planning ahead	Supports: friends, family, community, and other
	Prepare for and assist with transitions		What are the outcomes and are they meaningful?
	Wraparound services beyond what’s stated in the HF model		Consistency
			House vs. home

As can be seen from the preceding figure, and discussed more comprehensively in Appendix V, community members discussed housing as a complex interaction of factors at the individual, organizational, community, governmental, cultural, and historical levels. They identified the need to focus on individuals’ needs while also maintaining a standard of practice. The need for a relational approach to the provision of housing services was emphasized—not only between the individual with FASD and those that surround them, but amongst all involved parties. By focusing on the importance of relational practice, community experts acknowledged that housing services do not occur in isolation; interactions between all vested parties impact housing success. Our community experts were firm in their belief that many complexities must be considered in order to meet the needs of individuals with FASD, and that the individuals’ needs must be front and centre in our minds as we move forward with a housing plan.

SUMMARIZING OUR UNDERSTANDINGS

As you can see from the information in this section, the pathways to becoming unhoused and re-entering and maintaining housing are complex. Thus, our housing response must be complexity-sensitive to ensure we are meeting the ever-changing needs of individuals with FASD who are unhoused. By listening, forging new relationships, and engaging people through practice, we have immersed ourselves in both community and research knowledge. From this point, we were able to harmonize the information into a foundation which would light our way forward for the phase of framework development.



BY LISTENING TO EACH OTHER, FORGING NEW RELATIONSHIPS,
AND ENGAGING PEOPLE THROUGH PRACTICE, WE LIGHT OUR
WAY FORWARD TOGETHER.



■ SECTION 3: DESCRIBING OUR FRAMEWORK

Our goal through this project was to harmonize both research and community-reported knowledge into an evidence-based framework to support housing tenure. This framework helps contextualize individuals' experiences of having FASD and being unhoused, and identifies measurable goals to allow service providers both consistency

and flexibility in their work. In this section, we propose a broad, systems approach to understanding individuals with FASD's experiences of being unhoused. From this understanding, we introduce the framework guiding responsive and fluid housing service delivery centred upon listening, engagement, and relationship.

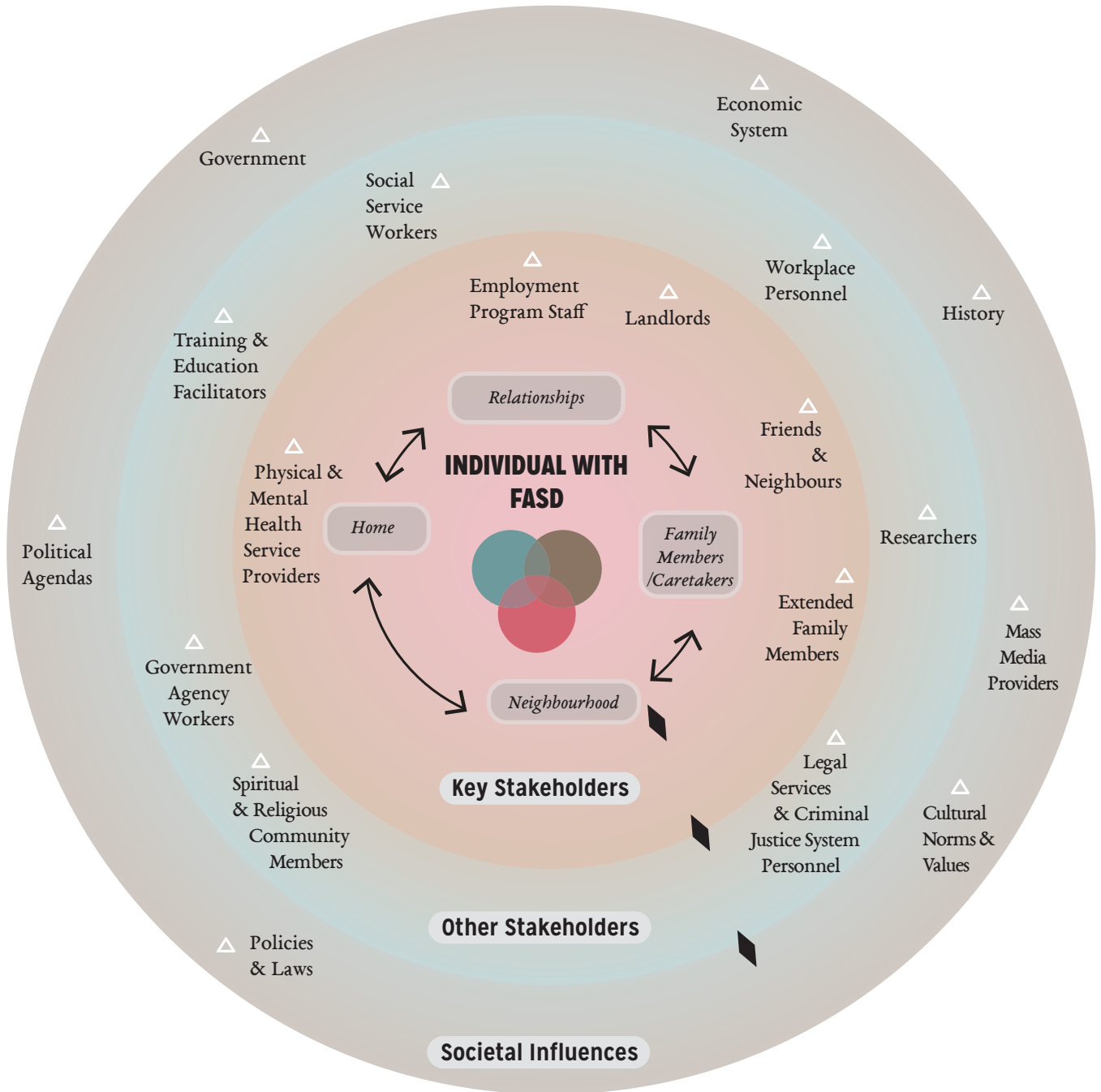
TOWARDS A PERSON-CENTERED UNDERSTANDING OF HOUSING INDIVIDUALS WITH FASD

Understanding the experience of being unhoused for individuals with FASD is complex. It involves understanding individuals' unique presentations of FASD and knowing what helps them function well in their day-to-day lives. We must also consider the people and services these individuals live with and interact with in the larger world along with the many system-wide factors associated with being unhoused. We propose using a broader, person-centred approach to understanding this population's experience of being

unhoused that takes into account all of these layers. Instead of oversimplifying the problem or pointing fingers at a single group, we set the context for all people to situate themselves within so that they can define relationships with others and work collaboratively towards a sustainable solution. Our **Person-Centred Stakeholder Map** (see visual; adapted from Bronfenbrenner, 1977) sets the context for the person-centred framework to housing that follows.

THROUGH RELATIONSHIP
WE IDENTIFY SUSTAINABLE
SOLUTIONS.

PERSON-CENTERED STAKEHOLDER MAP

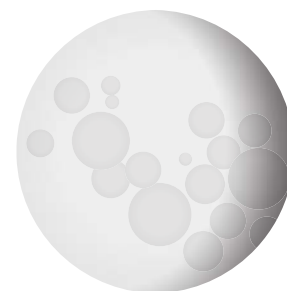


INDIVIDUAL WITH FASD is in the forefront, situated within their immediate environment. We first consider the extent to which individuals feel safe and comfortable in the place they consider to be their house and/or home. This encompasses “nothing about us without us,” and emphasizes the engagement of individuals with FASD around their housing options to create an individualized house and home that meets their unique needs. We intentionally consider the importance of the relationships that individuals with FASD have with important people in their lives and with their immediate environment (i.e., family members, caregivers, workers, neighbourhood). This follows from our person-centred approach.

KEY STAKEHOLDERS may be linked with individuals with FASD in order to prioritize services according to the individuals’ most pressing needs. For example, physical and mental health service providers would be considered key stakeholders for an individual experiencing liver failure due to chronic alcohol consumption or significant mental health disruption. Service providers will provide the best possible services when they prioritize the most relevant and practical services for each individual.

OTHER STAKEHOLDERS may be linked with individuals with FASD once their most pressing needs have been addressed. For example, staff members at an employment program may connect with an individual after she is sufficiently stable to manage some employment demands. Individuals with FASD will be best served when services are integrated. Service integration occurs through consideration of other relevant stakeholders, relationship building, information sharing (e.g., individuals’ needs), and collaboration to support the housing status and quality of life of individuals with FASD.

SOCIETAL INFLUENCES also impact individuals with FASD and housing service providers. For example, political agendas of the government partly determine funding allocation towards social services and supported housing programs. We suggest that policy makers reflect upon this person-centred model when reviewing and developing policies, with the goal of moving towards a system-wide, collaborative, and integrated model of service delivery to sustainably support individuals with FASD who are unhoused.



RESPONDING WITH A PERSON-CENTERED FRAMEWORK FOR HOUSING INDIVIDUALS WITH FASD

Housing frameworks must be fluid and complexity-sensitive to allow individuals with FASD and service providers the opportunity to make service decisions based on individuals' ever-changing experiences and needs. Processes within the framework involve gradual changes towards some end, and by its very definition, a process indicates non-static growth. As such, we see the housing process and tenants' experiences in the housing process as non-static, or non-categorical. From this understanding we necessarily created a responsive person-centred framework as an alternative to categorical housing practices.

The **Person-Centred Framework for Housing Individuals with FASD** (see visual) reflects a process of ongoing tenant engagement and re-evaluation of individual needs and service provision options. By focusing on achievable goal setting as a foundational component, this framework is geared towards providing options for individualized and systematic support. The framework accounts for not only the individual, but their environment, and the availability of services. In order for this framework to be applied consistently, continued interest and motivation must be demonstrated on the part of community caretakers, service providers, stakeholders, and individuals with FASD to foster housing tenure via the provision of person-centred services and accommodations.

WHO?

The framework situates understanding the individual at the centre. Assessment of tenants' supports, strengths, and needs occur upon first contact in order to develop an understanding of the individuals we are supporting so that we may help them to make decisions that best suit their needs. The individual's unique characteristics, strengths, needs, and existing system of supports are evaluated in order to explore not only possible housing trajectories, and the support services that may benefit the tenant along the way, but also to identify the type of outcomes and goals they may want to strive towards. Generally, assessments of supports and needs of an individual are completed during intake via the SPDAT, Life History Screen, and/or the VAT. We offer **FASD-Informed Tables** in Appendix II as translational resources that housing staff may use to complement these tools to assist in the identification of housing goals. It is important to note that as individuals progress through various programs, their abilities, skills, and needs are likely to change. Ongoing evaluation of the individual's needs and abilities helps the individual and their advocates to determine the level of support most beneficial to the individual, and to ensure services are best matched to the individual's needs so that they may experience success in reaching their goals.

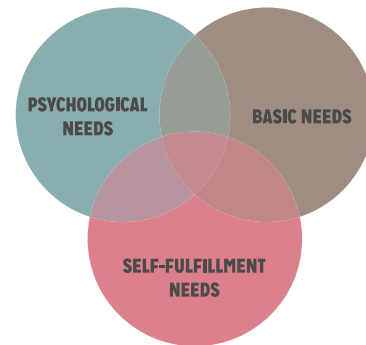
WHERE?

The assessment of the individual directs the pursuit of available housing options. Choices along the continuum of housing are determined in part by the assessment of the individual and their needs, alongside a consideration of housing availability. This continuum can include housing options such as emergency shelters including hospitals or shelters, outreach, or transitional housing programs. Specific approaches such as Housing First, treatment first, and/or measured alcohol consumption programs may also be considered. Housing choice impacts support choice and availability, and therefore reflects an intersection between individual needs and strengths and program options that will need to be considered in goal setting and goodness of fit. The housing supports offered should help the individual attain their physical, psychological, and self-fulfillment needs, including housing tenure. Importantly, placement will guide outcomes and outcomes may suggest the need for a change in placement.

HOW?

The “How?” portion of the framework focuses on housing tenure through the fluid tailoring of housing supports in relation to the unique characteristics and goals of the individual. The supports provided are the means by which an individual maintains their housing. Ongoing assessment of the individuals’ strengths, needs, and supports are necessary as the individual progresses through housing programs and support services to ensure services are

REMINDER

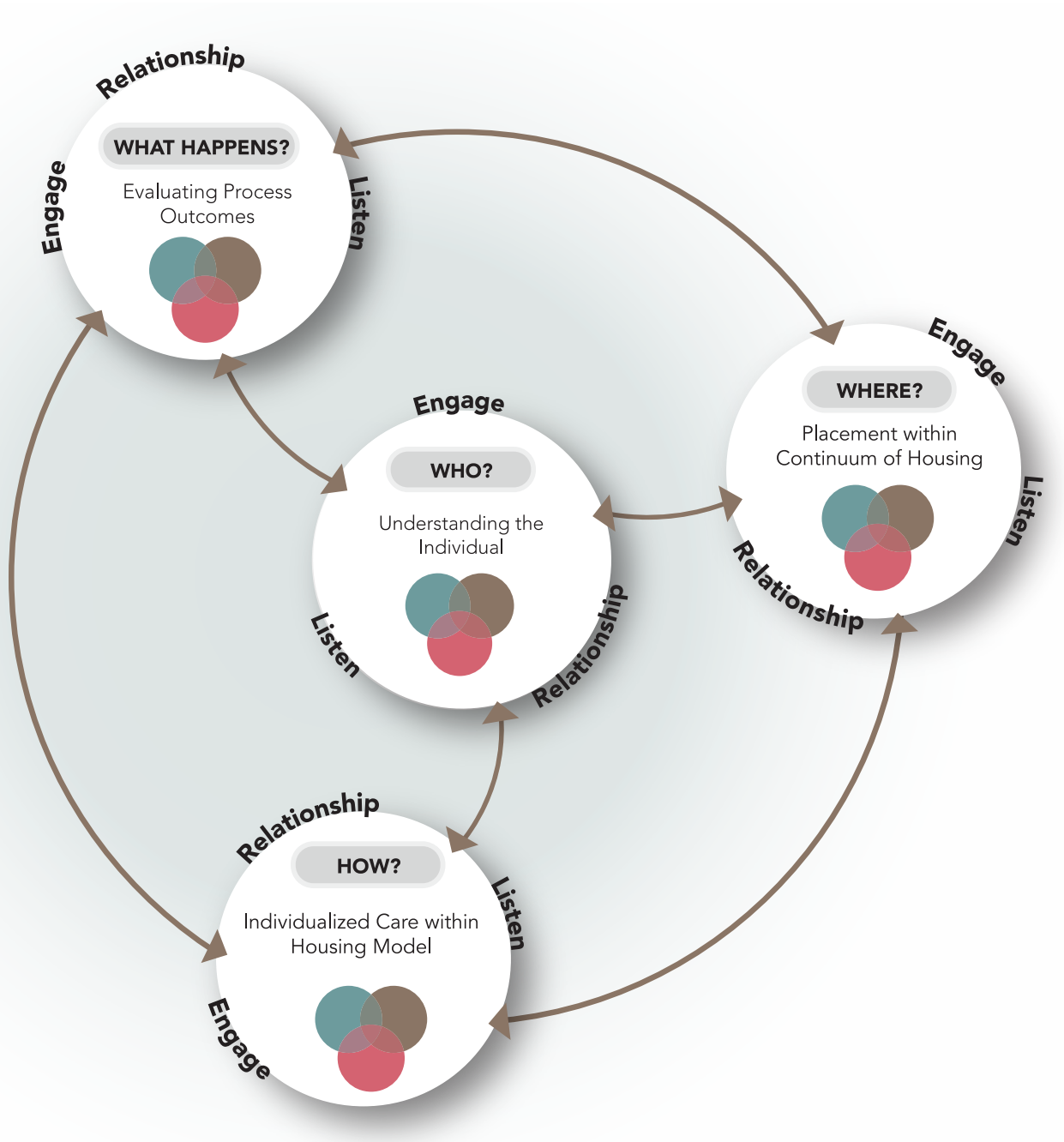


meeting the individuals’ evolving needs. Thus, regular program evaluations should also be occurring in order to understand what is working well for residents, and where program improvements or goal amendments may be beneficial.

