CHALLENGE BRIEF:

HOUSING THROUGH
AN AUTISM LENS

October 1st, 2021

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NATIONAL HOUSING STRATEGY

CMHC SCHL

Sinneave FAMILY FOUNDATION

Purpose of this document and acknowledgements

This document captures the patterns and insights of housing through an autism lens. It describes why we gathered participants and partners from the autistic housing system in this Solutions Lab and what we did to explore the legislative, programmatic, and lived experience of autistic adults in housing.

We hope that you can use this document to inform your work in bettering housing for autistic adults and/or adults with intellectual and developmental disabilities. We intend to present the challenge of securing safe, suitable, and supportive housing for autistic adults and spark your curiosity into how we can develop solutions.

We would also like to extend a sincere thank you to all the partners, participants and, in particular, the autistic advisors as well as the many people who contributed their stories. Without them, this project would not be possible. To learn more about the project team, please see our website.

This project received generous funding from the Canada Mortgage and Housing Corporation (CMHC)'s National Housing Strategy (NHS) under the NHS Solutions Labs, however, the views expressed are the personal views of the authors and CMHC accepts no responsibility for them. It is important to note that the results, information, and understanding of the experiences of autistic adults and housing could be broadly applicable to any person with intellectual and developmental disabilities looking for suitable and sustainable housing.

The opportunity

Canada Mortgage and Housing Corporation's (CMHC) National Housing Strategy. (NHS) envisions that by 2030 everyone in Canada will have a home that they can afford and that meets their needs. The National Housing Strategy includes a focus on new affordable housing units for people with developmental disabilities; however, housing solutions for individuals with developmental disabilities are not focused on autistic adults.

Housing through an Autism Lens (HAL) is a collaborative project that aims to address the difficulties many autistic adults face in finding and keeping the homes they want and need, especially as young adults and seniors. HAL is a **Solutions Lab** funded by the NHS and is an Ottawa-focused case study with nationally applicable results.

What is a Solutions Lab?

A Solutions Lab enables diverse groups of people to come together to develop solutions to challenges that no one person or group could solve alone. It is a collaborative multi-step process to advance challenges that are typically complex and systemic and need to be informed by the stories of the people in the system itself.

HAL is carried out by The Lansdowne Consulting Group / CTLabs, whose expertise is in the design and delivery of Solutions Labs.

Why are we here?

Autistic adults[1] face a housing crisis in many provinces, and population-based trends increasingly describe them as at-risk for food and shelter insecurity and homelessness. They, and their families, face two housing crisis "cliffs": 1) at the transition into adulthood (age 18–30 years) there is a lack of access to affordable housing (Ottawa's social housing waitlist has 13,000 people and is 7–10 years long) and 2) at the transition into seniorhood (50–55 years) when they need to sustain their housing once their original primary caregivers become too old to provide care, pass away, or when a broader circle of support is lacking.

Falling off either of these cliffs results in a precarious slide into a housing crisis. This issue is largely invisible, as individual family units continually cobble together makeshift, one-off stopgap solutions. There are too many stories in Ontario and elsewhere of autistic adults being put in long-term psychiatric or health care facilities and shelters, ending up homeless, or in the criminal justice system unnecessarily[2]. Continuing a model that is primarily crisis-driven is far more costly to our health care and social welfare systems than focusing on prevention and appropriate upstream housing solutions.

Explanation/Impact

In Canada, 1 in 66 persons is diagnosed with autism[3], denoting a significant population who experience, or will experience, barriers to securing stable and suitable housing. Research shows that most people with autism live at home well into adulthood, and often middle age, with their

1 We understand that Canadians on the Autism Spectrum have diverse opinions on language and how they wish to be referenced. We want to be respectful of everyone's unique preferences and are following the recommendations of the advocate advisors for this Solutions Lab and will use identity-first "autistic adults" in our communication.

2 National Autism Spectrum Disorder Surveillance System (NASS) report, PHAC, 2018.

3 https://www.canada.ca/en/public-health/services/publications/diseases-conditions/infographicautism-Spec¬trum-disorder-children-youth-canada-2018.html

family functioning as their fundamental source of support; are much more likely to be on social assistance; and have the poorest employment outcomes of people with disabilities[4].

There are unique housing-related risks faced by autistic adults due to heightened social and stress vulnerabilities; significantly higher than average co-existing mental illness and chronic health problems; variability across the ASD spectrum and related support needs; and specific pain points along the lifespan[5]. In addition to loneliness and isolation, autism can affect relationships and social communications. Circumstances and interactions with neighbours, roommates, landlords, etc. can be fraught and lead to conflict, and sometimes violence. Sensory sensitivities in the built environment also affect autistic adults more acutely as autistic adults have heightened sensitivity to visual, auditory, taste, and smell triggers.[6]

Finally, housing affordability also disproportionately affects the autistic adult population. Most autistic adults are living on social assistance and so are living close to poverty. Because of eligibility requirements, government-funded Developmental Services may not explicitly support individuals with ASD, where approximately only 38% of autistics qualify for government-funded support through developmental services[7]. Evidently, the majority of autistic adults struggle to find a quality home, contributing to inadequate support and unsuitable living environments that lead to more intensive—and costlier—downstream support.

Adults living with ASD also have the poorest employment outcomes of those with disabilities. Only 25% are employed and only 6% are competitively employed. Most earn less than the national minimum hourly wage, endure extended periods of joblessness and frequently shuffle between positions, further diminishing their housing prospects.

The "Double Cliff" of Housing Vulnerability

While a housing crisis can occur at any time over a lifetime, there are two particular points of housing pressure for autistic adults, one as they transition into early adulthood and the second in seniorhood. We refer to this as the "**Double Cliff**". (Figure 1).

Early adulthood: In early adulthood, autistic adults are striving to live independently and find the support they need. Living independently sometimes works and sometimes it does not. The most suitable options may not be readily available, other options may not be successful, or the adult experiences a change in physical or mental health, and so they might return home—or they can't or don't leave home at all.

Seniorhood: Later in life, the parents or family members may be no longer able to provide care, and/or they pass away. The autistic adult may face a second housing crisis (or a first if they didn't move out at all). This point is often an emergency resulting in autistic adults being moved out of their communities into the first available housing option which may or may not be suitable.

4 Weiss, Lunsky and Lowe, Psynopsis Magazine, Mar 2020

5 University of Calgary Public Policy School brief, June 2016; Sinneave Family Foundation brief on Supported Independent Living, 2019; Autism Ontario pre-budget submission, February 2020. Canadian ASD Alliance (CASDA) National ASD Strategy blueprint

6 Weiss, Lunsky and Lowe, Psynopsis Magazine, Mar 2020

7 University of Calgary Public Policy School brief, June 2016; Sinneave Family Foundation brief on Supported Independent Living, 2019; Autism Ontario pre-budget submission, February 2020. Canadian ASD Alliance (CASDA) National ASD Strategy blueprint

These two pressure points are distinct, and an autistic adult may not experience both; however, very often both these pressure points can result in a housing crisis. Consequently, we need a better understanding of what matches the needs of autistic youth and early seniors with housing needs and independent living.