WHAT?

This portion of the framework refers to understanding what goals are agreed upon by the individual and program staff prior to entering housing and community services. This portion of the framework is further developed in the implementation section. The individual and their support team will work to develop appropriate and attainable goals based on the individual’s basic, psychological, and self-fulfillment needs. The goals are determined collaboratively by the individual, their support workers, and natural supports with consideration of the type of housing in which they currently reside. The person-centred outcomes will not look the same for all individuals. The emphasis is on meeting the individual where they’re at to collaboratively develop a path forward, within existing systems of support, in a guided rather than fixed manner.

PERSON-CENTERED FRAMEWORK FOR HOUSING INDIVIDUALS WITH FASD



■ SECTION 4: IMPLEMENTING THE FRAMEWORK

In this section we identify mechanisms that support the process of goal setting, enabling service providers to be consistent and flexible in their work. In our responsive evaluation model, we recognize that not all programs will have the same goals; thus, in this model we identify a systematic approach to individualizing goals.

“Working on the operations level to develop a usable framework for housing is the best way forward.”



DESCRIBING A RESPONSIVE EVALUATION MODEL

A Responsive Evaluation Model Enacting the Framework for Housing Individuals with FASD (see visual) is structured as a circle, adapted from the work of Rutman and colleagues (2014). The format of this model aligns with our guiding lights and adopts a person-centred approach to both service delivery and program evaluation. In so doing, we recognize the interactions among individual, social, governmental, historical, as well as additional system-level factors and outcomes. The model centres around considerations of the individual with FASD's needs. Surrounding the individual, we consider the housing program's philosophy and theoretical framework, and housing resources and activities. The final three layers of the concentric model depict outcomes in the domains of basic, psychological, and self-fulfillment needs.

This model is influenced by several external factors including the rental market, tenants' access to funding such as that that for persons with developmental disabilities (PDD), government policy, and whether the housing is being provided in an urban or rural context. The assumptions surrounding the evaluation model are that services are relationally-based with an intentional focus on hope, collaboration, and strengths not only for the tenant but amongst professionals as well. The resources section describes what must be in place in order for the activities to

occur. The activities section covers the actions taken towards housing individuals with FASD, and finally, the outcomes depict person-centred tenant goals that may be measured in housing program evaluations. Each will be discussed in turn in the rest of this section.

The individual with FASD and their unique constellation of needs are located in the innermost circle of the evaluation model. The placement of the individual at the centre reflects our position that in order for housing services to meet tenants' needs, their needs must first be well understood. From this place of understanding, the individual with FASD and their support network can make responsive housing, support, and external service decisions to best meet the tenants' needs, including maintaining housing tenure. Surrounding the individual, the theoretical frameworks and philosophies underlying program delivery are expected to be person-centred, relational, and FASD- and systems-informed.

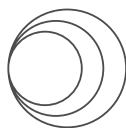
**WE ADOPT A SYSTEMS-
INFORMED AND PERSON-
CENTERED APPROACH TO
BOTH SERVICE DELIVERY AND
PROGRAM EVALUATION.**

For housing programs to exist and meet tenants' needs, the appropriate resources must be in place. Staff must be carefully selected according to their alignment with the tenets of the program (e.g., harm reduction, relational, human rights-based/Housing First) and should be representative of diverse backgrounds. Adequate training is provided to staff to ensure they are knowledgeable about—and comfortable working from—the lenses incorporated in the housing setting (e.g., trauma- and FASD-informed, harm reduction). Staff are supported in their work via regular supervision to ensure consistency of service and to prevent staff burnout. Funding must be in place in order to construct or rent the building, if appropriate, or to contribute towards subsidized rent. Buildings must be up to code and available to tenants, with building specifications matched to tenant needs. For example, double drywall to reduce the impact of damage or increase sound proofing, upper level units to manage visitation, and fob entry to reduce the need for key replacements.

And finally, a feasible evaluation structure is in place to allow regular evaluation of how the program is meeting tenants' needs.

The resources ensure that the activities may take place. The activities necessarily begin with the engagement of individuals with FASD who are unhoused. This may involve outreach activities and advocacy to ensure these individuals connect with housing service providers. After engaging the individual with FASD, an assessment must occur in order to understand the strengths and needs of the individual and the supports available to them. From this understanding, the individual and their supporters can make informed decisions about where along the continuum of housing the individual might best fit and the supports required for the tenant to maintain housing tenure and meet their individualized goals. Program evaluation is an integral part of the process as it allows program staff to build upon, celebrate, and share their successes, and make changes where needed.

**PROGRAM EVALUATION IS INTEGRAL
TO CELEBRATING PROGRAM
SUCCESSSES AND SUPPORTING
IMPROVEMENTS.**



All of the activities lead to the person-centred outcomes depicted by the three exterior circles of need. We decided to move away from hierarchically depicted needs centred upon the premise that lower-level needs must be met before attempting to meet higher-order needs. In our depiction of outcome needs, we have placed basic needs closest to the individual, and self-fulfillment needs furthest from the individual. However, displaying the outcome needs concentrically allows individuals with FASD and their service providers to tailor outcome needs to the individual's unique circumstances. This conceptualization permits the individual with FASD to identify their own outcome need goals which may come from a fluid combination of concentric levels of outcome needs.

Specific short-, mid-, and long-term outcomes have not been listed in the evaluation model as we recognize that outcome needs will vary according to the individual. Basic needs include physiological and safety needs such as shelter, food, and water and developing the sense of security and safety. Psychological needs include the sense of belonging and the development of relationships, and subsequently,

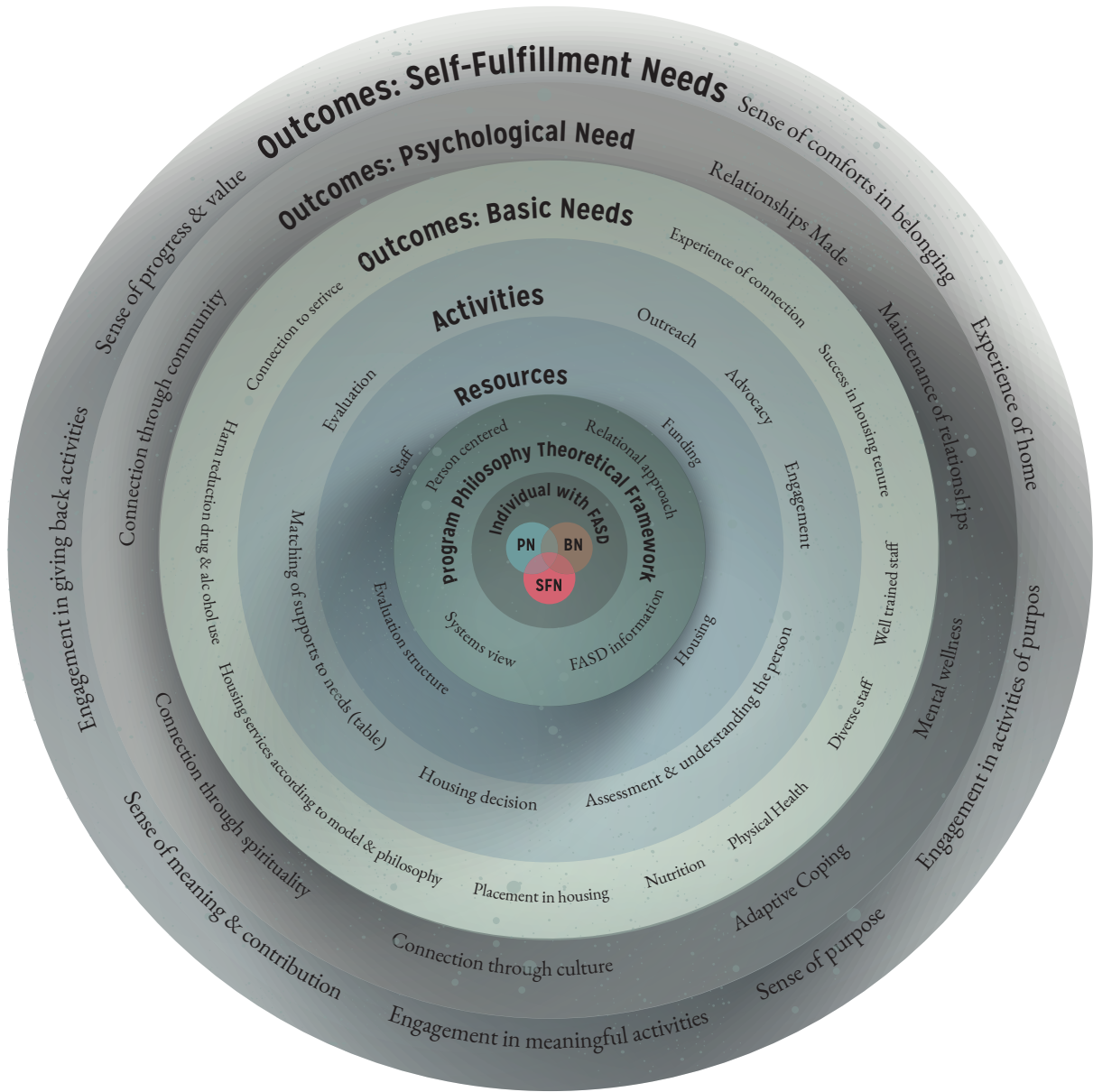
self-esteem in relation to a sense of accomplishment for having met one's personal goals. Finally, self-fulfillment needs reflect the sense that an individual has reached their full potential. This might result from employment or volunteer pursuits, involvement in the arts or whatever the tenant sees as their ultimate goal in life. Following from the description of the outcomes, you can see that we cannot simplify individual outcomes to a one-size-fits-all recipe. An individual with FASD



entering into housing after a chronic and prolonged period of being unhoused in combination with a severe addiction to crystal meth and accompanying psychosis may have very different goals than an individual with FASD with several community supports who has been unhoused for only the last six months after being unsuccessful in a group home in a new city. We propose a person-centred view of outcomes that can be collaboratively decided upon between the tenant and their supports.

**WE PROPOSE A COLLABORATIVE APPROACH TO
IDENTIFYING SUCCESS.**

RESPONSIVE EVALUATION MODEL ENACTING THE FRAMEWORK FOR HOUSING INDIVIDUALS WITH FASD



KNOWLEDGE AND ACTION: TOWARDS MEANINGFUL OUTCOMES

As can be seen in the outmost layers of the evaluation model, we've identified three areas of tenant needs and outcomes. For each of the need/outcome areas, we have created **Navigational Tables** (see visuals). The **Navigational Tables** are meant, 1) to guide individuals with FASD and their supporters towards meeting individualized goals, and 2) guide programs towards meaningful evaluation of program outcomes. The **Navigational Tables** are focused on what the individual with FASD needs, the reasons underlying those needs, the actions that the individual with FASD and programs can take, and the indicators available to housing staff to identify meaningful program outcomes.

NAVIGATIONAL TABLES

Each of the three **Navigational Tables** is dedicated to an area of tenant needs and outcomes: Basic Needs, Psychological Needs, and Self-Fulfillment Needs. The action items are not exhaustive, they are only meant as a starting point. The first column for each need/outcome describes what would be required in order for that need to be met (“I need...”), and why those requirements should be a focus of action (“because...”). The next two columns, respectively, describe the actions that the individual can take (“I will...”), and the organization can take (“We will...”), in order to help the

tenant meet their needs. We attempted to present information in each column from the perspective of the individual or staff. In both the tenant and organization columns, the information is written from a person-centred perspective, using “I” and “we” language. Under each action section, space is provided to record individual and organizational goals. Goals should be broken down into meaningful, concrete, and achievable steps. It is important to review and revise the goals regularly and to celebrate tenants' success. This approach helps tenants to recognize success on their own terms and allows their outlook to become future-oriented. In the final column suggestions are provided regarding how housing staff may want to evaluate their programs' success in meeting tenant needs. These suggestions fall under two categories: 1) staff recording practice specific to tenants' goals (e.g., through regular practice and commonly used measures), and 2) additional information to be sought from tenants, caregivers, staff, and other organizations through interviews or other manners. Examples of questions that might be used to explore outcomes are provided under each category. Under each action section, a space is provided to record outcomes associated with tenant and organizational goals and activities.

Basic Needs

I need...	I will...	The program will...	We will see if it's helping by...
<p>connections to resources</p> <p>because they...</p> <p>support building of safe relationships and trust</p> <p>facilitate access to necessary supports to help with goal attainment and reduce isolation</p> <p>help to proactively avoid barriers such as paperwork</p>	<p>ask for help when I need it. For example, I will:</p> <p>ask someone to help me with a difficult task such as filling out paperwork</p> <p>tell my supports what I need. For example, a ride, or meeting outside in a park</p>	<p>engage, connect with, & listen to the tenant. For example, we will:</p> <p>ask the individual about their past successes and barriers</p> <p>identify specific service options with the tenant</p> <p>support completion of housing applications. For example, reading questions aloud, and/or emailing the form</p> <p>talk to existing supports the individual might have. For example, probation, aunty</p>	<p>making any connection to service, and the experience of connection.</p> <p>Keep good notes:</p> <p>Does the individual have a housing connection and is all paper work complete?</p> <p>Talk to people:</p> <p>Ask tenant about their housing connection experience, and how they believe it may be improved</p>
	I will...	We will...	Outcomes...
<p>assessment of needs and strengths</p> <p>because it...</p> <p>allows for increased knowledge, understanding, & collaboration</p> <p>ensures I feel listened to & enter into housing that best meets my current needs</p> <p>helps me find safe shelter</p> <p>helps guide immediate housing placement</p>	<p>share things about myself so my supports can help me. For example, I will:</p> <p>share openly when answering questions about myself. For example, if I use meth, or sometimes punch walls when I'm mad</p> <p>introduce my workers and supports to each other</p> <p>tell my workers about any assessments & diagnoses I've had</p> <p>tell my worker why I don't want to live somewhere. For example if there is a neighbourhood I need to stay away from, or if I can't live in a basement because of bad things that once happened there</p>	<p>understand the tenant, and use that understanding to inform placement decisions. For example, we will:</p> <p>use assessment tools available to us (e.g., SPDAT, VAT, or Life History Screen) in addition to the FASD- Informed Tables provided within this report to learn about the tenant's strengths & needs</p> <p>collaboratively decide with the tenant what type of housing and program would be the best fit. For example, rent-to-own plans, and sober villages</p> <p>consider creative solutions to frequent dilemmas. For example, a restorative justice approach to property damage</p>	<p>Observing appropriate placement in housing.</p> <p>Keep good notes:</p> <p>Period of time from first contact to housed; reasons for matching individual to placement; days housed</p> <p>Talk to people:</p> <p>Ask tenants "How is your housing going? Why is this a good/poor fit for you?"</p>
	I will...	We will...	Outcomes...