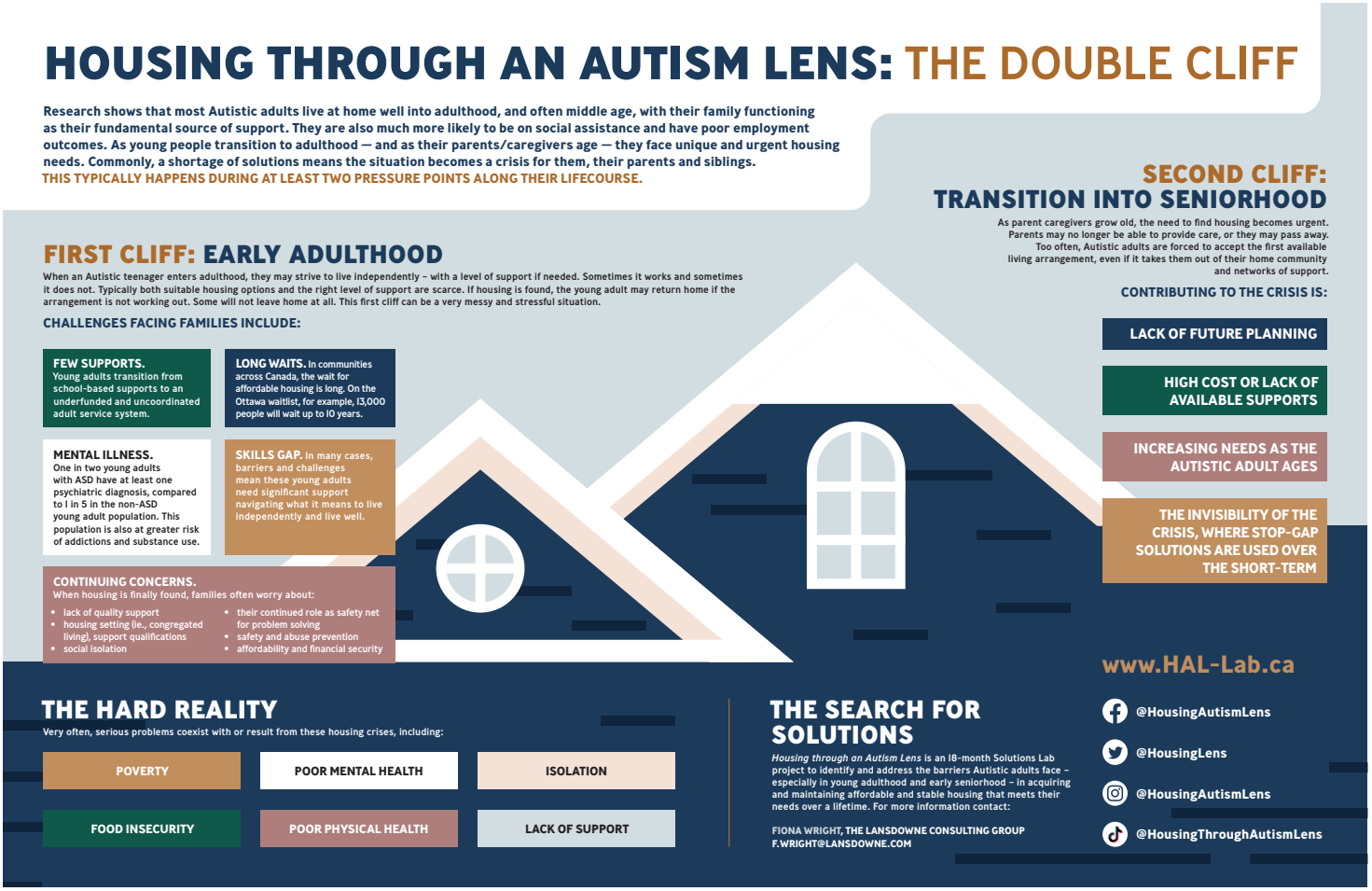


Figure 1: Double Cliff

Questions we are asking

Within this complex issue, we started HAL with many questions related to the issue of housing for autistic adults. Here are some of the issues we are thinking about:

- What is the housing experience for autistic adults?
- What are the challenges?
- Who is responsible for providing appropriate housing solutions for autistic adults?
- Who can, and will, take ownership?
- How do we ensure an autistic voice in solutions?
- What can be changed through policy alone? What about politics?
- Could government housing have requirements or incentives to report on or to include housing for autistic adults?

About the lab

Why a Solutions Lab?

For complex problems with different elements, interactions, and systems, such as housing, we need innovative ways of researching and developing solutions. Solutions Labs seek to expand our understanding of the issues and highlight new relationships and factors for consideration by bringing various participants to the table. Importantly, they use this deepened understanding to inform solutions for change and propose a way forward.

Problem Statement

There is a disconnect between understanding the diverse experiences of housing for autistic adults, what housing options are suitable and accessible, how service providers better support success, and how we might advance long-term housing solutions.

What are we trying to solve?

Using innovative and inclusive methodologies to draw out the lived stories of autistic adults and their families, we aim to make visible the unique housing challenges of this vulnerable population and identify appropriate, sustainable, and workable solutions. Our overarching problem questions are three-fold:

1. What experiences do autistic adults have of housing?
2. What factors contribute to long-term, sustainable housing for autistic adults?
3. What are the opportunities to innovate new long-term, sustainable housing solutions for autistic adults?

Benefits of solving this problem

To advance the right to housing for all Canadians:

- Include the autistic voice, representing the needs of 1/66 autistic Canadians and their families, in housing policy,
- Reduce the possibility of housing discrimination,
- Secure suitable, dignifying housing that allows autistic adults to participate meaningfully in their lives and society.

To eliminate the down-stream consequences and costs of poorly housed autistic adults:

- Facilitate autistics' meaningful contribution to the community and the labour market,
- Mitigate mental health impacts,
- Ensure better health outcomes,
- Prevent homelessness and hospitalization.

The HAL Solutions Lab is organized into five key phases of work. (Figure 2) This Challenge Brief outlines the findings of Phases 1 and 2 and is the springboard for Phase 3.



Figure 2: HAL Phase systems map

HAL: Context of Housing Affordability

We cannot talk about housing solutions for autistic adults without talking about the context of affordable housing. In Canada, housing is considered "affordable" if it costs less than 30% of a household's before-tax income. It includes housing provided by the private, public, and non-profit sectors, despite the common misconception that "affordable housing" is only rental housing that is subsidized by the government. Affordable housing includes all forms of housing tenure: rental, ownership, and co-operative ownership, as well as temporary and permanent housing[8].

8 https://www.ryerson.ca/content/dam/social-innovation/Programs/AffordableHousing(Nat%27l)-VisualMap.pdf

Figure 3 displays the affordable housing continuum and different types of housing contexts in Canada, ranging from homelessness to market homeownership. It is important to note that renters and people living in social and transitional housing, emergency shelters, and experiencing homelessness are disproportionately marginalized groups and are highly represented by young people, newcomers, racialized communities, single parents, single persons, low-income households, and people with disabilities, including autism.



Figure 3: Housing Continuum[9, 10]

The **right to housing** is the economic, social, and cultural right to adequate housing and shelter. It is recognized in Canada and the Universal Declaration of Human Rights and International Covenant on Economic, Social and Cultural Rights. Although the national, provincial, and municipal governments have declared that adequate housing is essential to one's sense of dignity, safety, inclusion, and ability to contribute to the fabric and societies, the multifaceted and multi-jurisdictional nature of the housing system is complex and at present, does not allow all Canadians the right to housing.

In Canada, there is a growth in unaffordable housing and the loss of affordable housing, resulting from the confluence of many factors at all levels of the housing system. Although we cannot encapsulate all the interconnected and interdependent issues at hand, we have summarised a handful of factors and implications at the global, national, provincial (Ontario) and municipal levels (Ottawa) relevant to HAL.

Global Affordable Housing Crisis

Countries all over the world are facing a housing crisis, with a massive shortage of homes for expanding populations that disproportionately impact people with disabilities, including autism. In a global context:

- Housing-related expenses are rising faster than salary and wage increases.
- There is a rise in migration, displacement, and homelessness.
- People are forced into overcrowded or badly maintained housing or housing that compromises their food security, healthcare needs and educational prospects[11].
- The global pandemic has affected the housing markets, employment and disproportionately affected people with disabilities, including autism.

9 ibid.

10 Note that many consider housing as a continuum to be an outdated model with the inherent sense that "success" is reaching the top of the continuum. This myth is harmful to the overall housing challenge.

11 Sinneave Family Foundation brief on Supported Independent Living, 2019

Canadian Affordable Housing Crisis

In a Canadian context, there have been cycles of housing trends, policy, and development such as the provision of rental and mortgage assistance and cash grants to home-buyers, the introduction of rent control across Canada, and housing development privatization. Over the past three decades, we have seen a shift in thinking to "*Housing as an Investment or Commodity*." There has been an increase in unaffordable housing for renters and owners, creating less housing stability observed across the country:

- In June 2021, the average selling price of a Canadian home was $688,000, a figure that has risen by more than 38 percent in the past year[12].
- The Bank of Canada's interest policy has influenced banks to dramatically reduce interest rates, allowing more people to buy and take on mortgages.
- We have observed an increase in investment property buying as assets and means of making income.
- The increase in investment properties does not translate into more ASD-friendly landlords and autistic tenants.

Ontario Affordable Housing Crisis

In Ontario, there has been a growth in home resale prices and market rents, which has significantly outpaced income growth.

Additionally, the province's housing programs that assist with rent cannot keep up with the demand for support and there is a lack of incentivisation for landlords to rent with people on social assistance.

- If someone is on OW/ ODSP assistance, there is no formal method of background checks, leaving room for stigmatization and discrimination such as landlords assuming antisocial or maladaptive behaviours and unreliability. If they do rent to someone on OW/ ODSP and the landlord-tenant relations fail, there is no formal process or resource to manage the dispute and the landlord cannot claim unpaid rent through the assistance services.

The 1997 Tenant Protection Act (TPA) reinforced "Housing as an Investment or Commodity" centred-thinking and eliminated many tenant protections. Although the TPA was repealed in 2006, the Vacancy Decontrol clause, however, was immediately re-implemented in its successor, "The Residential Tenancies Act", which is still in effect today. As a result:

- Landlords can set as high a rental starting price as they want, which can inflate the rent and cause other landlords to increase rent too.
- In Ontario, Landlords' Own Use claims have nearly doubled since 2015[13]; however, there is limited data into direct causality.
- If the housing market rises and the vacancy rate is low, there is little incentive for landlords to keep existing tenants and there has been a rise of no-fault evictions where the tenant has done nothing wrong (i.e., Own Use or "Reno-victons").

12 https://www.ryerson.ca/content/dam/social-innovation/Programs/AffordableHousing(Nat%27l)-VisualMap.pdf

13 ibid.

- A “Renoviction” is the removal of long-term tenants to perform superficial renovations which allows the landlord to drastically increase the price of a rental unit (i.e. price gouging)[14]

Inflation has caused house prices to increase and contributed to a false economy, whereby landlords are incentivised to sell or find new tenants and set new rates to keep up. For tenants who live in a unit with a stable, below-market rent, there is a perverse incentive for them to stay in unsuitable housing situations and keep their cheap rent. Often, people live in units that need upgrades or they are majorly over or under-housed, living in units with vacant bedrooms or overcrowding.