I need...	I will...	The program will...	We will see if it's helping by...
<p>to care for my physical health</p> <p>because it...</p> <p>helps me function at my best</p> <p>facilitates relationship building and development of life skills through co-tasks and food</p> <p>reduces my risk of harmful substance consumption and contraction of infection</p>	<p>eat regularly and healthily. For example, I will...</p> <p>tell my worker if I need food and make a plan on how to get food if needed</p> <p>eat at least 1 healthy meal a day</p> <p>take care of my body. For example, I will:</p> <p>tell my worker if I am worried about my health. For example: is my toe infected, have I been sleeping regularly, do I get my period once a month?</p> <p>see a doctor</p> <p>be as safe as I can around drugs and alcohol. For example, I will...</p> <p>tell my workers what I need to stay safe around drugs and alcohol. For example, do I need clean needles or regular doses of alcohol to manage withdrawals?</p> <p>keep harmful substances such as nail polish remover with staff if I am worried about drinking or taking them</p>	<p>assist tenants to meet their nutritional needs. For example, we will...</p> <p>offer one meal a day</p> <p>go with the tenant to food bank or grocery store</p> <p>prepare food with the tenant</p> <p>assist tenants to meet their health needs. For example, we will:</p> <p>ask health-related questions</p> <p>talk about health in a accessible, educational manner. For example, STIs, menstruation, and pregnancy</p> <p>help tenant to schedule and attend health appointments</p> <p>talk with tenants about what harm reduction would look like for them. Identify a plan for enacting this approach. For example, how to access safe needles</p>	<p>monitoring nutrition, physical health, and drug and alcohol use.</p> <p>Keep good notes:</p> <p>How often do you have food in your house? Harm reduction supplies used; drug & alcohol use</p> <p>Talk to people:</p> <p>Ask tenants, "What would you like to learn about nutrition?" Ask tenants, caregivers, and staff about their perceptions of staff's use of the harm reduction approach</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>

I need...	I will...	The program will...	We will see if it's helping by...
<p>certain features in my housing</p> <p>because they...</p> <p>create a safe environment</p> <p>prevent potential injury</p> <p>prevent unnecessary damage to the unit</p> <p>lessen landlord concerns if safeguards are in place</p> <p>increase probability that I will experience success</p>	<p>find the safest place for me to live. For example, I will...</p> <p>tell my worker what kind of place I think would be best for me. For example, a place where I don't need keys, a place with sunshine and lots of light, a place where I can walk to a park</p> <p>tell my worker about problems I've had in the past or problems I think I might have. For example, if I often lose my belongings, if I punch stuff when I'm mad, if loud noises make me scared, if I'm worried about being alone</p>	<p>find or provide safe housing. For example, we will...</p> <p>explore building accommodations to suit tenant needs. For example, key fobs, balconies, 2nd floor or higher, double drywall, auto-shut-off appliances, no closet doors, bachelor-style suites, limited or thick-paned glass</p> <p>provide guest management services. For example, video cameras in halls & entry ways, buzz in guests, serve as a 'gatekeeper' for guests</p> <p>maintain a positive proactive connection with police</p>	<p>monitoring housing tenure, successes, setbacks, and eviction.</p> <p>Keep good notes:</p> <p>Damages and periods without damage; eviction rates and reasons; timing of building changes in relation to housing outcomes</p> <p>Talk to people:</p> <p>Ask tenants, "Do you feel safe in your house? What about it makes it feel safe or unsafe?" Interview tenants and staff about their perceptions of guest management services</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>
<p>thoughtfully hired and appropriately trained housing staff</p> <p>because they...</p> <p>help me feel hope because I see similarities between us</p> <p>may create places for shared understanding</p>	<p>share my thoughts about staff and the things I'd like to see. For example, I will...</p> <p>tell workers what things they can do to help us work together. Are there things I like, don't like?</p> <p>tell workers what kind of things or people I'd like to see in my program. Do I wish there was someone there who spoke my language? Do I think there needs to be more cultural programming?</p> <p>ask my workers if there are peer supports or how I could become one</p>	<p>hire carefully and provide comprehensive training of staff. For example, we will...</p> <p>offer supervision around, and monitor staff's practice of the program's philosophy</p> <p>hire diverse staff with considerations of language, gender and sexual identity, ethnicity, culture</p> <p>provide training centred on: harm reduction, trauma and FASD, language, de-escalation tactics</p> <p>offer a peer support role/position</p> <p>seek supervision when struggling with certain philosophies such as harm reduction</p>	<p>observing staff diversity, and service provision according to model and philosophy.</p> <p>Keep good notes:</p> <p>Training checklists; topics of supervision; number of staff meetings; peer supports onsite</p> <p>Measures:</p> <p>fidelity measures</p> <p>Talk to people:</p> <p>Ask staff, "Do you find the training helpful and sufficient? If yes, why? If no, where could it be improved?"</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>

Psychological Needs

I need...	I will...	We will...	We will see if it's helping by...
<p>relationships</p> <p>because they...</p> <p>support the development of trust</p> <p>reduce feelings of isolation</p> <p>expand my support network</p> <p>increase feelings of belongingness & love</p>	<p>make connections. For example, I will...</p> <p>tell my worker about any relationships I have, or would like to have, and what is important to me in a relationship</p> <p>tell my worker about things that might be fun for me and how I could try them out. For example, I can make friends through groups and activities such as support groups, or community activities</p>	<p>provide relationally-based services. For example, we will...</p> <p>encourage and support tenants to reconnect with healthy support networks</p> <p>go with tenants and support them in establishing new connections and relationships</p> <p>emphasize the importance of individual & community connections</p> <p>build and maintain relationships with landlords</p>	<p>identifying connections made, and relationships maintained.</p> <p>Keep good notes:</p> <p>Frequency of engagement with friends and family, in groups</p> <p>Measures:</p> <p>Advocate-Client Inventory; support network mapping; scales that ask about tenants' isolation, connectedness, and feelings of belongingness, & love</p> <p>Talk to people:</p> <p>Ask tenants how they feel about their relationships and connections</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>
<p>mental wellness strategies</p> <p>because they...</p> <p>help me to focus on my strengths and develop strategies to better regulate my emotions</p> <p>help me to have better anger management</p> <p>create a safe place to work through experiences of trauma to improve my coping mechanisms</p>	<p>improve my mental health. For example, I will...</p> <p>tell my worker about thoughts or behaviours that may be troubling me, and things that help me. For example, do I have flashbacks of an event that makes me very scared? Do I have good sleeps if I draw or write before bed?</p> <p>ask someone to tell me about things that might help me to feel better. For example, making an appointment to see a doctor. They can help me to get an assessment if I would like one</p>	<p>promote and support mental wellness. For example, we will...</p> <p>discuss with tenants what may come before periods of difficulty, for example, missing a meal, and what seems to come before periods of success, for example, walking and listening to music leads to better sleep and mood the next day</p> <p>provide tenants information regarding options for working towards mental wellness</p> <p>incorporate tenants' strengths and needs into service decision-making and plans (see Appendix II)</p>	<p>improved psychological functioning, engagement with mental wellness supports, awareness of areas of strength and need.</p> <p>Keep good notes:</p> <p>Participation in addictions treatment; assessment; group intervention. Note strengths and needs</p> <p>Talk to people:</p> <p>Ask tenants, "How has your mental wellness changed for you? What have you done to lead to this change?"</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>

I need...	I will...	We will...	We will see if it's helping by...
<p>adaptive coping</p> <p>because it...</p> <p>improves my sense of agency and control over my behaviour</p> <p>improves my quality of life by addressing past trauma and proactively planning around triggers</p> <p>helps me to improve my relationship functioning</p> <p>helps me better manage strong feelings to reduce behaviours that may increase risk of eviction</p>	<p>identify my warning signs, and learn new ways to help myself when I get upset. For example, I will...</p> <p>tell my worker about sounds, smells, and situations that make me feel sad, mad, or scared</p> <p>make a plan to help avoid those things, or to help calm myself when I experience them. For example, taking a hot bath or cold shower, beading, colouring, or deep breathing</p> <p>tell my worker if there are certain times, for example Christmas, or events that are difficult</p> <p>ask my worker to help find a support worker I like and feel I can work with regularly</p>	<p>help tenants to further develop their adaptive coping skills from a proactive trauma- and FASD-informed lens. For example we will...</p> <p>help tenants to understand the events that precede success or difficulty</p> <p>provide visual reminders of techniques that are useful to tenants in moments of distress. For example, pictures of activities they may engage in when in that mood zone</p> <p>provide non-judgemental options for tenants wishing to reduce substance-use-associated harm</p> <p>celebrate tenants' success and share your observation of tenants' use of adaptive coping techniques</p>	<p>increasing sense of mastery and agency, and adaptive methods of coping.</p> <p>Keep good notes:</p> <p>Methods of coping and their frequency</p> <p>Talk to people:</p> <p>Ask tenants, "How do you calm yourself when things are difficult for you or upset you? How has this changed since working with the program?"</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>
<p>connection through culture, spirituality, community</p> <p>because it...</p> <p>builds natural network</p> <p>fosters my sense of belonging and purpose</p> <p>increases my coping abilities by teaching me new things such as cooking, and connecting me with higher powers such as nature, mindfulness, prayer, and rituals</p>	<p>learn about my culture and connect with others who give me hope and strength:</p> <p>ask about my culture. It may help me to learn new things about myself and where I've come from</p> <p>consider exploring different spiritualities - I might visit an elder, visit a Buddhist temple, or go into nature</p> <p>learn how to cook a certain dish, or make traditional items that I can wear or use to decorate my home</p>	<p>honour diversity of culture and spirituality in our service model. For example, we will...</p> <p>provide cultural opportunities through programming</p> <p>share our own cultural teachings or discuss how culture and spirituality are a part of one's identity</p> <p>offer connections to local cultural and spiritual centres and, if comfortable for us and the tenant, offer to attend</p>	<p>experience of cultural, spiritual, and/or community connection.</p> <p>Keep good notes:</p> <p>Number and type of events attended</p> <p>Talk to people:</p> <p>Ask tenants, "How has your sense of culture or spiritual or community connection changed since moving in?"</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>

Self-Fulfillment Needs

I need...	I will...	We will...	We will see if it's helping by...
<p>comfort and sense of belonging - a home</p> <p>because it...</p> <p>fosters my sense of pride as I see myself reflected in my house, & the house becomes more than a dwelling</p> <p>enhances my feelings of security, belonging, & safety</p> <p>doubles as intervention when I engage in therapeutic activities as a part of nesting. For example, sewing, beading, art</p>	<p>make this place my home. For example, I will...</p> <p>decide what I'd like to see in my house to make it safe, welcoming, & mine. For example, pictures of my friends or favourite animals on the wall, a blanket I made with my favourite colours and sayings on it, painting my room a soothing shade of blue</p> <p>decide what I'd like in my house to make it feel more homey. Maybe I'd like a coffee maker so I could invite someone over for coffee. Maybe I'd like some plants or a white-noise machine to make it into a more soothing space</p>	<p>proactively help tenants to create a home. For example, we will...</p> <p>talk with tenants about the concept of home—home as a feeling, not a structure</p> <p>acknowledge that many tenants may describe the streets as their home—a place where they had a family, a routine, and a sense of how to keep themselves safe. The new house may come with a sense of fear and loss</p> <p>offer to do homemaking activities with the tenant. For example, take pictures, make art, go to donation centres, or sew a blanket.</p>	<p>experience of home.</p> <p>Keep good notes:</p> <p>Use measures such as a rating scale asking tenants if their house feels like a home</p> <p>Talk to people:</p> <p>Ask tenants, "Why does, or why doesn't your house feel like home? What have you or others done to make your house feel like a home?"</p>
<p>to find purpose beyond housing</p> <p>because it...</p> <p>helps promote my improved functioning through physical, spiritual, & psychological health</p> <p>fosters a more complete sense of myself alongside meaning & purpose through connections with culture, nature, & community</p> <p>expands my social and support network which contributes to the development of a sense of my "home"</p>	<p>I will...</p> <p>.</p> <p>.</p> <p>work toward what I want in life. For example, I will...</p> <p>tell my worker what I want in life and what would make me happy. These might be activities in my house, or in another place. For example, I might want to talk to others about my experiences and how far I've come, write a letter to my premier about living without a house, get involved in a fundraiser or food drive for a good cause, or take a parenting course</p>	<p>We will...</p> <p>.</p> <p>.</p> <p>reevaluate tenants' needs after stabilization period. For example, we will...</p> <p>normalize the feelings of stress that occur during the period after becoming housed</p> <p>connect with tenants as they settle in to ask where they would like support, and if they would like us to participate. For example physical activity, organized sports, venturing into nature, creating art, therapy, community groups</p>	<p>Outcomes...</p> <p>.</p> <p>.</p> <p>experience of sense of purpose, and engagement in activities of purpose.</p> <p>Keep good notes:</p> <p>Activities & tenant engagement; tenant goals or wish list, & steps taken to achieve them; number of meetings to discuss tenants' goals</p> <p>Talk to people:</p> <p>Ask tenants, "What was your sense of purpose before you were housed. How has that changed during their time here? Can you paint or draw your experience of changing purpose?"</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>

I need...	I will...	We will...	We will see if it's helping by...
<p>meaningful contribution</p> <p>because it...</p> <p>gives me purpose</p> <p>helps avoid experiences of "now what?"</p> <p>broadens my skill-base & support and social network</p> <p>increases probability of success with the right fit</p> <p>facilitates movement towards feeling valuable</p>	<p>find education, training, employment, or volunteer opportunities. For example, I will...</p> <p>tell my worker if there is something I would like to learn, if I would like a job, or to volunteer</p>	<p>facilitate tenants' movement towards meaning pursuits and their full potential. For example, we will...</p> <p>ask tenants where they would like to see themselves in the future</p> <p>emphasize tenants' strengths & help them to see how they can use their strengths to make meaning in their lives</p> <p>place equal importance on education, training, paid employment, and volunteer pursuits</p> <p>talk through goodness of fit in all settings</p>	<p>engagement in meaningful activities, and experience of meaning and contribution.</p> <p>Keep good notes:</p> <p>Meaningful pursuit checklists</p> <p>Talk to people:</p> <p>Ask tenants, "What would you like to do but currently are not doing?" Ask organizations, "How can our tenants become involved?"</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>
<p>giving back</p> <p>because it...</p> <p>empowers me to reflect on and recognize my progress and skills</p> <p>fosters a sense of hope as community members & new tenants see peer supports they can relate to</p>	<p>share what's great about me, & how far I've come with others:</p> <p>ask my worker how I can give back to my program or the community</p> <p>share my successes with others. For example, talking with others about my experiences and what worked for me, or helping with or leading activities. I have done great things and others may like to learn from me!</p>	<p>promote the peer support model. For example, we will...</p> <p>offer paid and/or volunteer peer support positions</p> <p>emphasize tenants' achievements & strengths, & help them to see how they might share these with others</p>	<p>increased sense of progress and value, and giving back activities.</p> <p>Keep good notes:</p> <p>Giving back activities both through the program and in the community</p> <p>Talk to people:</p> <p>Ask tenants, "What do you have to offer back to your peers and community, and how do you/would you like to do that?" Ask staff, "How do you support tenants' efforts to give back?"</p>
	<p>I will...</p> <p>.</p> <p>.</p>	<p>We will...</p> <p>.</p> <p>.</p>	<p>Outcomes...</p> <p>.</p> <p>.</p>

■ SECTION 5: HARMONIZATION AND RESPONSIVITY: LIGHTING THE EVER-CHANGING WAY FORWARD

LISTENING

Responsive action to housing individuals with complex needs can be challenging. Through this project, we explored the most up-to-date research and FASD-specific community programs, and we listened to the successes, struggles, strategies, and concerns of community experts. In the end, we've come away with a resounding emphasis on creating intersections. Housing is the point of intersection between individuals and the systems that surround them. By definition, an intersection is a position where two things come together, where they connect. We suggest that listening is the first part of creating meaningful housing intersections; it was the first step we took in creating this framework. From this point of intersection, forward action can be taken from a place of understanding to navigate the multitude of interacting systems involved in housing individuals with FASD.

HUMANIZING

Several guiding lights may illuminate the path forward to systematic and responsive housing practice that meets tenants' needs. Taking a person-centred approach wherein all individuals are valued and are understood as having unique strengths and needs is the first guiding light. We support the movement away from categorical, deficit-based views of individuals with complex needs and their experiences of being unhoused and, instead, suggest that an understanding of the complex interplay of individual, relational, societal, cultural, and historical factors must illuminate the path forward. The interconnected

nature of all that surrounds us was reflected upon by community experts who called for systems-level change, while also emphasizing that "the system is us." Finally, the necessity of an engaged and relational approach to housing individuals with FASD shines bright under the lights of person-centred and systems-informed practice. Relational approaches demonstrate understanding of the complex interplay of factors that have resulted in the individuals' experience of being unhoused and allows for a true connection to be made so that person-centred work can occur.