Ottawa Affordable Housing Crisis

While there have been small increases in the number of affordable rental units funded over the past five years through the city, overall, the stock of affordable rental housing has decreased. This drop is due in part to demolition and redevelopment, inflating rents, low levels of rental construction, and lost stock through short-term rentals (for example, Airbnb)[15].

Additionally, the municipal government has a direct link to housing supply and is seen as the “gatekeeper” to new developments. Bylaws around building permits, green space, density, and zoning influenced by the “Not In My Backyard” (NIMBY) sentiment of constituents also impede the City’s support and ease of new housing development. Finally, houses have infra-structure timelines, where heating systems, roods, electrics and wiring, and asbestos are outdated and need renovations. Many of the 1970’s large-scale government construction and subsidized dwellings are due for costly repairs and renovations, representing a 50-year lifecycle of community housing needs.

The housing market is one of the most complex systems people experience on a daily basis. From the entire housing system, there are multiple perspectives and players, each with their own motivations. With an inflated market and the “housing as a commodity” mentality, the 70% of Canadians who own homes are banking on housing as an investment and to support their retirements and livelihoods. Unfortunately, the current system provides wealth for some and makes housing less affordable for others.

For autistic adults and other people with disabilities, they are more likely to limited incomes and depend on affordable housing[16] and have been disproportionately affected by COVID-19. Considering the complexity of housing, it is evident that we need long-term and globally-minded housing solutions with local impact.

14 https://www.ryerson.ca/content/dam/social-innovation/Programs/AffordableHousing(Nat%27l)-VisualMap.pdf

15 https://www.endhomelessnessottawa.ca/progressreports

16 https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.htm

Understanding the experience of autistic adults and housing in HAL: a multifaceted approach

We employed three methods to better understand the experience and context of autistic housing. We completed three methods of research, elaborated below:

1. a comparative analysis of existing approaches and promising practices in housing for autistics,
2. a technical and legislative review, and
3. an innovative approach to understanding the experiences and needs of autistic adults using Sensemaking.

1. Promising practices in housing

The Promising practices review summarizes the findings of an environmental scan of local, national and global solutions in addressing suitable and sustainable long-term housing for people with disabilities including autism. The review included academic literature, and evaluations or programs and services from NGOs, governments, private companies, and other organizations. We reviewed promising practices in housing as well as promising support models and promising models of affordable housing in the context of housing for people with disabilities including autism (alternative funding and financing models).

The review resulted in eight promising housing settings, four innovative support models, and five alternative funding and financial models. The full review is found in Appendix 2 where we described each setting, provided exemplary case studies for each model, and analysed their strengths, funding approaches, measures of success, and relevance to Ottawa.

Overall, our review indicated that there is no one-size-fits all solution for alleviating housing challenges for autistic adults. The right solution is as diverse as the autistic population itself and that there are multiple models within each housing setting as each housing model can vary by the characteristic of the structure, size, and number of people in the household.

2. Technical and literature review

The technical and literature review identified and summarized legislative and associated resources that are relevant to the housing issues/needs of autistic adults. In so doing, the intent of the review was to:

- Focus on relevant legislation at the Federal (Canadian), Provincial (Ontario), and local levels (Ottawa) that impact the housing needs of those along the autism spectrum
- Consider those factors that impact on finding, maintain and retaining housing when selecting legislation of relevance
- Reflect on the housing impacts of two significant cohorts within the autism community, namely younger adults (i.e. early household formation) and older adults (i.e. those approaching senior years), aligning with the double housing cliff model.

Based on the review undertaken, there are a number of legislated protections afforded to vulnerable populations and those with disabilities, especially as it relates to housing and associated supports/assistance. Priorities are afforded to these vulnerable groups, but the definition, extent and application of these measures are inconsistent when considering autistic adults as a discrete group. In some respects, this is complicated by the broad range of capabilities and needs of autistic adults.

While legislation helps to enshrine rights and establish authorities, the implementation of policies and programs has a substantial impact on how legislation is operationalized, and in most instances can be more impactful in the lives of individuals than the legislation. Likewise, the support and accommodation provided through programs and initiatives are highly dependent on an individual's needs. The full literature review and findings are included in Appendix 3.

3. Sensemaking

"SenseMaking" is the process by which people give meaning to their collective experiences. It is a narrative research process that gathers and interprets first-hand stories from across a system and involves people with lived experience and engagement within the system to interpret the data.

We engaged with autistic adults, families, care providers, and professionals to gather their perspectives of autistic housing through the Sensor and facilitated four Sensemaking workshops to interpret the data. Because of COVID-19, all workshops were held online, and stories were collected across Canada, but solutions will be focused on Ottawa. Sensemaking comprised the bulk of the discovery and innovation work within our Solutions lab.

The Sensor

The questionnaire used to collect the micro-stories and the context around those stories was called a Sensor. The Sensor was co-designed with participation from all parts of the communities being explored: autistic adults, family, friends and other caregivers to autistic adults, and professionals working with some part of the autistic community. The Sensor was hosted on a web-based platform—Spryng.io —where it was completed by contributors, and the resulting data was analysed and visualised. We used social media, traditional media, and other outreach efforts to invite anyone with connections to the autistic community to share micro-stories about positive or negative housing experiences.

Follow-up questions about the context of the micro-story gathered more information about what happened, and the contributor's personal interpretation of that lived experience. We asked about what needs were being met, the support provided, the decisions made, the involvement of the family, the available financial resources, and the demographic information of the autistic adult. The questions used sliding scales as opposed to ranking or dichotomous "yes" or "no" answers to capture subjectivity and nuance. The Sensor questions are included in Appendix 4.

Sensemaking workshops

In the Sensemaking approach, the community or system in question participates in the data analysis and 'makes sense' of the data instead of an external evaluator or researcher doing it. We led four Sensemaking workshops with participating stakeholders to analyse the data, identify emerging patterns and insights, and better understand Housing through an Autism Lens. The full Sensemaking findings and workshop content are included in Appendix 1.

HAL Limitations

We acknowledge that our analysis of housing through an autism lens is limited and does not represent all housing experiences for autistic adults and their families.

Although we have over 200 stories, a sample large enough to provide statistical power and insight into key themes, not all demographics were represented, and we did not succeed in collecting a significant quantity of data from people across the spectrum. This is a common complexity within all autism research. The data set is predominantly gleaned from white individuals and lacks diverse racial experiences, also representative of the lack of diversity within autism diagnosis and research in Canada. Since autistic individuals have varying ways of understanding and communicating, data collection was more challenging. Only individuals who could articulate and had access to a laptop/ computer could participate in data gathering exercises; however, they only represent a portion of the community.

Additionally, many autistic individuals, in particular older populations, are isolated and disconnected and they are difficult to involve in data collection purposes. COVID-19 exacerbated this issue of a narrow sample size. The team of scribes hired and trained to meet with people who needed help to tell their stories were not able to do their work because of lockdowns and stay-at-home orders.

Acknowledging these limitations, the HAL project and data remain of value. The HAL project and the Sensemaking process was intentionally guided by autistic advisors. They validated the analysis, workshop preparation, and delivery, and were provided space to challenge traditional neurotypical assumptions and biases throughout all phases of the project.

Key Patterns

This section highlights our understanding of the key issues, trends, and challenges that emerged from our stakeholders and participants in the lab and research methods and led to the lab's key insights.

This is not an all-encompassing diagnosis of the challenges related to housing for autistic adults; rather it is a series of insights intended to promote understanding and provoke discussion as part of the Solutions Lab. Each pattern is defined by themes that emerged during sensemaking and validated by the project advisors.

Pattern 1 – Agency and Housing Fit

Agency: The capacity of individuals to act independently and to make their own free choices.

Agency is often overlooked as a basic human need, particularly for autistics, but it is an important and a large determinant in housing for autistic adults. Our stories highlight that engaging autistic adults in determining housing options and offering varying combinations of access to independent spaces and support increases the likelihood of a satisfying housing fit.

We learned that agency has variation and autistic adults need systems that allow them to make suitable housing choices with varying levels of independence. Our data revealed that although agency and autonomy were important to autistic adults, they were seldom offered it. Being able to make choices and know that there are options to effectively help oneself reduces helplessness and correlates to better mental health, especially for young autistic adults.

In addition to housing options, our stories emphasized that with appropriate support and capacity development opportunities, more autistic adults could live independently and exercise agency in their lives. To do this required solid, individualized planning to treat people with unique needs as opposed to one-size-fits-all solutions.

Poverty and financial resources underpinned agency and the options available to autistic adults and their families. This extends to the larger discussion about the co-occurring issue related to the financial assistance provided to families and autistic adults to lead independent lives versus costs downloaded onto individual families.

Pattern 2 – Co-existing health factors correlate with negative housing experiences

Co-existing Health Factors: the simultaneous presence of two or more health conditions

There were no stories about positive housing experiences for autistic adults with co-existing health factors—there was a strong correlation between co-existing health factors and negative housing outcomes. The high count of co-existing health factors also highlights that autism exists

alongside mental and physical comorbidities. This was not unexpected, as autistics have a high prevalence of mental illness[17] across the spectrum, however, our findings suggest a direct link to housing as both an outcome and determinant.

Negative housing situations and instability compounded existing mental health issues in particular exacerbated anxiety and depression. Positive housing situations determined access to positive mental health-enhancing conditions including support, social interactions, feeling safety, protection, and calming sensory environments.

Co-existing health issues and the ability to manage these issues are connected to a lack of income and financial support to access services. Our findings also indicated that we need autism-informed mental health support to deal with specific mental health challenges that present differently than in neurotypicals, especially for autistic young adults. Lastly, support to manage co-existing health issues must be preventative and frequent as opposed to reactionary crisis-based interventions.

Pattern 3 – Income, support services, and housing stability

Income: Money received regularly, for work, from benefits or investments.

Income is immensely impactful on housing for autistic adults and highlights that securing housing for autistics is influenced by global, national, provincial, and municipal affordable housing crises. Stories consistently stated that lack of affordable housing creates unstable and unsuitable housing circumstances and decreases the housing options for autistics. Income, specifically, determined the ability to procure suitable housing and ensure housing stability and access to support services. One of the key things mentioned in nearly all the stories is the cost of support for an autistic adult to live independently.

Within most experiences, the work, and costs of providing services and support are downloaded onto families as opposed to public systems meaning that housing was dependent on individual income. Unstable income led to increased housing instability for autistic adults, exacerbating during times of transition and changing life circumstances.

Low income (as perceived by the story contributor) correlated strongly to multiple unmet basic human needs, with safety, subsistence, understanding, and protection amongst the highest.

The stories included the positive impact of autistic adults securing and maintaining employment. This not only provided increased financial stability, but also increased autonomy, self-efficacy, and opportunity for social interactions.

17 Davis TE, Hess JA, Moree BN, Fodstad JC, Dempsey T, Jenkins WS, Matson JL. Anxiety symptoms across the lifespan in people diagnosed with autistic disorder. Research in Autism Spectrum Disorders. 2011;5(1):112–118. doi: 10.1016/j.rasd.2010.02.006. [CrossRef] [Google Scholar] [Ref list]

Pattern 4 – Positive Housing Experiences are Physically, Emotionally, and Socially Safe

Safety: Being protected from physical and psychological danger, risk, or injury.

For autistic people to have positive housing experiences, safety was the top non-negotiable. The stories illustrate the intersection and interdependence between physical, emotional, and social-relational safety in securing housing for autistic adults. Safety in housing underpinned other human needs including subsistence, protection, and understanding, and determined the suitability of housing contexts.

Our stories also demonstrated that safety is connected to income and access to appropriate support. They indicated that ODSP (Ontario Disability Support Program) or OW (Ontario Works) is not enough to live off and when there is funding for housing, the afforded houses are often insufficient and unsafe and dependent on personal support and systems available to autistic adults to live independent lives. The only positive experience of housing and safety occurred for an autistic adult living within a well-off family that had access to paid and natural support.

Pattern 5 – Social Relationships Matter to Housing Outcomes

Social Relationships: Recurring connections and interactions that exist between people that are perceived by the participants to have personal meaning.

Social relationships are an often overlooked determinant of housing for autistic adults; however, the analysis highlighted the benefits of strong, supportive social relationships for autistic adults. Social relationships made autistic adults feel connected, supported, and safe. This insight challenges the stereotype that autistics lack feelings of empathy and suggests that societally, we need to de-stigmatise autism to encourage social interactions within communities and institutions.

Our stories re-conceptualised social relationships to include family, friends, neighbours, circles of support, colleagues, and pets. Positive social relationships encouraged autistic adults to live independently, helped them resolve problems, and provided mentorship to navigate challenges. Social relationships helped mitigate stressors associated with change and transition and feeling safe and understood in relationships led to reduced anxiety and depression. It was also noted that social relationships need to change over time and lifespan as family structures shift, altering the “built-in” relationships within the home (i.e., the “Double Cliff”).

Simultaneously, negative social interactions in housing settings exacerbated mental health issues and were traumatising for autistics. In many of the negative housing experiences in terms of social relationships, autistic adults experienced difficulty navigating roommates in shared accommodations that were unsuitable, where they had less agency and experienced barriers to affordable housing options.

Pattern 6 – Suitability (including sensory) is more than bricks and mortar

Suitability: The housing quality of being right or appropriate for a particular person, purpose, or situation.

Housing suitability was more than bricks and mortar for autistic adults and anyone supporting them: it was about finding the right place, at the right time, with the right support. The stories emphasize that conditions for optimal living and suitability will shift over the lifespan as family structures change, they gain independence, build relationships, and navigate peak times of transition, including the double cliff.

Suitability included aspects of housing such as privacy, built environments, social interactions with neighbours, roommates, landlords, the impact of surroundings, and environmental triggers, and connected to sensory issues. Sensory issues are of particular importance for autistic adults, especially those affected by the physical environment because internal and external senses impact one's ability to process, interact and communicate with others and feel connection and comfort in their environments.

While the autistic experience is varied and not well understood, the stories suggested that there needs to be a more individualized range of housing that fits the individual's degree of independence and capacities. Housing models should strive for options so autistics can exercise choice to find housing with mutual options that work for them and their families.

Housing suitability was determined by financial resources and access to appropriate support.

Pattern 7 – Access to Support (Paid and Natural) correlates with positive housing experiences

Support: Assistance is given to support daily living. Natural support includes the unpaid assistance given by family, friends, neighbours, or others in a personal network. Paid support includes paid assistance given by government-funded or privately hired staff.

Access to support was the most common issue amongst the stories. Effective supports help provide a safe environment for autistic adults to build skills, deepen capacity and work towards living independently. Access to support increased autonomy, helped autistics secure employment, and reduced social isolation and mental health issues. Our findings state the obvious—access to support positively correlates to housing outcomes, where the more support, the more positive the housing experience.

In our stories, support was most often downloaded onto the individual family as opposed to government or public support services. This is referred to as "natural support" and, therefore, depended on family financial and time capacity. We need to better understand how to develop policies, programs, and financial assistance models that support families and operationalise

legislation at the federal, provincial, and municipal levels. Additionally, the stories suggest promise in communities of care and peer-to-peer support models that create environments where autistics are empowered to nurture and support each other, suggesting that housing can mitigate the barriers described earlier, such as co-existing health issues, social relationships, and safety.

Insights and system reflections

Insights capture deep understanding and awareness of complex problems. They represent rigorous and systematic investigation and present new ideas into a particular issue. We have included a list of insights gleaned from the HAL sensemaking workshops, literature reviews, and findings. We hope this list inspires you and sparks your own insights about housing through an autism lens too.

Agency and making choices to fit the needs of individuals

1. Housing solutions need solid, individualized planning. Treating people as having unique needs, not one-size-fits-all solutions, ensures that effective and mutual options match with the individual's degree of independence.
2. Mental health support must be provided to autistic adults, and this support must also be provided frequently and in preventative forms as opposed to only reactionary crisis support that creates an endless cycle of crisis.
3. More attention needs to be given to teaching self-sufficiency and skill development, life coaching and making decisions as a protective factor for mental wellbeing, earlier in life and particularly within educational experiences.
4. We need a more holistic view of people with ASD starting at younger ages. Housing should also include teaching skills to be as independent as possible, so autistics are as self-reliant. This is a base to participate meaningfully in their communities, through networks of support, employment, or education. Choice making needs to evolve with age and maturity.

Sociocultural shifts

1. We need systematic efforts to destigmatise autism and debunk the notion that autistics are unempathetic people who do not need, nor have the capacity, to be in meaningful social relationships.
2. We need to conduct inclusive design to build spaces that do not make autistics feel disabled: Do they feel safe, accepted, and competent? This should be the basis for everything.
3. Social relationships are a form of support and other autistics are important supports for one another—we need to foster communities of support, particularly during times of housing transition.
4. The system needs to make housing information and support accessible to autistics so that they can better understand legal information and how to access, use, and navigate housing systems and services; this will enhance agency in decisions meaning.

Support systems and financial resources

1. Support underpins the ability for autistic adults to navigate systems, maintain social relationships, and develop independence. It is essential in any housing solution.
2. Getting support for housing is downloaded onto the individual/family. From a policy perspective, any government involvement to support Autistic adults must focus on natural support—the need to understand what natural supports are composed of to develop policies, programs, and financial assistance to sustain natural supports.
3. Within service and support systems, there is a need for ASD-specific training and capacity building, proper rules, regulations, training, vetting of employees, reduction of staff turn around, regulatory bodies, standards of care as defined by a panel of professionals and self-advocates, proper crisis respite, etc.
4. Support, social relationships, and financial stability are intersectional with suitability. In housing, the bricks and mortar of a house alone, rarely produce successful, suitable housing.... a wide range of accommodating factors are required for sustainability. It is about finding the right place, right time with the right supports, and positive social relationships.

What do you think? What are your insights?

1

2

3

4

5

6

Questions we are asking

Long-term sustainable housing is clearly a complex problem, with no obvious solutions. Our Solutions Lab; however, highlighted that all housing solutions for autistic adults must be grounded in:

1. A lifespan approach, considering what needs might change over the life course of an autistic adult.
2. An individualized approach to housing and support, that is "living, breathing" support that is portable and flexible to life changes and changes in need
3. Agency of the autistic adult, that they have a right to make their own choices for themselves. This may include supported decision making for those adults whose needs are more complex.

Given this, we have many outstanding questions related to the issue of housing for autistic adults. Here are some of the issues we are thinking about. Please add your comments as you see fit.