EVOLVING

These philosophies lit the way through the phases of our framework development—from the way we collected and analysed evidence of multiple kinds and from multiple sources, to the iterative and collaborative development of the responsive person-centred framework itself. Throughout the process, we learned that we don't always need to do more, we need to do different, and that without truly listening to one another we will persist down the wrong road. We understood the necessity of shifting from conventional, depersonalized categorical approaches to housing service provision and evaluation to instead offer you a harmonizing, translational, relational, person-centred, process-oriented, and systems-informed framework for practice.

THE FORWARD PATH OF RESPONSIVITY

We envision this framework as the first step of many in the implementation and maintenance of meaningful housing service delivery and evaluation to better understand how to meet the needs of individuals with FASD. Future steps may include inviting others to join the conversation, such as landlords, government officials, and individuals with FASD from a variety of living situations, and a pilot project to investigate housing service providers' perceptions of the utility, accessibility, and feasibility of this framework as a translational tool to assist practice and program evaluation. With a systematic framework to guide evaluation, housing providers will be better able to celebrate and share their successes, and continue to evolve their responsive practice to best meet the needs of tenants with FASD.



“Enough talking, let’s make change!”



APPENDIX 1-V

APPENDIX I

About Fetal Alcohol Spectrum Disorder: A Focused Literature Review

Understanding the complexity of FASD and diversity of individuals with FASD was foundational to this project. The following information is provided to help establish a shared understanding regarding some of the needs related to FASD that might impact housing efforts.

What is FASD? The term fetal alcohol spectrum disorder (FASD) is a diagnostic term that refers to a broad spectrum of presentations and disabilities caused by prenatal alcohol exposure (Cook et al., 2016) and injury to the developing brain. FASD encompasses the terms fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), partial FAS (pFAS), alcohol-related birth defects (ARBD), alcohol-related neurodevelopmental disorder (ARND), and neurobehavioural disorder associated with prenatal alcohol exposure (ND-PAE) (Doyle et al., 2017). FASD is a lifelong disability (Brownstone, 2005) that can look and present differently across individuals. It is broadly characterized by abnormalities in the central nervous system (i.e., brain and spinal cord), with or without a distinct cluster of facial anomalies (Astley, 2004).

Prenatal alcohol exposure. After 40 years of research, alcohol has become widely recognized as a teratogen that affects the developing structures and functions of the brain in an unborn child (Doyle et al., 2017). No amount of alcohol consumption is considered safe during pregnancy. Globally, an estimated 9.8% of women consume alcohol during pregnancy, of which 1 out of 13 will deliver a child with FASD (Lange et al., 2017), and 1 out of 67 will deliver a child with FAS (Popova, Lange, Probst, Gmel, & Rehm, 2017).

Who does FASD affect? The estimated global prevalence of FASD is 7.7 per 1000 people (Lange et al., 2017); it is 1.7 per 1000 people for FAS (Popova et al., 2017). In Canada, FASD was previously estimated to affect 1% of the population (Canada FASD Research Network, 2018). Given that FASD is difficult to diagnose and often left undetected, these numbers are believed to underestimate the prevalence of FASD (Health Canada, 2017). Current studies estimate that nearly 4% of Canadians have FASD (FASD Research Network, 2018). For example, an estimated 2% to 3% of Canadian elementary school students were found to have FASD (Popova, Lange, Chudley, Reynolds, & Rehm, 2018). In Alberta, researchers estimate that at least 4.4% of individuals have FASD (Thanh, Jonsson, Salmon, & Sebastian, 2014). Annually from 2003 to 2012, between 739 and 1884 people with FASD were born in Alberta (Thanh et al., 2014). Some researchers suggest that the prevalence of FASD is 16 times higher

in Indigenous communities than in the general Canadian population (Popova, Lange, Probst, Parunashvili, & Rehm, 2017). However, others criticize the representativeness of these estimates as statistics suggesting overrepresentation of births of children with FASD are often derived from Indigenous communities in which community leaders have already identified alcohol crises (Salmon, 2011). Thus, existing statistics are thought to misrepresent the many First Nation, Métis, and Inuit communities and peoples across Canada (Salmon, 2011).

Why is FASD difficult to diagnose? Clinicians diagnosing FASD must attain reliable documentation that the individual's biological mother consumed sufficient alcohol during pregnancy (Cook et al., 2016). Obtaining this information can be challenging for clinicians. For example, birth records may not be available, biological mothers may be unknown or inaccessible, or biological mothers may deny or underreport their level of prenatal alcohol consumption due to the associated stigma. Without the confirmation of prenatal alcohol exposure, FASD may not be diagnosed. As an exception, clinicians do not require confirmation of alcohol exposure for individuals with all three dysmorphic facial features associated with FASD, given that this cluster is highly specific to prenatal alcohol exposure (Astley, 2013). Clinicians may also find it challenging to diagnose FASD given that most of the deficits associated with FASD are not specific to prenatal alcohol exposure, that is, they can be partly explained by other adverse prenatal and postnatal exposures and events (Astley, 2004). For example, impaired intellectual functioning, which can be caused by prenatal alcohol exposure, could also be accounted for by genetic factors or by a serious head injury that occurred during childhood. When other risk factors exist alongside prenatal alcohol exposure, each risk factor may be considered fully, partially, or not at all responsible for any given deficit in an individual with FASD (Astley, 2004).

How does FASD impact society? There are significant system costs associated with FASD. In North America, "prenatal alcohol exposure is considered the most common cause of developmental disability" (Abel & Sokel, 1987; Canada FASD Research Network; Health Canada, 2017). Researchers estimate that the cost of fetal alcohol effects to society ranges between \$4 billion to \$9.7 billion per year (Lupton et al., 2014; Thanh, Jonsson, Dennett, & Jacobs, 2011). These system costs are related to health care, treatment services, developmental disability services, special education, lost productivity, semi-independent living support services, and residential services (Lupton et al., 2004).

How does FASD impact individuals' functioning? Individuals with FASD present with a wide range of impacts, including physical, cognitive, and behavioural deficits (Astley, 2004). According to the Canadian guidelines for diagnosis of FASD (Cook et al., 2015), people with FASD show severe impairment in three or more areas. The combined effect of dysfunction in neurocognition, self-regulation, and adaptive functioning, and their interaction with environmental factors, leads to a wide range of consequences associated with prenatal alcohol exposure (Kable et al., 2015). FASD is not easily identified as a disability, which impacts providers' ability to recognize the disability and deliver effective services (Badry et al., 2015). Diagnosis of FASD is important because it can help to support individuals' eligibility to receive funding through Assured Income for the Severely Handicapped (AISH) or Persons with Developmental Disabilities (PDD) programs for rent, food, and other basic needs (Badry et al., 2015). When FASD is left undiagnosed and untreated, it leads to challenges that can affect different health and social areas (Brownstone, 2005). For example, individuals with FASD may experience addictions and mental health issues, display inappropriate sexual behaviour, have disrupted school experiences, employment problems, legal issues, or difficulties with independent living (Dolan et al., 2012). They may also have substantial involvement with the criminal justice system, the health system, and/or the child welfare system (Badry et al., 2015).

Physical aspects of FASD. Individuals with FASD may not have facial feature anomalies, have partial facial feature anomalies, or have all three facial feature anomalies. Most features can be explained by damage to the brain during the prenatal period, and the features can be replicated in animals through prenatal alcohol exposure (del Campo & Jones, 2017). The presence or absence of FASD facial features depends entirely on the timing of prenatal alcohol consumption during gestation. Distinctive facial features are not present for most individuals with FASD, and are not easily identifiable without use of diagnostic tools (Cook et al., 2015). Generally, FASD is considered an invisible disability and best characterized by cognitive and regulatory impacts that have implications for daily functioning.

Cognitive dysfunction / brain impairment. FASD may impact overall cognitive functioning or specific cognitive domains. For example, individuals with FASD may show deficits in complex cognitive tasks that involve areas of the brain such as the hippocampus (involved with consolidating information into long-term memory) and prefrontal cortex (involved in planning, problem-solving, decision-making, and moderating behaviour).

They may lack in the higher-order skillset that is required to organize and control one's thoughts and behaviours to achieve long-term goals (Cook et al., 2015). Other individuals have difficulty with language, academic achievement, memory, and/or attention (Cook et al., 2015).

In turn, individuals with FASD often show difficulties with overall adaptive skills, which include areas such as social communication, social skills, social competence, activities of daily living, and other basic life skills required for independent living (Cook et al., 2015). The impairment in adaptive skills often does not improve with age (Crocker et al., 2009), and occurs across different environments such as school, work, home, or in the community. Individuals with FASD may be financially victimized or involved in criminal behaviour due to the influence of others involved in criminal activity (Cook et al., 2015). They may also show a chronic inability to manage money, maintain a safe and clean household, maintain a job, practice consistent personal hygiene, show proper coping skills, or care for their children (Cook et al., 2015).

Emotional aspects of FASD. Some individuals with FASD show a chronic pattern of emotional dysregulation that is not attributable to environmental conditions (Cook et al., 2015). They show abnormalities in their hypothalamic–pituitary–adrenal (HPA) axis (Hellemans et al., 2010), the central stress response system in humans responsible for “fight, flight, and freeze” responses during time of perceived danger. Dysregulation in the HPA axis is also commonly found in individuals with anxiety and depressive disorders (Hellemans et al., 2010). Prenatal alcohol exposure increases the activity of the HPA axis which results in increased sensitivity and vulnerability to life stressors (Hellemans et al., 2010). In turn, when individuals with FASD are exposed to stressors during childhood and adolescence, they show increased vulnerability towards developing depressive and anxiety disorders (Hellemans et al., 2010).

Individuals with FASD have been found to experience substantial psychopathology in mental health outcome studies (Doyle et al., 2017). For example, people who have been exposed to at least one binge-drinking episode prenatally are twice as likely as those who were not exposed to develop substance use disorders, and paranoid, passive-aggressive, and antisocial traits (Doyle et al., 2017). Researchers have found that attention-deficit/hyperactivity disorder symptoms are the most common types of psychopathology found with individuals with FASD, along with other disruptive behavioural disorders and delinquency, including oppositional defiant disorder and conduct disorder, substance use disorders, and depressive disorders (Doyle et al., 2017). The wide range of psychopathology associated with FASD, including impulsivity, mood

disorder, and substance abuse also place these individuals at higher risk of suicide compared to the general population (Doyle et al., 2017).

How can we support individuals with FASD? Because FASD is a lifelong disability, individuals with FASD require ongoing support from well-informed providers. Ideally, communities would develop a continuum of supports to address the wide range of areas affected by FASD (Brownstone, 2005) including the physical, cognitive, and mental health/adaptive aspects. Many individuals with FASD will require continuous interventions and support throughout life (Brownstone, 2005). With respect to housing, individuals with FASD require individualized and personalized programming to support their personal and housing needs (Brownstone, 2005). Housing programs for individuals with FASD may require flexibility in rules, harm reduction strategies, guest management, a focus on developing social networks, and built-in daily support (Badry et al., 2015). Additional supports may be required for memory, cognitive, or sensory disabilities, daily living skills, financial management, homemaking, school, employability skills, work, medication management, organizational skills, making/keeping appointments, controlling impulsive decisions, maintaining relationships, and encouraging positive leisure activities (Brownstone, 2005).

Ultimately, it is important for providers working with individuals with FASD who are unhoused to recognize when the challenges and problems faced by these individuals may be due to their prenatal exposure to alcohol (Badry et al., 2015) along with the associated trauma experiences. It is equally important to acknowledge that despite experiencing significant trauma and life chaos, individuals with FASD often show hopefulness and resilience in seeking stability in their lives, for their families, and in their housing (Badry et al., 2015). When service providers understand the range of needs, functional limitations, vulnerabilities, and strengths of individuals with FASD, they will be better-equipped to engage with these individuals, provide suitable services, and help them navigate within different support systems.

APPENDIX II

Towards an FASD-Informed Approach: Making Sense of What I'm Seeing

The **FASD-Informed Tables** (see visual) were developed to support community members in taking an FASD-informed approach that is grounded in an understanding of the complexity of FASD and individuals' experiences of being unhoused. The tables are designed to create a working environment that promotes responsiveness to the physical, cognitive, and adaptive strengths and vulnerabilities of this population. In other words, "One size cannot fit all." An FASD-informed approach provides the context for a shared understanding of individuals with FASD, helping people to make sense of what they may see through a FASD-informed lens. It equips people to broaden their thinking around individuals with FASD and to respond by integrating their knowledge about FASD and individuals' experiences of being unhoused into practice. The tables also help to respond to community experts' call for "a common language regarding homelessness and FASD." Content in the tables is partly adapted from information provided by Cook et al., (2015), Astley (2004), Hutchison (2015), the Vulnerability Assessment Tool (VAT)—Canadian Version (Canadian Observatory on Homelessness, 2016), the Service Prioritization Decision Assistance Tool (SPDAT) for Single Adults (OrgCode Consulting Inc., 2015), and the Life History Screen (LHS). The tables are intended to be used as a translational tool in combination with the VAT, SPDAT, and LHS, to provide service providers with overarching practice guidelines around FASD that they can infuse into every step of the housing process with individuals.

Applying the FASD-Informed Tables

Trevor, a 24 year-old male with suspected FASD first came to the attention of a social worker after seeking accommodation at an emergency men's shelter and asking about longer-term housing options. After waiting for several weeks, Trevor connects with a housing case manager named Angie. Angie uses the SPDAT to collect background information from Trevor. She learns that Trevor has some work experience in construction, which he enjoyed, but that he lost his job after showing up at work under the influence of substances. She also learned that Trevor's previous roommate was a drug dealer. Following a serious verbal altercation with his roommate, Trevor was evicted from his home. Finally she also learned that Trevor was convicted of drug trafficking. During her interview with Trevor, Angie notices that Trevor has positive intentions for himself, but struggles with planning and setting realistic short-term goals. Trevor speaks about his desire to start his own construction company, buy a home, and "flip houses" to make income. He has a friend who deals drugs who he thinks may be able to loan him money to start his own business. Trevor is also adamant that he will abstain from hard drug use, despite several recent relapses. Angie looks at the FASD-Informed Tables as she considers his history: restricted job opportunities due to his criminal record, insufficient income for housing, substance use, difficulty controlling anger, difficulty planning, and vulnerability to others with criminal involvement. She realizes that as a result of his possible FASD, Trevor may have underlying brain-based reasons for his behaviours that have increased his vulnerability to substance use, his difficulty with emotional regulation, and his challenges in adaptive functioning.

With this shared understanding, Angie and Trevor collaborate to prioritize his needs and break down each of his goals into small achievable steps using the Navigational Tables. She considers that at this time, Trevor is likely to require income support to maintain his housing, and he may be more likely to succeed in a home that has some tolerance for his substance use. Once a suitable home is found, Trevor and Angie work together to find an appropriate substance use program. He tells Angie that he would prefer to be connected to a treatment program that uses harm reduction, as he wishes to abstain from hard drugs, and continue to use alcohol and marijuana.

Continued...

Afterwards, Angie pulls on Trevor's interest in construction to connect him with a construction foreman who is known to offer employment to qualified and hard-working individuals with criminal records. On the occasion where Trevor missed a rent payment because he spends his income support on substances, Angie returned to the FASD-Informed Tables for reassessment.

She and Trevor discuss his ability to manage money independently at this time and come to the agreement that Trevor have part of his income support paid directly to his landlord. By referring to the translational tables, Angie was better able to make sense of Trevor's situation through a FASD-informed lens and translate this knowledge into practice by being responsive to his needs throughout the housing process.