Questions	**Your comments**
How might we improve the system based on these key insights?	
Who is responsible for providing appropriate housing solutions to autistic adults? Who can, and will, take ownership?	
What solutions exist? What solutions are needed? Who needs to collaborate to develop and implement these solutions?	
How might we make consideration or autistic adults a social benefit for developers and social housing development projects?	
What can be changed through policy alone? What about politics?	
Could government housing have requirements or incentives to report on or to include housing for autistic adults?	

Questions	Your comments
Should affordable housing be the priority for value capture techniques, as opposed to other public benefits? How might we best determine how to extract those benefits?	
How might we capture the full life cycle benefits of affordable housing (savings in healthcare, unemployment assistance, etc.)?	

Next steps

There are many potential paths forward and we want to hear your voice. Moving forward, we will engage with our workshop participants and partners to ideating solution ideas. This will set the stage for HAL **Phase 4: Developing prototypes**. Typically, prototypes focus on creating change, addressing systemic challenges in practical ways, and bringing together groups of stakeholders that have typically worked in silos. After prototypes have been tested and refined, we will develop roadmaps to implement what worked.

What do you think is important to consider when prioritizing which ideas to prototype?

To date, the following principles have been proposed for solutions that:

- Take the system in the right direction
- Benefit / require collaboration across the system
- Are supported by autistic adults
- Are a mix of 'low hanging fruit' and more complex projects that need to happen

HAL Learning opportunities

Making Sensemaking workshops more accessible

During HAL, the team learned about how to run sensors more effectively for the autistic community. The original Sensemaking workshops were redesigned several times based on trial and feedback from the autistic advisors to ensure they were relevant, approachable, and effective. Even with stepwise interaction with our advisors, process errors were made, and solutions were found only after failure points. Future research might explore how to make the Sensemaking experience more approachable and valuable for Autistic adults so that this population would trust and invest more deeply in this process tool so that more of their stories might be collected to better understand a greater portion of the continuum of lived experience.

Ensure representation in Sensemaking workshops

To uphold Sensemaking principles and the notion of "*nothing about us without us*" it is essential to ensure representation from multiple players within the housing system, support and social services, policy and operational perspectives, autistic adults, and families and networks of autistics.

Solutions labs work within complex systems that require multiplayer solutions; therefore, future iterations must strive to increase representation and engagement.

Specific demographics

From the beginning of our Sensemaking process, after analysing the demographic data from our micro-stories, it was evident that certain experiences were missing. Our Sensemaking process omitted a robust analysis of autistic adults with more complex needs (as well as their families), non-white autistics, and adults in the "double cliff" transition. This is not uncommon for autistic research based on who is typically formally diagnosed, however, future research is needed to better understand the housing experience of autistics in other demographic minorities.

Future projects should expand the network of partners to ensure diversified networking and outreach streams and greater engagement with the Sensor. In addition to expanding their network, scribes could be hired to facilitate the collection of micro-stories from autistic adults and their families who face barriers to contributing their stories to the Sensor.

Conclusion and final remarks

HAL was designed to drive positive transformation in housing for autistic adults. It is a Solutions Lab, striving to better understand the autistic experience of housing and ideate positive solutions. It is the beginning of the conversation.

This Challenge Brief presents findings, patterns, and insights from our Sensemaking process, literature review, and environmental scans. Participants coalesced around seven key insight areas that might better help us understand the housing experience of autistic adults:

- Agency,
- Co-existing Health Factors,
- Income,
- Safety,
- Social Relationships,
- Suitability (including sensory), and
- Support (Paid and Natural).

Moving forward into ideating solutions, we hope to engage key players within the housing system and autistics and use these findings to develop strategies that are both innovative and realistic to better housing for all autistic adults and their communities.

To our stakeholders and workshop participants, thank you for your time and insight. HAL would not be possible without your ongoing support and efforts. We look forward to working through the remaining phases of HAL and disseminating our final roadmaps for change.

Glossary

Agency: the capacity of individuals to act independently and to make their own free choices.

ASD: the acronym used for “Autism Spectrum Disorder”. Often shortened to Autism.

Autism: The clinical model defines Autism, or Autism Spectrum Disorder as a lifelong neurodevelopmental disorder that affects the way a person communicates and relates to people and the world around them. It can affect body language and posture, social interactions and relationships, how a person engages with their interests, and sensory processing capacities.

Autism exists in all cultures, ethnicities, races, and gender identities.

While the Public Health Agency of Canada references the Diagnostic and Statistical Manual of Mental Disorders (DSM5) in classifying autism as a disorder, many autistic people prefer the terms, neurological "difference" or "condition," which remove the negative associations with the word, "disorder." Being autistic means that your brain may process information differently than non-autistic, or neurotypical, people.

Autism exists on a spectrum, which means that while all people on the spectrum will experience some of the differences mentioned above, the degree to which each autistic person experiences them and the amount of support they need, will vary. This is sometimes influenced by whether the person on the autism spectrum has any co-occurring health conditions. It is also influenced by the accessibility and relative safety of the environment and society autistic people inhabit; a society that we all contribute to and live in

Co-existing health factors: the simultaneous presence of two or more health conditions

DSO: the acronym used for "Developmental Services Ontario". DSO is the access point for services and programs for adults with developmental disabilities in Ontario.

ODSP: the acronym used for "Ontario Disability Support Program". ODSP is a program of the Government of Ontario that provides income and employment support to eligible Ontario residents who have disabilities.

Micro-stories: individual stories collected in the Sensemaking process.

OW: the acronym used for "Ontario Works". OW is a program of the Government of Ontario the provides both employment assistance and basic financial subsistence to people who are temporarily not connected to the labour market.

Safety: being protected from physical and psychological danger, risk, or injury.

Sensemaking: the process of making sense of or giving meaning to something, especially new developments and experiences.

Sensor: the tool used to collect micro-stories

Social Relationships: recurring connections and interactions that exist between people that are perceived by the participants to have personal meaning.

Income: money received on a regular basis, for work, from benefits or investments.

Solutions Lab: a space that enables diverse groups of people to come together to develop solutions to a problem that no one person or group could solve alone. These challenges are typically complex and systemic.

Storyteller: the person who contributed their story to the Sensor.

Suitability (including sensory): the housing quality of being right or appropriate for a particular person, purpose, or situation.

Support (Paid and Natural): Assistance given to support daily living. Natural support included the unpaid assistance given by family, friends, neighbours, or others in a personal network.

Paid support includes paid assistance given by government-funded or privately hired staff.

Appendices

Appendix 1 – Sensemaking findings and workshop content

We facilitated four Sensemaking workshops with stakeholders across the housing system for autistic adults from April–July 2021 to identify emergent themes and patterns from the set of micro-stories and Sensor data. Stakeholders ranged from autistic adults, experts, family members, and people with lived experiences of housing and autism. The 2-hour workshops were held virtually, and all content was guided and reviewed by the autistic advocates.

Workshop 1 – introducing the data

Workshop 1 introduced the micro-story data, including the Sensor responses and demographics of the micro-story contributor.

Just over one third of the stories was from autistic adults (36%), from a family or friend of an autistic adult (37%), or a professional to adults with ASD (26.9%). Over half of the autistic adults lived in shared accommodation or with family, over half were single (53%), 77% were white, 63% had below average income (perceived), 16% had average income (perceived) and 21% had above average income (perceived). Just under half of the stories were about males (48%), 39% were female, and 5% were non-binary or transgender and most of the stories described autistic adults under 40 years old (77%).

The bulk of housing experiences in our stories happen when the autistic adult moved and had other life transitions but did not have support from their parents and likely took place in early adulthood or early seniorhood, regardless of access to paid or natural support and income. Just over half of the stories were negative, 24% were mixed, and 22% were positive.

After presenting the demographic variables, we asked the participants a series of questions as follows:

Who are we curious about? (Demographic variables and questions people gravitated to)

- Mental health
- Supports
- Transitional ages
- Co-existing mental health and other issues
- LGBTQ+
- “Wholeness of a person”
- Levels and Types of support
- Sensory sensitivity

- Income
- Comorbidities
- Family involvement
- Homelessness
- Social relationships

Recognizing that complex problems are composed of components **and** the relationships between them, we asked about intersectionality and interconnectedness and what relationships people were curious about in our stories.

- Between caregivers and money/perceived socioeconomic status/employment
- Multiple variables at once
- Mental health and supported independent living
- Multivariate analysis
- Older women vs. unmet need vs. income
- Housing outcome versus contributor
- Human needs scale and the positive experiences of housing
- Income and financial resources for housing and how it changes with age
- Autonomy versus support
- Support access vs making choices
- Paid vs non-paid support
- Older women and housing options
- Age and access to support

Questions our participants had about the stories?

- How can we build mental health supports into Autism informed housing?
- Are there general trends in what a positive housing experience looks like/ who gets a positive housing experience (demographics)?
- What is emotional safety?
- Does family support have anything to do with feelings of safety and social relationships?
- What type of support and services are older adults looking for in housing?
- How do younger and older autistic adults differ in perceived level of income and housing?
- What group is most concerned about physical safety? Does this differ based on age or gender?
- How do autistics define home?
- How does cultural identity impact housing experiences for autistics?
- How to support people with changing needs? I.e. flexibility
- How to build community and reduce social isolation for someone who wants to be alone?
- What are positive social relationships and how can we sustain them?
- How do we create circles of support for autistic adults?
- What type of supports and services are young adults looking for in housing

Who is missing from our stories?