How Tenant's Body Function May Be Affected

What I might see	Why I might be seeing this	What I might ask or do
<p>Difficulties completing written tasks or applied hands-on tasks</p> <p>Frustration when trying to do these physical tasks</p>	<p>Impaired motor skills, handwriting skills, or difficulties with copying/drawing</p> <p>Abnormalities in tone, reflexes, balance, coordination, and strength</p>	<p>Can I provide accommodations within the education and/or job setting? (e.g., a scribe; additional time to complete tasks; reduced shift length)</p> <p>Which education programs / job opportunities is the individual most likely to experience success in?</p> <p>Does the individual require additional income to pay for housing and other basic needs?</p>
<p>Inability to drive or operate machinery</p> <p>Unexpected reactions to medication</p>	<p>Impacts of brain injury and unique brain development (e.g., seizure disorder)</p>	<p>Is the individual receiving appropriate medical care?</p> <p>Does the individual require assistance with going to medical appointments or taking medication?</p> <p>Does the individual require support around taking public transit? (e.g., planning public transit to new places; in need of transit passes)</p>

How Tenant’s Thinking May Be Affected

What I might see	Why I might be seeing this	What I might ask or do
<p>Saying one thing but doing another</p> <p>Not following instructions</p> <p>Expressing frustration with paperwork</p> <p>Becoming easily angered when asked to explain themselves</p>	<p>Impaired communication skills:</p> <ul style="list-style-type: none"> • Lacks in expressive or receptive language skills • Difficulties with increasing abstract language and/or higher-level language skills (e.g., comprehension) <p>Cultural or language differences impacting verbal and/or non-verbal communication</p> <p>Hearing and/or visual impairment</p>	<p>Is there a communication barrier? Learn the individual’s language pattern and present information strategically. Verify the individual’s understanding by asking them to explain what was said in their own words. Encourage them to ask for clarification</p> <p>How can I help the individual understand wordy applications and contracts? Use simple step-by-step instructions and short, concrete sentences and examples</p> <p>Could I help the individual understand by using visuals?</p> <p>Is English the individual’s first language? Would the individual prefer to have a translator?</p> <p>What is the individual’s cultural background? Would the individual prefer to have a cultural broker present? Do not interpret a lack of eye contact as a lack of motivation</p> <p>Does the individual have adequate hearing and vision?</p>

What I might see	Why I might be seeing this	What I might ask or do
<p>Illegible writing or frequent spelling mistakes when filling out forms</p> <p>Saying they don't understand forms or their responses don't match the question being asked (e.g., rental agreement)</p> <p>Miscounting money, difficulty sticking to their budget</p> <p>Expressing hesitancy to engage in new learning due to difficulties they experienced in school</p> <p>Difficulty remembering new information even just after it is when recently presented</p>	<p>Learning disorder with a specific impairment in:</p> <ul style="list-style-type: none"> • Reading • Writing • Mathematics <p>Underdeveloped academic skills due to disrupted school experiences or frequent absenteeism</p> <p>Difficulties with:</p> <ul style="list-style-type: none"> • Organization • Rapid thinking 	<p>Has the individual received a comprehensive psychological assessment? If so, what cognitive strengths and weaknesses does this individual have, and what accommodations were suggested? If not, is the individual interested in having an assessment? How can I assist with making the referral?</p> <p>Has the individual experienced any head trauma? If so, were they medically examined for possible brain injuries?</p> <p>Which academic strengths does the individual have? (e.g., may perform well in math even though reading is difficult)</p> <p>Can I provide accommodations within the education and/or job setting? (e.g., access to a reader; use of a calculator)</p> <p>Is the individual interested in academic upgrading or working towards a General Equivalency Diploma (GED)?</p>

What I might see	Why I might be seeing this	What I might ask or do
<p>Missing doctor appointments</p> <p>Breaching probation</p> <p>Missing doses of their medication or forgetting to refill their prescription</p> <p>Repeating mistakes, such as forgetting to grab bus tickets before leaving their apartment</p> <p>Forgetting to pay rent or utilities</p> <p>Often losing things</p> <p>Forgetting to turn off the oven or lock the door</p> <p>Able to repeat back new information but then does not act on that information</p>	<p>Memory impairment:</p> <ul style="list-style-type: none"> • Overall memory (long-term recall of information) • Working memory (temporarily holding and manipulating information to perform tasks) • Verbal memory (memory for written or spoken language) • Visual memory (memory for images and other non-verbal information) <p>Inability to transfer new memory learning into action without applied training/practice</p>	<p>How can I help this individual remember important tasks? (e.g., verbal reminders; phone reminders; carrying a notebook; setting up pre-authorized payments; consistent appointment times, locations, and providers)</p> <p>Provide support to ensure task completion, modelling appropriate actions (e.g., planning a bus route and getting bus tickets ahead of time)</p> <p>How can I use the individual’s strengths to help her remember important tasks? (e.g., visual cues for people with stronger visual memory)</p> <p>Role-play and ask the individual to demonstrate and practice new skills</p> <p>If a rule is broken, say, “I know it’s hard to remember everything we are asking you to remember. How can I help you remember that rule when you need to?”</p> <p>Communicate rules, instructions, and directions one at a time, in concrete terms. Review these regularly and repeatedly, having the individual describe them in their own words</p>

What I might see	Why I might be seeing this	What I might ask or do
<p>Only partially complete instructions (e.g., shovelled half the walk, then did not put shovel away before leaving)</p> <p>Forgetting the bus route despite having been shown twice last week</p> <p>Frequently distracted when should be working (e.g. talking to coworkers about their interest in cars when they should be mopping)</p>	<p>Attentional symptoms that may impact their ability to:</p> <ul style="list-style-type: none"> • Sustain attention • Attend to important information • Resist distractions • Learn new information 	<p>Complete tasks together when the individual is learning, until the activity has become habitual</p> <p>When is this individual best able to focus? (e.g., when sleeping well; when eating well; after exercise; when taking medication as prescribed)</p> <p>What strategies might help this individual best complete a task? (e.g., shorter learning or work sessions; prompting when distracted; environmental modifications)</p>

How Tenant's Well-Being and Life Function May Be Affected

What I might see	Why I might be seeing this	What I might ask or do
<p>Reacting with tears or yelling when confronted about problem behaviour</p> <p>Self harming behaviour (especially during high stress times)</p> <p>Yelling at landlords, neighbours, or roommates to get their point across</p> <p>Being evicted due to altercations which occur during intoxication</p> <p>Participating in reciprocal conversation is difficult - they may frequently interrupt others when speaking or do not allow them time to add their thoughts</p> <p>Discussing blowouts with or damaged relationships with siblings, parents, or friends</p>	<p>Vulnerability to stress due to brain differences (e.g., sensitive stress response system)</p> <p>Abuse and/or emotional/physical trauma, which may or may not be a direct cause of being unhoused, resulting in additional vulnerability to stress</p> <p>A mood disorder, anxiety disorder, or other disruptive disorder</p> <p>Difficulty with regulating sensory input (e.g., noise, lights, smells, tastes, and tactile sensations may be dysregulating)</p> <p>Substance use issues that exacerbate existing emotional/behavioural dysregulation, further impairing functioning</p>	<p>Is this individual easily threatened by environmental interactions? Could their reactions reflect a need for perceived self protection? How might we increase feelings of safety?</p> <p>Work with the individual to begin to identify fear provoking situations</p> <p>Are there environmental sensory modifications that can be made? (e.g., uncluttered environment; individual over group meetings; noise-cancelling headphones; black-out curtains)</p> <p>How can I work with this individual in a trauma-informed manner? (e.g., providing reassurance; establishing safety; being supportive; providing choice)</p> <p>Help the individual develop and use effective coping strategies while reducing ineffective strategies. Use positive, clear reinforcement for positive coping behaviours</p> <p>Learn to recognize signs that a individual is becoming stressed (e.g., flushed face, heavy breathing, sweaty, tense body) and intervene early (e.g., taking a break, relaxation techniques)</p> <p>Teach the individual to identify and communicate when getting upset - in either verbal or nonverbal ways</p> <p>Together, generate a non-punitive safety plan they can practice and implement when afraid or angry</p>

What I might see	Why I might be seeing this	What I might ask or do
<p>Outstanding legal issues / trouble with the law leading to arrest and/or incarceration</p> <p>History of violence in the form of defiant, aggressive, or threatening behaviour, or damage to the home</p> <p>Difficulty replacing driver's license or identification if lost</p> <p>Verbally lashing out at staff then offering apologies for their behaviour</p>	<p>Difficulties with:</p> <ul style="list-style-type: none"> • Inhibiting or stopping behaviour, especially when it is a frequently experienced response • Controlling impulses: they may act before their brain is able to process an alternative response • Thinking ahead to what might happen next • Generating new solutions to problems or challenges • Moving between two sets of ideas or two thoughts (may get stuck in a "rut") 	<p>What might be at the root of the observed behaviour? Aggression because they're overwhelmed? Scared? Impulsive? Considering the <i>function</i> of the behaviour allows us to help identify a support that may provide a meaningful alternative to that behaviour</p> <p>What coping skills does the individual have (or has the potential to learn) to help with self-control? Consider role-playing high risk situations or other applied strategies to help in the acquisition of new strategies</p> <p>How can I work together with this individual to help them effectively problem-solve? (e.g., providing simple steps; offering concrete options to choose from; designate a mentor who will help when the individual asks for advice or support)</p> <p>Establish, teach, and model structure and consistency. Plan changes in routines/transitions carefully, modelling advance planning and problem-solving strategies</p> <p>If there are outstanding criminal charges, advocate for assessment of FASD or appropriate court support prior to sentencing if a diagnosis has not been made</p>

What I might see	Why I might be seeing this	What I might ask or do
Easily drawing in predators (e.g., taken advantage of for money)	Social difficulties:	Socially, consider the individuals' developmental levels
Overly trusting of others and lacking insight around safety	<ul style="list-style-type: none"> • Struggle to maintain healthy relationships that may reflect cognitive differences, greater difficulty understanding others' perspectives, lack of predictability in their own behaviour 	Explore creative learning approaches (e.g., role-play various social situations and social skills and have the individual practice with different people)
Depending on others to make important decisions for them	<ul style="list-style-type: none"> • Social competence, including social communication skills, boundary setting, and reciprocity 	Who does the individual come into contact with? Consider the influence of both natural supports and professionals
Being in an exploitive or abuse relationship		What prosocial interests does the individual have that may increase their social circles? (e.g., sports, music, craft, cultural/spiritual activities) Help the individual find activities that are calming, fun, and accessible
Involving themselves in criminal behaviour		
Experiencing or engaging in sexual assault, domestic violence, and prostitution		
Spending little time in fulfilling prosocial activities		

What I might see	Why I might be seeing this	What I might ask or do
<p>Difficulty with meal planning/ cooking</p> <p>Difficulty maintaining employment</p> <p>Forgetting to shower or engage in other hygienic practices</p> <p>Difficulty securing sufficient income and/or inability to manage money</p> <p>Cleaning tasks around their apartment are often not completed</p> <p>Leaving children unattended or allowing them to engage in unsafe activities</p> <p>Housing instability</p>	<p>Adaptive skill deficits can occur across environments:</p> <ul style="list-style-type: none"> • School • Work • Home • Community <p>These difficulties may reflect the functional impacts of underlying cognitive and mental health challenges</p>	<p>Are there skills that the individual is interested in developing? (e.g., money management, cooking)</p> <p>Which basic needs are currently unmet? How can I most quickly help the individual meet their unmet needs?</p> <p>How can I link the individual with income support and help with the application (e.g., PDD, AISH)?</p> <p>If appropriate, consider the need for a representative payee</p> <p>What is the individual's current housing status? If unhoused, in what housing program would the individual be most likely to succeed?</p> <p>Set reasonable goals that are consistent with the individual's functional age and abilities. Use concrete, literal terms. Teach the individual how to generalize from one context to another</p>

APPENDIX III

What's Happening on the Ground?: Community Housing Programs

In order to create a harmonized and responsive person-centred framework, we needed to understand what type of housing programs existed in our communities. Specifically, due to the dearth of research conducted on FASD-specific housing or with individuals with FASD, we wanted to see if any such services were experiencing success and, if so, to what they attributed this success. Below we discuss what we found

Over the past decade, researchers have undertaken few initiatives to better understand and address the pressing housing needs of individuals with FASD. Attempts to estimate the prevalence of FASD amongst the unhoused population remain limited. Thirteen years ago, Brownstone (2005) began to explore the housing experiences and needs of individuals with FASD in her innovative research. Since that time, few have carried on that line of research. According to the demographics researchers provide in current research literature, it appears that few service providers or researchers collect FASD diagnostic information from the individuals they house. In practical contexts, few housing programs are identified as FASD-specific. In all likelihood, many individuals with FASD may be accessing services without knowing or disclosing their diagnostic status. Thus, service providers are attempting to provide the best possible services to tenants with FASD with little evidence to guide the way.

Brownstone's (2005) decade-old call for FASD-informed and -specific housing programs fits just as well in today's social context. Brownstone (2005) interviewed nine adults with FASD, and six parents of individuals with FASD, who represented 14 individuals with FASD. Via interview, Brownstone explored the characteristics of individuals with FASD in relation to their housing needs. All 14 individuals reported having been relatively unhoused, and 13 reported having been absolutely unhoused. Those who are relatively unhoused may couch surf or reside in temporary or substandard shelter, and those who are absolutely unhoused live on the streets and may access shelter services (Chan, D'Addario, & Sherell, 2005). At the time of the interviews, Brownstone (2005) found that only three participants had maintained their residence over the previous month and had no plans to move for at least one month. Parents of individuals with FASD expressed concern regarding their children's quality of life and housing, and a general misunderstanding of their children's diagnoses. "We need a place where 'FASD' belongs... without it, our children will never get the help they need." (Brownstone, 2005).

Brownstone (2005) identified a list of housing programs that may have been serving individuals with FASD at the time the report was published. She noted that two FASD-specific housing programs during that time were reportedly unable to continue running past their initial implementation periods due to funding gaps and limited resources (Brownstone, 2005). In 2018, several of the programs Brownstone mentioned have been closed. That several of the programs identified by Brownstone closed in the ensuing years without sufficient publicly available detail about their successes and challenges, means we are left with little empirical data from which to make decisions. Going forward, administrators would benefit from a housing framework with embedded data-collection mechanisms that would provide evidence to support and inform housing decisions and policy. Evaluations may provide clarity regarding the feasibility of implementing and preserving programs for this population, the ever-evolving needs of and impacts on the residents they serve and the outcomes for the community as a whole. Community experts will benefit from one another when they are able to share the successes and challenges associated with housing services for individuals with FASD.

Through the program descriptions that follow, we hope to highlight the need for ongoing program evaluation in order to better understand the connection between unique elements of service and housing outcomes, particularly as they apply to individuals with FASD. From a responsive evaluation framework, service providers may examine tenants' needs, the programmatic actions taken to meet those needs, and the extent to which program and stakeholder goals are met. To provide a current state of housing programs that may be available to adults with FASD, we have compiled a list of relevant housing providers across Canada, with a particular focus on Alberta (AB).

FASD-Specific Housing Initiatives

Hope Terrace, Bissel Centre, Edmonton, AB [in partnership with Homeward Trust, AB]

Who: Adults with suspected or diagnosed FASD who are experiencing housing instability

When: January 2016 to present

What: A congregate, permanent supportive housing program.

Goals: Provide long-term, individual-based housing to individuals with FASD. Foster “self-reliance;” a concept which is individual-based and allows for a lifetime of care.

How: Tenants referred by community members; no housing readiness required prior to housing; 24/7 staff supports available. Relationship-based harm reduction approach to working with tenants. Staff provide tenants with harm reduction supplies including new needles and pipes; drug and alcohol use is allowed in tenants’ units but is prohibited in common areas. The building has a cultural room onsite for smudging. Service providers include sexual health nurses who provide monthly visits and a part-time occupational and a full-time addictions therapist onsite. In case of incarceration, tenants’ apartments are held for at least three months, depending on length of custody.