- LGBTQ+
- Non-verbal autistics

- Indigenous autistics
- Racialized minorities
- Individuals with dual diagnosis
- Individuals who have gone through the child welfare system
- Autistics in institutional living situations
- Older autistic adults (seniourhood)

Workshop 2, 3 and **4**

The following sections merge the content from the Sensemaking workshops 2,3 and 4. During workshop 2, we presented all the statistically significant differences from the Sensor data. We presented data that compared two variables and the relationship between them using graphical representations and tables. Following the Sensemaking process, we wanted to know if these differences were important and what contributed to them. We asked the participants the following questions:

- Do you notice any patterns?
- What interpretation(s) might be possible from the data and patterns you notice?
- What questions do you have based on what you are seeing?

In workshop 3, we explored the micro-stories as written by the contributors. We discussed why stories are important to capture ideas, give voice to marginalized peoples, contextualize the data, and as eloquently stated by the advocates, allow for richness and honesty. The micro-stories were categorized based on each theme and the story outcome (i.e., negative, positive, mixed). During the workshop, we asked participants to share insight into what leads to a positive experience of housing for each theme. Seven key themes emerged, included in our Challenge Brief as Key Patterns. These were defined with the participants and validated by the project advisors:

- **Safety:** being protected from physical and psychological danger, risk, or injury.
- **Co-existing health factors:** the simultaneous presence of two or more health conditions
- **Social Relationships:** recurring connections and interactions that exist between people that are perceived by the participants to have personal meaning.
- **Income:** money received regularly, for work, from benefits or investments.
- **Agency:** the capacity of individuals to act independently and to make their own free choices.
- **Support (Paid and Natural):** Assistance given to support daily living. Natural support included the unpaid assistance given by family, friends, neighbours, or others in a personal network. Paid support includes paid assistance given by government-funded or privately hired staff.
- **Suitability (including sensory):** the housing quality of being right or appropriate for a particular person, purpose, or situation.

The following sections present our Sensemaking findings. It merges the content from each workshop and includes insight from the participants, partners, and advisors. Each pattern below contains the definition, a summary, content that emerged in the workshop, as told by the participants, figures, and highlight stories from the Sensor. As such, some content is in the first person, however, the stories and comments have been redacted to remove any personal identifiers. For the original stories, the contributor consented to us to share them amongst the lab participants and publicly.

Pattern 1 – Agency and Housing Fit

Agency: The capacity of individuals to act independently and to make their own free choices.

Agency is often overlooked as a basic human need, but it is an important and a large determinant in housing for autistic adults. Our stories highlight that housing options available to autistic adults, including varying combinations of access to independent spaces and support, the greater the likelihood of a satisfying housing fit.

We learned that agency has variation and autistic adults need systems that allow them to make suitable housing choices with varying levels of independence. Our data revealed that although agency and autonomy were important to autistic adults, it is seldom achieved. Being able to make choices and know that there are options to effectively help oneself reduces helplessness and correlates to better mental health, especially for young autistic adults. In addition to housing options, our stories emphasized that with appropriate support and capacity development opportunities, more autistic adults could live independently and exercise agency in their lives. To do this required solid, individualized planning to treat people with unique needs as opposed to one-size-fits-all solutions.

Poverty and financial resources underpinned agency and the options available to autistic adults and their families. This extends to the larger discussion about the co-occurring issue about the financial assistance provided to families and autistic adults to lead independent lives versus costs downloaded onto individual families.

Sensemaking workshop content

- The current insistence on teaching compliance to social norms, rather than life skills, is setting young adults up for failure. They are not taught to have autonomy and may consent to harmful interventions. Choice-making needs to evolve with age and maturity.
- As a family member, I now see how critical a basic human need for autonomy is—and its correlation to mental health—for a young Autistic adult. “Being free” is the most important development our son cited in his recent move to independent but supported living.
- As a parent and also as a “professional,” many parents have way too much involvement and override what their adult child may want. I think it is very important that the adults have the opportunity to make their own choices, even if the family doesn’t agree. But of course, as a mother, that is hard advice to take.
- The stories highlight the need to make housing information and supports accessible to individuals on the spectrum so that they can find what they need and understand the information or how to access use, and what a service does since they are making most of their decisions meaning if an experience is positive or negative may depend on the decisions they make and the information they have and understand (sometimes information may be had but not understood and an individual will not always state if they don’t understand due to fear and anxiety).
- Community service/support connections and longer-term transition process planning are key in these stories.
- The need for solid, individualized planning. Treating people as having unique needs, not one-size-fits-all solutions.

- Positive experiences of agency involve social networks and/or options available to create a housing solution that was mutual and beneficial. The positive experiences of agency involved appropriate support, tailored to the individual. Some refer to the support to perform tasks of daily living, others to support in dealing with volatile people in negative situations, about supports being poorly implemented, and about difficulties navigating complex social situations related to housing with no or inadequate support. What this might tell us about building positive housing experiences for autistic adults is that the skills for daily living need to be taught and may need to be continually supported.
- Older autistic adults later diagnosed had negative experiences of agency—they did not have access to support and were unfamiliar with navigating systems that could support them.
- Lack of choices in housing, as well as relationships and support, contributes to anxiety and disenfranchisement.

Highlight stories

In 2008 our son moved into a condo apartment we had purchased for him. He had reached an age and stage of maturity that we felt made him ready to live independently. It was exciting times, both for him and us his parents. Was he really ready? Could he adapt? Could we adapt? With third party supports the situation, we feel has been very successful. He manages his apartment well and has learned to cook a variety of meals. He is not the most social being and so we worry a bit about loneliness, but it seems to be less of an issue with him. With third party supports once a week at his apartment, and the active support of his parents, we feel that, overall, he has a good life.

My friend lived in an apartment in a duplex. Their parents lived on one side and he lived on the other. He lived fairly independently but could get help from his parents if he needed it. He enjoyed doing many things on his own like making meals and having visits from friends. A support worker helped him maintain and keep his apartment in good shape. His parents could come over the help or visit when they wanted.

Pattern 2 – Co-existing health factors correlate with negative housing experiences

Co-existing Health Factors: the simultaneous presence of two or more health conditions

There were no stories about positive housing experiences for autistic adults with co-existing health factors—there was a strong correlation between co-existing health factors and negative housing outcomes. The high count of co-existing health factors also highlights that ASD is not a stand-alone health issue and exists alongside mental and physical comorbidities. This was not unexpected, as autistics have a high prevalence of mental illness across the spectrum, however, our findings suggest a direct link to housing as both an outcome and determinant.

Our micro-stories were broken down by health factors and compared with housing outcome. The table below demonstrates that compared to the total sample, autistics with anxiety, depression, other mental health challenges, and physical health challenges have higher percentages of negative housing outcome.

Health factor (count)	Housing outcome NEGATIVE	Housing outcome MIXED	Housing outcome POSITIVE
Anxiety (133)	**60%**	24%	16%
Depression (95)	**67%**	21%	12%
Intellectual disability (80)	**56%**	19%	25%
Other mental health challenges (67)	**71%**	21%	8%
Physical health challenges (57)	**70%**	16%	14%
None of the above (29)	45%	17%	**38%**
Don't know (11)	45%	27%	27%
Prefer not to say (1)	0%	0%	0%
Total sample (209)	**54%**	**24%**	**22%**

Negative housing situations and instability compounded existing mental health issues and exacerbated anxiety and depression. Housing determined access to positive mental health-enhancing conditions including support, social interactions, feeling safety, protection, and calming sensory environments.

Co-existing health issues and the ability to manage these issues are connected to a lack of income and financial support to access services. Our findings also indicated that we need ASD-informed mental health support to deal with specific mental health challenges that present differently than in neurotypicals, especially for autistic youth. Last, support to manage co-existing health issues must be preventative and frequent as opposed to reactionary crisis support.

Sensemaking workshop content

- Behavioural issues, lack of mental health supports, and a lack of executive functioning supports are recurring factors across many of these stories.
- Intersectionality is only beginning to be discussed in this community. Lack of services that meet the needs of minority populations would make it difficult for individuals to be seen, feel safe, be connected.
- Also, the people who decide for ODSP how much is enough to live off of should read the stories about sexual harassment and health code violation living conditions, and about people committing suicide due to being unable to access safe housing.
- For housing to be at least slightly more positive mental health support must be provided, this support must also be provided frequently and in preventative forms as opposed to only reactionary crisis support that creates an endless cycle of crisis.
- We need to advocate for more capacity in the health care system to not "diagnostically overshadow" health challenges for people with ID and ASD.

- More attention needs to be given to teaching self-sufficiency and skill development, life coaching and making decisions as a protective factor for mental wellbeing, earlier in life and particularly within educational experiences.

Highlight stories

Because of chronic illness, I am on a disability pension and have extremely low income. I cannot afford suitable housing. Where I live is not safe, it is noisy, there are ventilation, cleanliness, and plumbing issues. I have been sexually assaulted in my home twice by contractors. The constant lack of safety, the noise, the repeated bed bug infestations, and their chemical treatments have me constantly stressed out and have also triggered an auto-immune condition that has made my chronic illnesses worse. There is little or no understanding of autism and one management person actually told me it means a person is violent. I have needed help with facing Management regarding incorrect rent increases; Housing services was no help as there has been corruption involved, and there are no advocates. I need independent housing, and this is all I can afford.