Outcomes: According to their formal program evaluation, participation in Hope Terrace housing was positively related to residents’ housing stability, with 85% remaining permanently housed “[a]t any given reporting period...” Hope Terrace tenants’ SPDAT scores in the domains of self-care and daily living skills, personal administration, and money management improved since program entry, indicating enhanced housing maintenance skills. Approximately half of tenants housed in 2016 have since remained housed at Hope Terrace. Eviction is only caused by excessive violence. The most attended programs offered by Hope Terrace included group cooking classes, the sensory room, peer support and training sessions, cultural activities, and weekly outings.

*Mackenzie Housing Project, Mackenzie Region, AB***Who:** Six residents with FASD**When:** May 2016 to present**What:** Pilot project to improve the long-term housing stability of individuals with FASD**Goals:** Improve the mental health status, quality of life, and employment or volunteer activities of residents and decrease incarceration rates for residents.**How:** Staff available onsite 24/7 to provide security, daily programming, and volunteer opportunities. The program staff hoped that by engaging in these programs, residents would develop life skills and explore their areas of strength.*Captains Place [funded by the North Eastern Alberta Fetal Alcohol Network, in partnership with Centre of Hope], Fort McMurray, AB***Who:** Three males with diagnosed or suspected FASD who are unhoused**When:** unknown**What:** Supportive housing program**Goals:** Provide housing and mentorship to individuals with FASD**How:** A small team of onsite mentors provide guidance with daily activities, mental health assessments, and transportation to appointments. Program staff aim to help residents progress towards independent living within 12 months of initial enrollment, although staff recognize that individual needs may dictate longer periods of participation. Little information was available regarding the intake process, attainment of housing, and the residents' demographics for either Centre of Hope or Captain's Place programs at the time of this report.

Centre of Hope, Fort McMurray, AB

Who: Individuals without houses in the Fort McMurray municipality

When: 2005 to present

What: Daytime drop-in center

Goals: Assist individuals to increase their self-sufficiency

How: Intake services, outreach services, and housing programs are available at the drop-in center. A breakfast program provides morning meals and an afternoon snack is available to tenants. Centre of Hope provides a mailing address so that tenants may receive mail at the center. The drop-in center offers showers, computer access, clothing, and personal hygiene items. Two outreach programs offer access to water, snacks, and feminine hygiene items to women and those who do not access any shelter programs. Little information was available regarding the intake process, attainment of housing, and the residents' demographics for either Centre of Hope's programs at the time of this report.

Dun Kenji Ku—The People's Place, [operated by Options for Independence], Whitehorse, YT

Who: Adults with FASD

When: 1999 to present

What: Supportive congregate-site housing program

Goals: Provide more than the provision of shelter by focusing on tenants' safety, quality of life, and networks of support.

How: Staff supports available 24/7. Onsite services include cooking, cleaning, and maintenance assistance. One meal provided each day. Tenants maintain their relationships with existing community supports while residing at Dun Kenji Ku. The Options for Independence program offers residents choice regarding the amount and types of services they receive and, aside from safety and housing responsibilities, residents are under no requirement to interact with program staff. Case management is tailored to the individual's needs, and can include assistance with daily living skills, links to community services, and opportunities for socialization.

*Blood Ties' Landlords Working to End Homelessness (LWEH) program,
Whitehorse, YT*

Who: Local landlords and adults with FASD who are unhoused or at risk of becoming unhoused

When: 2014 to present

What: Housing program operated through Blood Ties Four Directions Centre Society and in partnership with the Fetal Alcohol Spectrum Society Yukon (FASSY).

Goals: Support residents' independent living by fostering relationships and focusing on conflict resolution between landlords and tenants affected by FASD.

How: The program staff sign the lease with the landlord and are responsible for rent payment and unit maintenance. The tenants then sublet the unit. Staff liaise with landlords and tenants to foster a supportive and secure connection between them.

Neighbourlink, Hinton, AB

**Although not a housing program, Neighbourlink provides secondary housing supports that can help residents feel a sense of pride in their living space and a greater sense of being at home.

Who: Individuals experiencing poverty or unemployment while living independently.

When: 2000 to present

What: A volunteer-run furniture and appliance donation and delivery center

Goals: Support independent living and a foster a sense of home in recipients

How: Local residents and businesses donate gently used fridges, washing machines, mattresses, and other appliances or furniture, and volunteers pick up and deliver the donated items.

Non-FASD-Specific Housing Initiatives

Due to the limited number of FASD-specific housing programs, individuals with FASD who experience housing instability are also likely to access general community housing services. For the majority of these programs, very little information regarding evaluation, outcomes and, in some cases, program descriptions are available. Most housing programs aim to support single adults who are experiencing housing instability by providing referrals to community services and support with addiction and mental health needs.

In sum, there are many provincial programs geared towards meeting the needs of unhoused individuals in various ways. Little publicly accessible information exists regarding the effectiveness of these programs and their accompanying philosophies in meeting the needs of individuals who are chronically unhoused in Alberta. Little consensus exists, not only in the community but also in the empirical literature, regarding the long-term impacts of housing programs for individuals with severe mental illness. Further program evaluation is needed to determine how we are meeting the basic, psychological, and self-fulfillment needs (including housing outcomes) of individuals with mental illnesses such as FASD.

APPENDIX IV

Comprehensive Housing Literature Review

As one of the starting points of this project, we immersed ourselves in current research to better understand the evidence behind housing programs, and for whom the housing programs were best suited. In particular, we were searching for research on the success of housing programs for individuals with FASD. The focus of our literature review was on permanent supportive housing programs for individuals with mental illness, substance use problems, and who are unhoused, and the connections to housing tenure. In this document, we explore our approach to the literature review, approaches to housing, including Housing First and its variants, and housing participant characteristics and their connection to housing outcomes.

Before introducing the findings, it is important to touch upon non-permanent outreach, shelter, and transitional housing programs that were not the focus of this review. Interested readers may access a more comprehensive overview of these programs by reading Dolan et al., 2012.

Non-Permanent Housing Programs

Although our focus for this review was on permanent supportive housing programs and housing tenure outcomes, we recognize that a continuum of housing options is required to meet the needs of individuals who are unhoused. Outreach, emergency, and transitional programs are briefly discussed in turn before the introduction of our empirical literature review findings.

Outreach. Although there has been a movement to avoid the use of transitional or outreach housing programming and to move to the immediate provision of housing to individuals who are unhoused, Lettner, Doan, and Miettinen (2016) argue that outreach programs are still needed. They discuss how many of the published empirical studies of housing programs likely exclude individuals who never access social services, or who are not easily engaged by housing program staff. Their study examined the outcomes following the provision of Multi-Disciplinary Outreach Team (M-DOT) street-level services. Many of the participants were hospitalized in the service process, a factor that the researchers connect to participants' subsequent attainment of housing. At the end of the study, Lettner and colleagues found that 60% of the M-DOT participants were staying indoors. Although not a focus of our review, articles like this suggest the need for outreach programs to access some of our most vulnerable citizens, some of whom may need access to emergency services or transitional programs into more independent living.

Emergency Housing and Services. Dolan and colleagues (2012) identify shelters, drop-in centres, and other crisis services under emergency housing. Hospitals might also be classified as an emergency service accessed before an individual can connect with outreach or other service providers to enter into the housing process. As emergency services were not a focus of this review, we can only comment that emergency services may be an important part of the housing continuum for some individuals who may not have made connections with housing support workers, or who may benefit from a gradual transition into housing.

Transitional Programs. Transitional programs are another housing option for individuals who are unhoused (Dolan et al., 2012). From their review, Dolan and colleagues suggested that transitional programs, in which tenants progress through increasingly independent living options, can be detrimental to the tenant. By moving tenants into increasingly independent residences as they demonstrate improved functioning, housing staff can prematurely or incorrectly assume that the individual has internalized the living skills and moved past the classic symptoms of FASD that, historically, has impeded their functioning, including obtaining and/or maintaining tenancy. For those who have experienced long-term trauma, periods of being unhoused, substance abuse, disrupted support networks, and mental illness, it is likely that long-term supports will need to be in place to prevent the individual from cycling through the revolving doors of service (Kushel, Hahn, Evans, Bangsberg, & Ross, 2005). For many, the expectation of rapid independence result in disaster or crisis, prompting their re-engagement of supports. While there may be some for whom this type of programming would be successful, we do not know much about transitional programming for individuals with FASD. Through their literature review, Dolan and colleagues (2012) conclude that transitional programming has a place in the continuum of housing for certain sub-groups of individuals.

Methods

We began our review of the literature by searching terms using the following search limiters in the PsycInfo, ProQuest, and Web of Science databases: “disorder*” OR “mental illness*” OR “intellectual disabilit*” OR “special needs” OR “cognitive disabilit*” OR “developmental disabilit*” AND “housing” OR “shelter” OR “group home” OR “homeless*.” Our search was limited to human studies that were published in peer-reviewed journals from “housing” OR “shelter” OR “group home” OR “homeless*.” Our search was limited to human studies that were published in peer-reviewed journals from

2007 to 2017. We included both qualitative and quantitative experimental, observational, and case studies.

Due to the sheer number of articles associated with our search terms, we made a decision to focus solely on permanent housing intervention and outcomes related to housing tenure for adults with mental illness and/or intellectual disability. This meant that transitional programs or intervention related to substance use, employment, etc. were excluded unless explicitly connected with the housing program and related to housing tenure outcomes. Some researchers have separated the terms permanent supportive and permanent supported housing models. Kirsh and colleagues (2011) define supported housing as a strengths-based approach that allows tenants much choice in their housing pursuits. Housing and support services are separated, and treatment often is not required in order to maintain housing tenure. Under this model of housing, tenants are often offered permanent residency in market rentals (i.e., scattered-site). Supportive housing, Kirsh and colleagues declare, is different from supported housing in that rentals are offered on a time-limited basis with a focus on programming. Throughout the literature, the terms supported and supportive housing are often used interchangeably; thus for this review, we will settle on the term permanent supportive housing to capture both concepts.

We did not focus on outcomes other than housing (e.g., incarceration, hospital use, and cost savings) unless those variables were discussed as predictors of housing tenure. We excluded studies with housing interventions and outcomes for individuals solely with physical disabilities. From our search terms and filters, 5,771 results were produced. After reviewing the titles and abstracts of the 5,771 articles, we narrowed our list to 304 articles for further inspection. After close analysis of the abstracts and removal of duplicate articles, we had 126 articles to read in their entirety. Of those 126 articles, 77 met our inclusionary criteria. Forty nine were excluded for reasons including that they were non-peer-reviewed, involved treatment other than housing (e.g., substance use), transitional or shelter program, or had no housing outcomes.

Housing First

Tenets of Housing First (HF). The vast majority of articles we reviewed examined Housing First-based programming. According to the Pathways Housing First Fidelity Scale (Stefancic, Tsemberis, Messeri, Drake, & Goering, 2013) programs fully adhering to the HF model must meet 38 requirements in five domains, including housing choice and structure, separation of housing and services, service philosophy, service array, and program structure. Each item on this scale is rated from 1 to 4, with 4 indicating the highest level of fidelity. Alternate versions have been created for Assertive Community Treatment (ACT) and Intensive Case Management (ICM) to reflect the nature of service accordingly. Team-based case management is used in ACT for individuals identified with high needs, while ICM is a model of individual-based case management with brokered services for those identified with moderate needs. A comprehensive overview of the HF model is provided here to allow a comparison of program descriptions published in the empirical literature; descriptions which many have identified as inadequate (e.g., Benston, 2015).

According to the HF fidelity measure (Stefancic et al., 2013), organizations must demonstrate housing choice and structure. In this domain, residents must have choice in multiple aspects of their housing. Residents should be moving into their private, permanent, community integrated housing within 4–6 weeks, and they should be paying no more than 30% of their income on rent.

Organizations must also show separation of housing and services wherein there are no requirements of housing readiness other than tenants' commitment to meet with staff once per week. This means a standard tenant agreement exists with no contingencies of tenancy. Staff are committed to rehousing tenants when necessary and continue to offer offsite social and clinical services even if tenants experience eviction.

In the domain of service philosophy, organizations must show that they are offering tenants full choice of services, including the refusal of them. This means no imposition of psychiatric and substance use treatment. Staff have knowledge of, and systematically implement assertive engagement alongside harm reduction and motivational interviewing techniques free from coercion. Finally, staff encourage tenants' self-determination and independence and engage in frequent person-centred service planning spanning a wide domain of intervention foci.

Service array is also integral to HF programming. Tenants are to receive assistance to move into their units and are offered an array of ongoing support services. Ideally, tenants are able to access housing staff 24/7 by phone, and these staff connect tenants to services when appropriate. Tenants should have the option of at least monthly psychiatric services, and integrated stagewise substance use treatment according to their needs. Supported employment, social integration support, and nursing services are readily available.

The final domain of the HF model is program structure. Ideally, staff are to provide priority service to those with the highest needs. High need is signified by the presence of being unhoused, mental illness, and/or substance abuse. Staff are expected to take a team approach to service, and maintain a low tenant to staff ratio (i.e., up to 10 tenants per full-time staff). Frequent high-quality and comprehensive meetings are expected to occur. A peer-specialist is staffed, and tenants have the opportunity for program input through committees, peer advocates, or governing committees.

Program Descriptions

There are many components to the HF model. In the articles we read for this project, the comprehensiveness of program descriptions varied widely. The At Home/Chez Soi (AHCS) project was comprehensive in its description (Goering, Streiner, Adair, Aubry, Barker... Zabkiewicz, 2011), and included a cross-site calculation of fidelity to the Pathways Housing First Fidelity Scale (Macnaughton, Stefancic, Nelson, Caplan, Townley,...Goering, 2015). The average overall fidelity score across domains and sites at early and late implementation of AHCS were 3.47/4 and 3.62/4 respectively. The average range of the domains across sites at early implementation ranged was 2.88–3.90/4, and the range of later implementation was 3.39–3.94/4 (Macnaughton et al., 2015). Separation of housing and services had the highest fidelity ratings across both time points, and the lowest fidelity ratings were in the service array domain. Notably, all sites struggled with housing availability. Aside from the AHCS study, researchers were much less comprehensive in their descriptions of housing programs. Across all 77 studies of varying types including HF and treatment first, the following program components were identified.

As some researchers published multiple papers relating to the same site (e.g., qualitative and quantitative), there is overlap in these numbers:

- 50 immediate housing supports
- 46 permanent housing supports
- 38 scattered-site housing
- 25 congregate-site housing
- 2 treatment compliance required
- 6 sobriety required
- 43 no housing readiness required
- 10 offered unit choice; choice of location (3); choice of all services (3); some unspecified choice (12)
- 4 assisted with move in/out
- 5 harm reduction philosophy
- 13 recovery-oriented culture
- 7 required income paid directly as rent
- 7 required one staff visit per week
- 6 legal rights to tenancy
- 6 24/hr onsite supports
- 22 treatment voluntary: offsite
- 13 treatment voluntary: onsite
- 6 individualized services including cultural adaptations

- 18 up to 30% of income to rent; 11 Section 8 vouchers equivalent to up to 30% income paid as rent
- 2 provided a rent allowance of \$600

As one compares the comprehensive model outlined by the HF fidelity model to the housing descriptions provided above, one can understand why concerns have been raised regarding the vague descriptions of housing programs within the empirical literature (Benston, 2015; Dolan, et al., 2012; Leff, et al., 2009). The most regularly reported housing program components were immediate and permanent housing supports in scattered-site format. Many did not require housing readiness, and subsidies were provided so that tenants paid no more than 30% of their income towards rent. Due to variability in program component reporting, and few researchers providing fidelity analysis, it is difficult to ascertain which program components are integral to program success (Kirsh, et al., 2011). This strongly suggests the need for the implementation of a consistent evaluative framework, and the widespread dissemination of results so that service providers can better understand the most effective elements of their practice and continue to evolve their service models.

As Macnaughton and colleagues' (2015) identified in their mixed-methods analysis of fidelity to the HF model across the AHCS sites, the use of fidelity measures and feedback were perceived as useful by housing staff to prevent them from drifting away from program components and facilitated the improvement of the programs' functioning. As of yet, we do not have a firm understanding of what program components are necessary and for whom (Leff et al., 2009).

Participant Characteristics

Researchers described the participants included in their housing studies according to a variety of characteristics. Across articles, the mean age of participants in housing programs was 44, and the mean percentage of males comprising the samples was 72%. Three of the articles accounted for transgendered individuals. Thus, the evidence is strong for programs' successes with middle aged men, and less so for women and especially less so for gender diverse individuals.

Across articles that listed ethnicity:

- 31 articles had an average of 53% White or Caucasian,
- 18 articles had an average of 20% Aboriginal or Indigenous,
- 27 articles had an average of 38% Black or of African Descent,
- 7 articles had an average of 11% Latino or Hispanic,
- 8 articles had an average of 11% Asian or Pacific Islander, and
- 4 articles had an average of 8% multiracial individuals.

Thus, the majority of evidence supports housing programs for individuals of European and African descent, and to a lesser extent those of Indigenous ancestry.

Participants had high levels of unemployment (mean percentage (M) = 93%), were single (M = 84%), and were chronically and/or absolutely unhoused (M = 65%). Many researchers examined housing programs' effectiveness with veterans. Individuals with schizophrenia comprised the majority mental health diagnosis in the samples (M = 49%, and sample size (n) = 27), followed by individuals with bipolar disorder (M = 25%, n = 10), major depressive or other mood disorder (M = 24%, n = 16), and post-traumatic stress disorder (14%, n = 5). In one project, 22% of the sample had a developmental disability, and traumatic brain injury was experienced by an average of 51% participants in two other studies. An average of 66% of individuals within the 35 published studies we accessed reported substance use or met criteria for substance dependence. The majority of researchers reported on participants' alcohol use; many also tracked participants' drug use. Considering this information, the evidence most strongly reflects housing programs' success with individuals who are unhoused, and have schizophrenia, bipolar, and depressive disorders, who may be veterans, and who struggle with substance use. None of the studies we read identified FASD amongst its participants. Thus, we were unable to access any empirical data that explored housing programs for individuals with FASD.

Housing Tenure

As has been mentioned in prior analyses and reviews (e.g., Benston, 2015; Dolan et al., 2012), we found that definitions of housing tenure varied throughout the publications. For instance some researchers reported housing outcomes by days housed, some by percentage of time housed, and others as percentage stably housed. Thus, comparability across studies is difficult, and the results don't lend themselves neatly to meta-analyses.

The state of the literature continues to point to the need for a consistently implemented evaluation framework that can be used by housing staff to examine both program components and the associated outcomes. Furthermore, a consistently applied evaluative framework would allow further exploration of outcomes other than housing tenure. Such a framework would allow for comparability between programs, so that we may discover what components of programming are integral to success, and also to identify processes or components of successful programs that haven't yet been identified in the empirical literature. Several reviewers of housing models, and HF in particular, identify the same inconsistencies while also providing evidence for the success of current permanent supportive housing approaches.

Housing Outcomes

Reviews of housing success. A few researchers have attempted to amalgamate the evidence based on housing model type to provide an overarching view of housing success.

The earliest review we accessed was conducted by Leff and colleagues (2009). In this review, three models were compared to non-model housing, or treatment as usual (TAU). They identify the three model types as residential care and treatment housing, residential continuum model housing, and the permanent supported housing model.

Residential care and treatment housing included room and board, cooperative apartments, or halfway house-style settings. Abstinence is required in these programs, which were described as “high-demand—high readiness housing models.”

Residential continuum model housing was also described as a “high-demand—high readiness housing model.” In this form of rule-based housing, tenants are expected to leave their residence daily to engage in productive pursuits (e.g., treatment, training, work). In this housing model, tenants’ level of recovery guides their progression through levels of housing. This model has been criticized as counterproductive and even harmful to residents, as they are destabilized and lose valuable personal relationships each time they move (Leff et al., 2009).

Finally, they identify permanent supported housing models, a concept that fits under our definition of permanent supportive housing models. In this model, housing is permanent for as long as the tenant so chooses and, for the most part, allows them more independence and flexibility in their treatment. Housing First and treatment first models fit here, in what Leff and colleagues (2009) deem as “low-demand or least restrictive environments.” Non-model housing includes shelter programs or other TAU options.

Leff and colleagues’ (2009) analysis identified permanent supportive housing as the most researched model amongst the 13,436 participants included in the research studies, followed by residential care and treatment. They found all three models were superior to TAU in predicting housing stability. The three models did not differ statistically from one another, although the effect size for permanent supportive housing was largest. Rog and colleagues (2014) also, more recently, found that the provision of housing was consistently connected to housing tenure despite the model of housing. Considering the state of the evidence at that time, Leff and colleagues (2009) advocated for more research to be conducted so that we may better understand if one size fits all and “what models work best, in what ways, and for whom” before widespread implementation of a single mode of service.

Benston (2015) similarly cautioned against the widespread implementation of permanent supportive housing, including HF-based programs, prior to a sufficient evidence base. Instead of being driven by research, she described the HF movement as socially, politically, and economically based. In her review of the most up-to-date literature of randomized control trials and quasi-experimental studies in the United States, Benston similarly found that compared to TAU, experimental housing programs with accompanying case management led to better housing outcomes. As was the case with housing program descriptions, Benston criticized the inadequacy of researchers’ descriptions of case management approaches. She also voiced several concerns with the research base including sampling and selection bias, attrition, and the design and implementation of the programs and studies.

Concerning sampling and selection, Benston identified that participants are referred to or chosen for housing programs in a variety of ways, and that this approach has the possibility of excluding individuals with the highest needs (e.g., chronically and absolutely unhoused, violent, criminal history, no connection with service centres). Furthermore, she raised concerns about inadequate explanations of study attrition. Similar to the findings from our review, Benston found that reasons for attrition included participants refusing follow-up, not wanting to continue the program, being “lost,” and/or leaving against staff advice. Some articles in our review state that violence would be cause for eviction (Stahl, Collins, Clifasefi, & Hagopian, 2016); however, very few statistics were provided by researchers regarding the number of individuals evicted for violence.

Overall, Benston (2015) voices concern over the lack of standardization in care for housing programs serving some of the most vulnerable citizens. Even where evidence is given regarding housing model fidelity, Benston raises doubts that program staff are adhering to housing model tenets, such as those of HF, given evidence of staff members’ contradictory beliefs and values (e.g., focus on sober living and treatment mandates). Overall, Benston is dissatisfied with the state of the evidence, and calls for much more quality research in order to inform housing policy and implementation.

Dolan and colleagues (2012) engaged in a comprehensive literature review of a variety of housing supports. From their substantial body of work, recommendations included consistent use of language, the provision of a variety of housing options, a movement away from shelter-based programming, cautionary usage of the HF model with populations for whom it has not been researched, and the inclusion of individuals who are unhoused in the development of housing initiatives.

Overall, Dolan and colleagues (2012) focused on the individual while also recognizing the systems-level influences on tenants’ housing outcomes. Although not implicitly stated, their recommendations suggest the need for a relational approach to housing individuals with complex needs through their suggestions for improved communication and community involvement. Their recommendations suggest the provision of a continuum of housing and hesitancy in applying a one-size-fits-all model.

In a more focused review, Woodhall-Melnick & Dunn (2016) examine HF outcomes. This review was conducted prior to the AHCS project and, thus, the researchers primarily focused on studies from the United States.

They found strong evidence for decreased experiences of being unhoused and increased housing tenure for those who participate in HF compared to those who engage in TAU. They called for additional research in order to better understand the model's effectiveness with specific subpopulations. Similar to Benston (2009), Woodhall-Melnick and Dunn (2016) cautioned against the unilateral implementation of HF due to concerns with the state of the research base. They state that although evidence supports the positive connection for a large group of people between participation in HF and time stably housed, we do not know enough about long-term outcomes or outcomes other than housing tenure. Burgeoning evidence of the effectiveness of HF in diverse Canadian communities was provided relatively recently in a large-scale HF project implemented in five provinces.

The ground-breaking AHCS study was a randomized control trial of 2140 participants, across five sites including Vancouver, Winnipeg, Toronto, Moncton, and Montreal. Two-year follow-up data is available for 84% of the participants. Collectively, it was found that 73% of those who participated in HF were in stable housing at 24 month follow-up, as compared to 43% of individuals who engaged in TAU (Adair et al., 2017). Individuals across the study were assigned to either Assertive Community Treatment (ACT) or Intensive Case Management (ICM) according to their perceived level of need.

Those identified with high needs were randomly assigned to receive ACT under HF, or TAU (n = 950). Those who were randomized to ACT spent significantly more time stably housed (71%) than those receiving TAU (29%; Aubrey, Goering, et al., 2015; Aubrey, Tsemberis, et al., 2015). Individuals with moderate needs were randomly assigned to receive ICM under HF, or TAU (n = 1198). More of those who were randomized to ICM (78%) spent half or more of their time stably housed over two years as compared to those receiving TAU (39%; Stergiopolous, Hwang, et al., 2016). Notably, 31.5% of the TAU group were never housed in comparison to only 5% of the ICM group with moderate needs. Both scattered-site and congregate-site formats were used, and some sites had further program modifications that will be discussed below. Scattered-site programs are those which assist tenants to find rental units naturally dispersed throughout the community. In the scattered-site format, the goal is to have few individuals with similar characteristics or needs clustered together in the same building. Congregate-site programs house individuals with similar characteristics or needs within the same building. In a comparison of scattered-versus congregate-site service format in Vancouver, AHCS researchers found comparable percentages of time stably housed for individuals in scattered sites (74.5%) and congregate sites (74.3%) in comparison to TAU participants (26.3%;

Somers, et al., 2017). That being said, the majority of empirical evidence lends support to the scattered-site service format. Beyond the type of housing service provided, many researchers have examined characteristics of tenants, the environments from which they come, and the supports around them as correlates of housing tenure.

Predictors of Housing Tenure

Both quantitative and qualitative methodologies are used by researchers to inform our understanding. Both methodologies were included in this review. Summaries of the quantitative and qualitative findings are presented in turn.

Factors. A variety of quantitative factors have been examined in relation to housing tenure, and housing failure. At this time we do not have a consistent picture of who does well in permanent supportive housing programs, and who struggles to maintain tenure. Several researchers have found that females do better in housing than males (e.g., Adair et al., 2016; Pearson et al., 2009); however, others have found that being female predicts housing loss (Schutt & Goldfinger, 2009), or that gender is not at all predictive of housing tenure (Clifasefi, Malone, & Collins, 2013; Iaquina, 2016; Stergiopolous et al., 2016).

Similarly, older age has been identified as a predictor of housing tenure (Adair et al., 2016; Collins, Malone, & Clifasefi, 2013; Van Straaten et al., 2017), while younger age has predicted greater probability of housing loss (Malone, 2009; Montgomery, Cusack, Szymkowiak, Fargo, & O’Toole, 2017). As with gender, researchers have also found that age is uncorrelated to housing tenure (Burt, 2012; Iaquina, 2016; Pearson et al., 2009).

Some evidence suggests that ethnicity may be a predictor of housing tenure (e.g., Adair et al., 2017; Burt, 2012; O’Connell et al., 2008; Yoon, Bruckner, & Brown, 2013), while others have failed to find a connection between ethnicity and housing tenure (Collins et al., 2013). Conflicting evidence also exists for psychiatric symptoms or disorders, involvement in the justice system, and substance use disorders (e.g., Adair et al., 2016; Adair et al., 2017; Burt, 2012; Lee, Wong, & Rothbard, 2009; O’Connell, Kaspro, & Rosenheck, 2008; Palepu, Patterson, Moniruzzaman, Frankish, & Somers, 2013). Stronger quantitative evidence exists for long periods of being unhoused as a correlate of housing failure (Adair et al., 2017; Burt, 2012; Van Straaten et al., 2017; Volk et al., 2016), although some researchers have found length of time unhoused to be a null predictor (Collins et al., 2013).

The quantitative evidence leaves us without a clear picture of individual characteristics predictive of housing tenure. Some researchers have also used qualitative methodology to explore the factors staff and tenants associate with housing tenure.

Experiences. Researchers have used narrative explorations of staff and resident experiences to begin to explore reasons for tenants' housing tenure and departure. Both tenants and staff connect many factors with housing tenure. Some researchers found that most every tenant they interviewed primarily connected their housing attainment and tenure to the absence of rules around sobriety (Collins, Clifasefi, Dana, et al., 2012). Tenants experiencing success in housing have also attributed their positive experience to their own intrinsic motivation (Gabrielian, Burns, Nanda, Hellemann, Kane, & Young, 2015). Kirsh and colleagues (2011) heard residents speak of the importance of family and long-term service provider support alongside subsidized rent as key connections to housing tenure. Tenants also spoke of the importance of guest management, or being careful about who they invite into their place, in the tenure of their housing (Macnaughton et al., 2016).

Tenants have expressed that both tangible features of housing such as privacy, laundry facilities, television, and meals, and less tangible features of housing such as feeling "at home," being independent, having a social life, and choice have contributed to their satisfaction and retention of housing (Pearson et al., 2009). Many tenants have spoken positively of HF and have said it allows them to be future-oriented (Polvere, Macnaughton, Piat, 2013). Housing staff have also identified factors of importance in relation to housing tenure. These include educating landlords about the strengths, difficulties, and illnesses their tenants may be facing (Kirsh et al., 2011).

Staff and tenants have also provided narratives about factors connected to housing failure. Nelson and colleagues (2015) found that tenants connected negative experiences in housing with substance use, hopelessness, negative social contacts, and isolation. Staff echoed the connection between lack of community integration and tenants' isolation with housing failure and stated the importance of facilitating community connections for their tenants (Kirsh et al., 2011). Iaquina (2016) identified that tenants may require assistance to work out disputes with their landlords, and typically do not do well with rigid rules and regulations. Others have also found a connection between rules and housing failure, and mentioned violence as a reason for eviction (Anucha, 2010; Collins, Clifasefi, Andrasik, et al., 2012). Tenants especially voiced concerns about violence when in residences with communal living areas (Anucha, 2010).

Finally, factors that were connected to both positive and negative housing outcomes were identified. Iaquinta (2016) found that residing in a familiar neighbourhood has its perks and downfalls for tenants, speaking to the need to evaluate tenants' unique needs. Staff's interpersonal style was another factor related to both the probability of tenant success and failure: when staff are trained well, they are able to deescalate tenant situations, when staff aren't trained well or respond in a confrontational manner, they inevitably escalate the situation and place the tenant at risk of eviction (e.g., for a violent act; Collins, Clifasefi, Andrasik, et al., 2012).

Overall, the evidence suggests that HF has greater success than TAU at keeping individuals housed. However, in the current state of knowledge, we are not in a place to know with confidence who we are serving well, and whose needs we have yet to meet. Choice, non-abstinence-based housing, and consistent and long-term supports are mentioned as key factors related to housing tenure. However, the exploration of key tenets of housing models is just beginning and much more research is needed before we know the key elements associated with tenants' housing tenure.

Variants of HF

Several researchers made variations to the HF service model, and/or provided services to unique populations of individuals. Their findings are discussed below.

Cultural Adaptation. An adaptation to the HF service model was incorporated in the Toronto arm of the AHCS study (Stergiopoulos et al., 2016). In this adaptation, ethnically and linguistically diverse service providers were trained to provide strengths-based, holistic, anti-racist and anti-oppressive services to tenants of moderate need who identified as Black African, Black Canadian/American, Black Caribbean, East Asian, Indian-Caribbean, Latin American, Middle Eastern, South Asian, or South East Asian. Tenants (n = 237) were randomized to the adapted HF program or TAU, and those who were randomized into culturally adapted HF were stably housed more of the time (75%) than those who received TAU (41%; Stergiopoulos et al., 2016).