At 65, my husband and I thought we would not still be actively parenting children. Our autistic son has a brilliant mind, but lots of anxiety, depression, and physical challenges. Despite searching for housing options for him, we have been unable to find any independent housing that fits his needs. His anxiety prevents him from getting a job or completing programs designed towards helping him get a job, so he survives on ODSB support combined with parental support. Once we came close to success with a housing option, but it failed as he was not allowed to bring his dog, which he needs for his anxiety. He needs support periodically for daily living chores, and a place with that available either does not exist or is too expensive. As parents, we feel that our job is to prepare our children to be independent, positive contributors to society. It feels that we will have this challenge until our death, and then what will become of our son?

Pattern 3 – Income, support services, and housing stability

Income: Money received regularly, for work, from benefits or investments.

Income is immensely impactful on housing for autistic adults. It determined the ability to procure suitable housing and ensure housing stability and access support services. One of the key things mentioned in nearly all the stories is the cost of support for an autistic adult to live independently. As shown in the table below, below-average income (as perceived by the story contributor) correlated strongly to multiple unmet basic human needs, with safety, subsistence, understanding, and protection amongst the highest, with the percentage higher than the average.

Unmet human need (count)	Perceived level of income BELOW AVERAGE	Perceived level of income AVERAGE	Perceived level of income ABOVE AVERAGE
Safety (79)	**72%**	15%	14%
Understanding (63)	61%	16%	23%
Subsistence (51)	**80%**	**2%**	18%
Freedom (49)	60%	15%	26%
Belonging (37)	61%	22%	17%
Protection (36)	**76%**	21%	**3%**
Affection (30)	**47%**	23%	**30%**
None – needs were met (30)	**38%**	15%	**46%**
Participation (30)	55%	18%	27%
Identity (15)	64%	21%	14%
Creativity (6)	**67%**	17%	17%
Transcendence (spirituality) (4)	**75%**	**25%**	**0%**
Prefer not to say (3)	33%	33%	33%
Total sample (209)	**63%**	**16%**	**21%**

Within most experiences, the costs of services and support are downloaded onto families as opposed to governments, meaning that housing was dependent on individual income. Unstable income within the family led to increased housing instability for autistic adults, exacerbating transitions and adapting to change. The stories included the positive impact of autistic adults securing and maintaining employment. This not only provided increased financial stability, but also increased autonomy, self-efficacy, and opportunity for social interactions.

Sensemaking workshop content

- One of the key things mentioned in nearly all of the stories is the cost of support for an Autistic adult to live independently and the financial burden and barrier it becomes.
- For housing experiences to become more positive, the issue of the cost of support for an individual and or their family in addition to the cost of living in safe housing needs to be dealt with.
- Autistics are overwhelmingly quantifying that our basic needs are not being met. This is systemic ableism that is keeping us from feeling safe and supported. It's a system issue that permeates all aspects of housing, ODSP, employment…
- Income and financial support allowed for autistic adults to have their own space, employment and financial support contributed to positive housing.

- Describes case for the majority of autistic and DD individuals, who live on low income and lack family/friends support, forced to live in poverty and terrible living environments.
- A positive good story of how “securing and keeping” a job can drastically change failure to secure a comfortable, secure home to a safe, secure, comfortable home.
- Underemployment, income being insufficient due to the additional expenses accompanied by having ASD and requiring executive and or sensory support, being too disabled in the eyes of the public, or not disabled enough in the eyes of the government, are all themes that can be seen in many of the stories.
- Negative health factors continue to worsen over the lifespan as people with ASD are not able to pass interviews and join the employment world. Very loyal workers but have trouble getting their foot in the door. Also, employment skills need to start at home when they are younger. Once again, the government spends all their focus on cognition and communication instead of functionality in the younger years.
- We need a more holistic view on people with ASD starting at younger ages. Housing should also include teaching skills to be as independent as possible. Self-reliant for everything they are capable of and then source out for the mentoring and social guidance and support in getting employment or at least something where they can contribute to society and have a purpose. This would also improve health factors.

Highlight stories

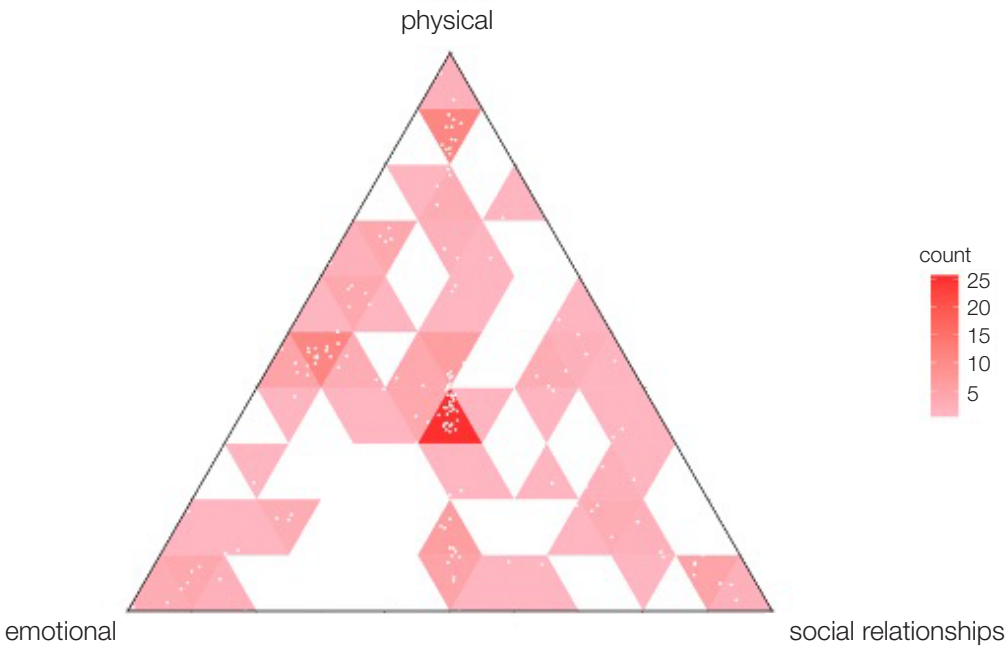
I am on ODSP and work 3 days a week minimum wage. I still cannot afford to even rent an apartment. I don’t like change and want to stay in my childhood home, but my parents are getting older and I don’t have the money. I’m afraid of what will happen when I lose my home and my family.

Due to repeated episodes of unemployment due to my undiagnosed autism (I was diagnosed in my mid-50s) I was forced to live with my parents and friends. Without my own place and my own permanent address, I felt constrained. I was the hidden homeless, not the person you’d see on the street or in a shelter, but owing to my privilege, I was conscious of being not too far from actually homelessness.

Pattern 4 - Positive Housing Experiences are Physically, Emotionally, and Socially Safe

Safety: Being protected from physical and psychological danger, risk, or injury.

For autisic people to have positive housing experiences, safety was the top non-negotiable. The stories illustrate the intersection and interdependence between physical, emotional, and social-relational safety in securing housing for autistic adults, as shown by the heat map below.



Safety in housing underpinned other human needs including subsistence, protection, and understanding, and determined the suitability of housing contexts. Our stories also demonstrated that safety is connected to income and access to appropriate support. They indicated that ODSP or OW is not enough to live off and when there is funding for housing, the houses are often insufficient and unsafe and depend on support and systems available to autistic adults to live independent lives. The only positive experience of housing and safety occurred for an autistic adult living within a well-off family that had access to paid and natural support.

Sensemaking workshop content

- I believe this has a lot to do with not seeing ASD as a neurological difference but a behavioural problem. A more compassionate approach needs to be addressed starting in the younger generations working towards making decisions, not being forced, understanding the nervous system response to sensory interactions, teaching people with ASD that people are safe to go to when they need help (instead of treating everything as a behaviour). Do they feel safe, accepted, and competent? This should be the basis for everything.
- There was only one positive experience of safety—that required financial investment to set up the systems that enabled the autistic adult to live safely in their apartment. For the stories that were able to find affordable housing, they were at risk from the public, neighbours, and support staff. Often affordable housing is in dangerous neighbourhoods. This is very bad for a population with social communication differences.

- Reading these stories made me feel ill. People in power and who control the aspects of government, laws, rules, and regulations need to read these stories so that they understand what they are doing wrong. Particularly those related to group homes, hospitals, and the service and support cliff that occurs in Ontario at the age of 18.
- There is clearly a need for proper rules, regulations, training, vetting of employees, pay raise or at least the provision of an expensive benefits package to reduce staff turnaround, regulatory bodies, standards of care as defined by a panel of professionals and self-advocates, proper crisis respite, and that's just the tip of the iceberg.