Managed Alcohol Program. Pauly and colleagues (2016) examined the effectiveness of a managed alcohol program (MAP) in a Canadian context. The MAP was based upon HF principles and delivered in a congregate setting with tenants' mandatory participation in regularly scheduled dosing of alcohol. All participants in this program identified as Indigenous, and cultural components were woven into programming. In comparison to the matched controls, of

whom none were housed at study completion, 72% of the MAP participants were housed at one year (Pauly et al., 2016).

Tenants identified feelings of safety (safety both from people on the street and from toxic substances, and trust and respect from staff) as leading to their desire to remain in the program. Tenants also mentioned staff's assistance with guest management, and as referees when tensions arose between residents as perceived connections of their housing tenure. Finally, residents spoke of MAP as not only being a house but a home centred on their feelings of safety and the relationships made and repaired during their time there (Pauly et al., 2016).

Los Angeles' Homeless Opportunity Providing Employment (LA's HOPE).

LA's HOPE is a housing and employment program from the United States based upon HF tenets (Burt, 2012). The participants involved in this project were deemed some of the hardest to serve, as they resided in the infamous Skid Row area of LA. Many of these individuals were infrequent shelter and social service users identified with severe mental illness and substance use disorders and lengthy periods of being unhoused. Participation was contingent upon participants' expressed interest in housing and employment. Fifty percent of those who participated in LA's HOPE maintained housing at 13 months' follow-up as compared to 1% of the TAU group. These findings show that HF can work with even the hardest to serve; however, they similarly demonstrate that there are still individuals for whom HF does not lead to housing tenure.

Conclusion

Overall, we see that the evidence supporting the effectiveness of housing programs to keep tenants housed is compelling, particularly for HF. However, there is much we still do not know. Currently, 15–20% of individuals who enter into HF programming do not remain housed, and it is unclear who this group is and why this approach may not be a good fit. Are those individuals more successful in treatment first programs? Do they benefit from entering a transitional program first? Some researchers have heard tenants express how difficult the transition from being on the street to being housed can be. This transition may be particularly salient amongst the FASD population, of whom many experience difficulty with change. At this time it is unclear whether tenant characteristics are most related to program success, or if it is the program type, program support approaches, or some interaction between the three. Future research and ongoing program evaluation is needed to help us better understand how to support this as-yet-unhoused group.

APPENDIX V

What Community Experts Are Saying About Housing Individuals with FASD

During the Housing Initiatives meetings in November 2017, community experts came together to discuss the current state of housing for individuals with fetal alcohol spectrum disorder (FASD). Parents of individuals with FASD, individuals with FASD, researchers, and housing and service providers collaboratively engaged in conversation and provided notes on their thoughts about the strengths and weaknesses of current service models.

Thematic Analysis of the Housing Initiatives Meetings Data

The information provided to us at the Housing Initiatives meetings is presented thematically in four sections: Service Provision—What’s Happening?; Service Provision—What’s Needed?; Proactive Problem Solving—Thinking Ahead; and How Do We Provide These Services? Throughout this section, Housing Initiative attendees are referred to as attendees, community experts, and community partners.

Service Provision—What’s Happening? To frame the conversation, housing was explored from the starting point of the Housing First (HF) model. This provided a stepping-off point and a reference to help organize and drive the conversation around current practice. Many attendees agreed with several components of the HF model, most notably the importance of having choice. Other areas of alignment included immediacy, consistency, and permanency of supports, the provision of safe and affordable housing, and the separation of housing and services. However, some wondered “Is HF an ethical response for everyone with FASD?” Our community partners seemed to agree with the values in HF, but not necessarily “the practice principles of implementation.” They spoke of the need to balance “the philosophy of choice with the detriment of choice for some clients with FASD.”

Experts strongly believed that choice is a vital component to services but also that “assistance with choice may be needed” so as to “avoid setting someone up to fail, or compromising their present housing options.” In practice, many have observed that real choice is not often offered to tenants, and that “HF principles are not guaranteed in all programs.” For instance, although scattered-site HF has the most empirical support in relation to housing tenure, many attendees referred to congregate, often FASD-specific housing options in the community.

The reasons behind organizational decision making around the choice between congregate- and scattered-site programming were not discussed, and it is unclear whether these decisions were made based on characteristics of the population or feasibility considerations. Some suggested that wraparound care beyond that provided through HF is needed. Finally, experts “agreed that in a perfect world [housing is not] contingent on participation, sobriety, etc.,” suggesting that compliance-based programming is more prevalent than may be assumed.

Community experts identified that some practical considerations also impede the provision of services under HF principles. One attendee stated that current policies often do not suit the needs of those they were meant to assist, and another narrowed in on paperwork as a bureaucratic barrier. Concerns about funding were expressed, and it was highlighted that the money isn’t there to hire the right workers or pay for 24/7 coverage. Furthermore, attendees expressed that finding housing on less than 30% of an individual’s income is pretty tough in the current rental market, and that tenants’ funding is compliance based even through HF is not supposed to be. Finally, in relation to choice and safe housing, community experts pointed out that choice is dictated by the market, and that “slumlords are not providing the best options, but they’re willing to rent to our clients.” They are doing their best in a system that isn’t necessarily built to accommodate the type of service they’re aiming to provide.

Concerning assessment, decision making, and placement, many community partners identified that the SPDAT is the service prioritization tool most often used in Alberta to make housing decisions based upon individuals’ level of need. A general air of dissatisfaction was expressed towards this tool. Some said that the self-report data gathered through this and other measures often is inaccurate, and that the tool is not FASD-specific. Furthermore, community partners expressed concerns that the SPDAT is sometimes used inappropriately to exclude individuals from the housing process. Another barrier identified for individuals with undiagnosed FASD is the cost of and ability to obtain psychological assessments. As such, attendees believed that differentiations should not be made between individuals with suspected and diagnosed FASD when making housing decisions. This suggests that systemic issues such as the cost of service prohibit individuals from seeking services that might assist them in the housing process.

Service Provision—What’s Needed? Community experts consistently expressed the need for service adaptability and flexibility for individuals with FASD, and clearly stated that “One size cannot fit all.” They recognized

the need for “service plasticity,” and noted that although service needs to “be flexible and personalized” it must also “meet standards.” They indicated that “housing needs to be unique to the individual accessing it,” while also asking tough questions such as, “How do we keep it simple?,” and “How do you navigate client choice and appropriate care to maintain safe, stable housing for someone with FASD?” An individual with FASD offered that housing staff shouldn’t work from a place of too many rules or too much leniency, saying “I can’t follow that. It’s set up for failure.” It seems as though a balance of flexibility within limits may be the consensus.

The need for a spectrum of housing was repeatedly mentioned, and it was emphasized that “HF is only one part of a continuum of housing for people with FASD.” In their experience, attendees see that some tenants may want to stay sober, and for them congregate sites just don’t work. Others may need a “secure, locked facility.” Community experts acknowledged that this will be “a difficult conversation but that something [is] needed.” In particular, transitions between levels of care were identified as a service gap that required attention.

Attendees stressed that “housing is determined by urban models,” and that the availability of resources in addition to geographical and political factors affect services and their alignment with current housing models. Many highlighted the need for a multicultural understanding of individuals’ experiences of being unhoused and philosophies of living. This included learning about the unique housing needs of immigrants who may be experiencing trauma and culture shock. Overall, attendees called for culturally diverse staff, the need to develop relationships within rural communities and with their leaders, the acknowledgement of colonialism and its part in our understanding of individuals’ experiences of being unhoused, and the need to bring back and incorporate Indigenous knowledge into housing models.

Finally, community partners called for a move from a focus solely on the housing model to a focus on the tenant’s individual characteristics and needs. Some attendees pondered whether all components of HF were critical to its success. On the topic of choice and autonomy in relation to some tenants, one attendee expressed: “Depends, the question is would you leave a 12-year-old to fend for themselves?” Memory, money management skills, behaviour under intoxication, and the cognitive ability to make informed decisions were factors they considered when evaluating whether HF was a good fit for tenants. Understanding that it is a spectrum disorder, experts reflected that individuals with FASD will also have a spectrum of needs.

Attendees viewed it as a problem that “staff are trying to make the individual FIT the program,” and they called attention to the need for systems-level change and took it a step further to say “the system is us.”

Proactive Problem Solving—Thinking Ahead. Many community partners spoke of the hardest to serve, tenants deemed “unhousable,” and the unserved. They mentioned that the characteristics of the hardest-to-serve include a “triple threat” of addiction, mental illness, and disability. Others mentioned a criminal record of violence and drug induced psychosis, particularly with crystal meth. Some attendees had experienced guest management difficulties with tenants who are active sex trade workers, and referred to difficulties with “carnivores” taking advantage of vulnerable tenants. They emphasized the “need to be willing to take on individuals of great difficulty,” for example providing examples of an individual who hoarded fecal matter, and another who was evicted eight times with a damage bill of \$100,000. Eventually, attendees pointed out, these individuals may be labeled by landlords and some service providers as “unhousable,” indicating that we currently do not have the means to support tenants with the highest needs.

Discussion also centred on the reasons tenants leave their housing. In some cases, community experts described transitions to more independent living: termed as “successful exits.” One congregate program was discussed that aligned with HF principles in that they would only evict due to violence. Other community partners shared that tenants are constantly evicted for a variety of other reasons including addiction, noise, housekeeping considerations, police involvement, and roommate considerations.

On the topic of problem solving and tenant management, attendees wondered “Should we be moving toward provisions that could avoid the loss of housing for individuals with FASD?” The resounding answer seems to be yes. Emphasis was placed on the need for a process of resolution for tenant issues rather than a quick move to eviction. Community experts believed that we need to “support people and focus on restorative approaches,” and that “it is easier and cheaper to fix damages than it is to rehouse someone.” The thoughts were that working from a proactive stance may help to relieve some of the pressures tenants face because, “a scared brain is not a good learning brain.” They suggested reaching out to landlords to understand why tenants are being evicted, and working from there in a real and honest conversation realizing that landlords must also protect their investments.

Community experts provided creative solutions to frequent dilemmas, such as the need to liaise with landlords, rent-to-own plans, tiny houses, sober villages, “one stop shops,” and shared databases to relieve some of the pressures experienced by tenants. Many provided concrete suggestions regarding universal precautions to support tenants, specifically focused on the physical attributes of living spaces. Some of the physical changes suggested included double drywall, fob entry, second floor suites or higher, appliances that automatically shut off, no closet doors, bachelor suites, guest management services, solid wood doors, balconies, thick-paned glass, painting suites in soothing colours, and considering noise (e.g., as triggers or as soothing). Finally, attendees suggested that tenants may benefit from an advocate to help them to navigate the system that they experience as full of barriers, and as such, may want to avoid. They highlighted that there are “gaps between sectors that need bridging.”

How Do We Provide These Services? Listening was identified as an integral component to planning and services: “What we think they [tenants] want – is that aligned with what they want?” From a lived perspective we heard, “Nothing about us without us.” Without that perspective, the decisions and changes made may be “unrealistic” for tenants. There was a push for supports and service providers to ask tenants, “What’s it like being you?” For some individuals with FASD, the answer may be that “No one gets me. Always [people are] telling me what to do.” In addition to the voices of individuals with FASD, many felt that the voices of parents and landlords are missing. There was a push for us to ask what they want and expect from housing programs. One attendee reflected that “BEING HEARD—listened to—[is] so key. [I] heard this and [it] excited me there is change to come.”

Attendees wondered how we could improve collaboration, communication, and relationships, and how they were related to housing success and failure. They expressed that when “agencies don’t work collaboratively, client gets mixed or confusing messages,” and that consistent and open communication is needed: “It takes a village.” They recognized that relationship and trust building are key for tenants and that “fear comes along with accepting help.” From the lived perspective, tenants want to see that staff are “not getting up and leaving like all [the others] did.” The importance of collaboration, communication, and relationships was emphasized at multiple levels: between staff, tenants and families, agency staff, staff and landlords, within communities, and between sectors.

Another focus was on work culture, training, and capacity. Attendees shared that housing services “must be a team approach.” Many pointed to the need for a shift in practices, and said that housing personnel must “learn not to take it

personally – it’s not about [them],” and that tenants “don’t live at [their] work. [They] work in [tenants’] homes.” From a lived perspective, tenants wanted “no judgement. We don’t want a pity party. We want heart work. We want to see your intention.” Many expressed the need for a “fail forward” work culture, saying “If [staff] can’t fail forward, how can [they] encourage it?” They conceived that part of this shift would be promoted through training, which would allow for “consistency of responses from staff.” They wanted “training that is action-based: How do we do this work?” How training is delivered will be important; for instance, one attendee said “The explanation of the roads, paths, and weather conditions in the FASD brain map was the clearest and most relatable I have ever heard.” We need to understand what’s needed for staff in order to “keep them around” and prevent them from becoming “burned out.”

There was a resounding call for shared language and understanding. An attendee stated that “a common language regarding homelessness and FASD is a key component in ensuring consistency in service delivery across the continuum of service,” and “amongst all the systems.” For instance, definitions (e.g., homelessness) can vary depending on cohort or culture. An overabundance of acronyms was identified, and it was clear that intentional use of language is important as tenants “would rather look bad than stupid, and sometimes will not ask for clarification” when needed. Finally, the word client was acknowledged as problematic: “We are not clients! Clients are not here!”

Many wondered how natural supports could be better engaged: “non-professional, unpaid people identified by the client.” This may include both family and community members. For instance, some shared that it can be helpful to identify a “go-to taxi driver” or organize events at community centres to bring people in. In one community, it was shared that there is a “community walker” who is asked to look for missing people, such as tenants with FASD who may have been missing from their residence for several days. Finally, attendees wanted to know more about training and paying tenants’ as another avenue for support.

Debate centred on the definition of meaningful housing outcomes for individuals with FASD as attendees asked “How are we defining success in housing? Is this the same for our funders, our clients?” They advocated for the need to “shake up the system. Meaning, who is evaluating the programs that are in place and already funded? I mean ones that don’t work... cause all I hear is there’s not enough money, but are we really using money efficiently?” In contrast, we also heard that “The need for funders and government to determine

accountability seems to be a barrier in the delivery of service... There is a need to re-examine funding models and come up with radical adjustments to the way success in services delivered is measured. In other words, reducing the need for data and emphasizing direct client care.” How do we best evaluate the process and the outcomes, and what are meaningful outcomes—what is housing success? For some, ideas of success included: getting up in the morning, a successful romantic relationship, getting groceries on their own, and keeping the house clean.

In the final theme identified in our review, attendees discussed the difference between a house and a home. Perhaps related to both language and outcomes, they pondered, “Is that our job—to make a house a home? Is it our job to make it possible to understand what a home is? Home is an abstract process—[what if tenants] haven’t experienced it? How to [help them] make it?” Some stressed that tenants may have “no sense of belonging or they may not feel that they are part of the community.” They wondered how to “humanize the system,” and make an “emotional connection [with tenants] to show them they belong and have a place.” At the end of the day, attendees expressed the need to “treat the home as theirs,” “my home as mine; respect.”

Conclusion

Similar to what the current research evidence tells us, community experts see that some elements of current housing initiatives are working for tenants, while much is left unknown. Community experts desire consistency in service alongside flexibility in a continuum of housing, and they call for evaluation that focuses on much more than housing tenure. Repeatedly, our community partners spoke of the need for person-centred service that appropriately meets the needs of tenants with FASD. All too frequently, they spoke of tenants’ needs not being met. For some, this was due to the individuals’ high level of needs, for others, this was because housing staff were trying to make the individual fit the program rather than providing long-term responsive service to match tenants’ needs. That being said, many attendees had experienced housing successes and were happy to come together to communicate about all of the good work being done.

The conversations that happened at the Housing Initiatives meetings were sometimes difficult, as people from different systems (e.g., housing, FASD, parents, individuals with FASD) and with different perspectives came together with a common goal in mind. Attendees expressed a readiness for action through sentiments such as “It will take time and hard work, but it is possible.” Overall, everyone seemed hopeful about possibilities while acknowledging that “the problem is complex, but there is a will to change things.”



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