Highlight stories

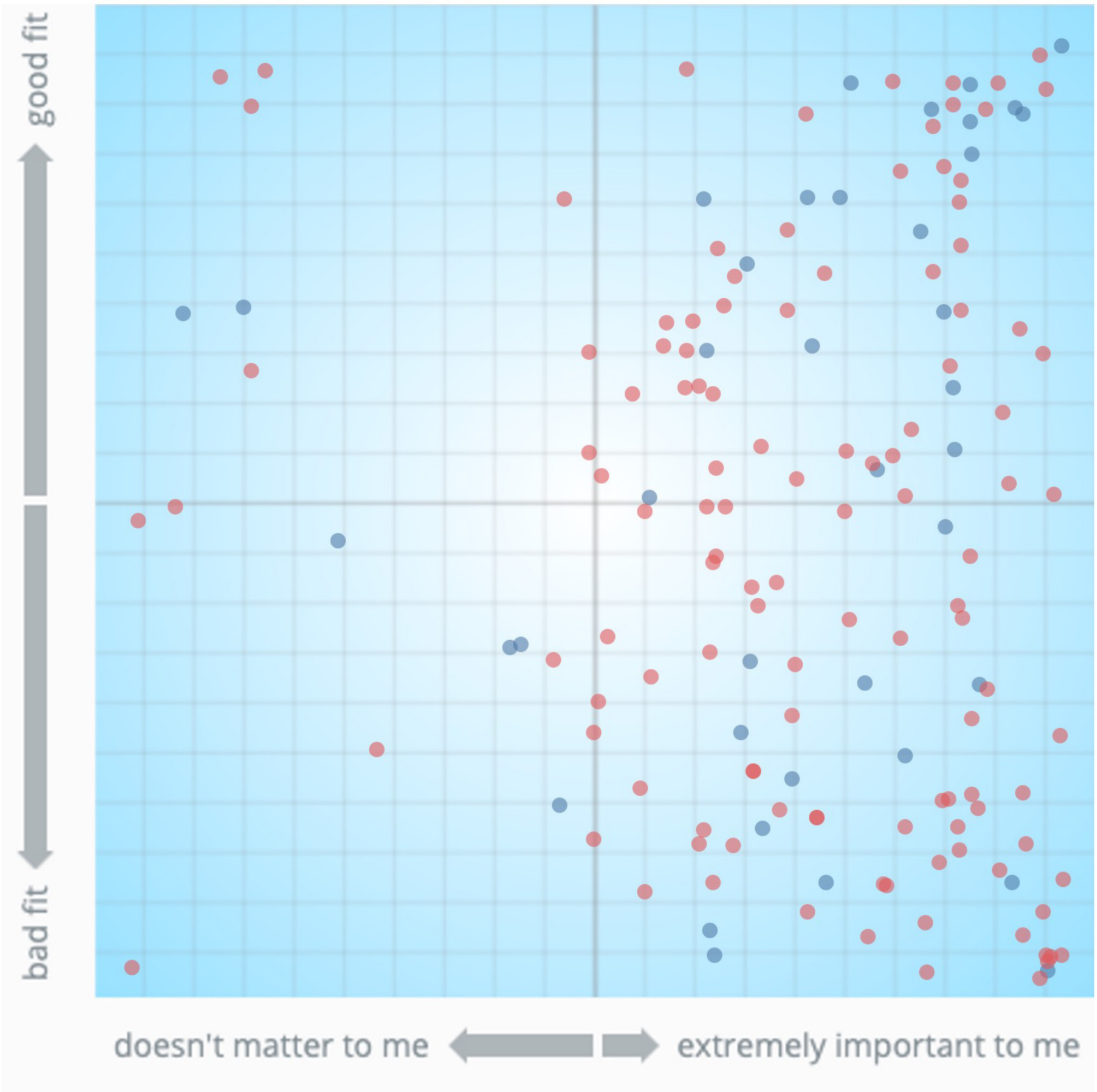
In one place I lived in, in a shared rented apartment, a man in the neighbourhood was stalking me but there was no security on the ground floor so he was able to slip in through the door. It was an ordeal to keep him from coming into the apartment and I was terrified to leave. For months I was looking over my shoulder or had to hide in nearby shops.

I have been in women's shelters twice. I have lost almost all my belongings multiple times due to having to move in a hurry. I am sad for all I went through. It was inhumane. I have lived in probably 20 different places. It is amazing I have actually survived this much for this long. Safe and affordable housing is a human right. Rent based on income for people on the spectrum is needed. Housing also needs to be in a quiet area because living among urban sounds and stress and density is not sustainable for me. I don't know about my future and I'm scared. My family doesn't accept my diagnosis and I have had to stay away from them for my own safety. I don't look autistic and that makes it hard to get my needs met. Even when I tell people they don't believe me.

Pattern 5 – Social Relationships Matter to Housing Outcomes

Social Relationships: Recurring connections and interactions that exist between people that are perceived by the participants to have personal meaning.

Social relationships are an often-overlooked determinant of housing for autistic adults; however, the analysis highlighted the benefits of strong, supportive social relationships for autistic adults. Social relationships made autistic adults feel connected, supported, and safe. This challenges the stereotype that autistics lack feelings of empathy and suggests that societally, we need to de-stigmatize ASD to encourage social interactions within communities and institutions. We asked the question in the Sensor, *how important are social relationships?* As displayed on the axis below, relationships are important to people, and there was scattered response as to if they were achieved (i.e. “fit).



Our stories re-conceptualized social relationships to include family, friends, circles of support, colleagues, and pets. Positive social relationships encouraged autistic adults to live independently, helped them resolve issues, and provided mentorship to navigate challenges. Social relationships helped mitigate stressors associated with change and transition and feeling safe and understood in relationships led to reduced anxiety and depression. It was also noted that social relationships need to change over time and lifespan as family structures shift, altering the "built-in" relationships within the home (i.e., the "Double Cliff").

Simultaneously, negative social interactions in housing settings exacerbated mental health issues and were traumatizing for autistics. In many of the negative housing experiences in terms of social relationships, autistic adults experienced difficulty navigating roommates in shared accommodations that were unsuitable, where they had less agency and experienced barriers to affordable housing options.

Sensemaking workshop content

- This tells a story that moves, and major life transitions are the primary cause of distress, regardless of the contributor or socio-economic status. There are ubiquitous experiences and challenges with transition, regardless of socioeconomic status.
- Not fitting in and not feeling safe in relationships around the home was upsetting—we need to appreciate how much more sensitive we need to be to the notion of "fitting in" and how to define and respect this.
- Social relationships are a form of support and other autistic adults are also important supports—how do we foster communities of support?
- The lesson learned here is that even the most minimal issues, when moving out of the family home to more independent living, are more successfully solved with some degree of support from family, friends, and professionals.
- There were a lot of negative experiences with co-inhabiting with roommates that were unsuitable. Difficulty navigating roommates in shared accommodations is a necessity due to unaffordable housing options. People with ASD have communication and social interaction differences which create high stress living with others. This can lead to high stress, isolation and even danger. Because supports are either not available or are inexperienced with ASD behavioral issues can lead to medicating the ASD individual as opposed to solving the underlying problem.
- Because of high-stress housing situations usually due to roommates or neighbours issues ASD adults move often when transitions are a big trigger. Change is difficult as is the unknown.

Highlight stories

I am an Autistic woman of colour without family support. In addition to the challenges already of finding affordable housing on a single-person income (finding truly non-discriminatory employment is another challenge), being Autistic makes it difficult to find roommates and neighbours who understand sensory disorders. While my past roommates were reasonable people, it is hard to negotiate things that would lessen sensory triggers. The "no pets" policy that many landlords adopt makes it hard to find housing, as I have a cat who is an uncertified support animal. Thanks to a flexible landlord and a lot of good luck, I am currently able to afford a one-bedroom apartment in a split multi-level house—it felt like winning the lottery when this arrangement worked out!

When I was in the second year of my bachelor's degree, I lived in a house with roommates for the first time. I did make friends that I've stayed in touch with since then. However, one lesson I learned is that if you are a tenant in a house owned by someone else, you have no control over how many visitors the owner brings over or how long they stay. As a result, the owner's mother and her mother's boyfriend stayed over for the whole winter semester along with everyone else in the house. On an April morning after winter classes were done for me, I was having breakfast in the house kitchen and the boyfriend walked through in just his underwear. That was awkward. I discreetly closed my eyes until I heard him leave the room. I didn't really talk to him at all for the remainder of my stay in the house (I moved out at the end of April).

Pattern 6 – Suitability (including sensory) is more than bricks and mortar

Suitability: The housing quality of being right or appropriate for a particular person, purpose, or situation.

Housing suitability was more than bricks and mortar for autistic adults and anyone supporting them: it was about finding the right place, at the right time, with the right support. The stories emphasize that conditions for optimal living and suitability will change over the lifespan as family structures change, they gain independence, build relationships, and navigate peak times of transition, including the double cliff. Suitability included aspects of housing such as privacy, building, social interactions with neighbours, roommates, landlords, the impact of surroundings, and environmental triggers, and connected to sensory issues. Generally, housing suitability was determined by financial resources and access to appropriate support.

Sensory issues are of particular importance for autistic adults, especially those affected by the physical environment because internal and external senses impact one's ability to process, interact and communicate with others and feel connection and comfort in their environments. While the autistic experience is varied and not well understood, the stories suggested that there needs to be a more individualized range of housing that fits the individual's degree of independence and capacities. Housing models should strive for options so autistics can exercise choice to find housing with mutual options that work for them and their families.

Sensemaking workshop findings

- Housing Suitability in positive experiences of housing had interconnected components. The situations were structured for success—financial, accommodations, circle of support-family / service provider or friends.
- All of these stories seem to involve a lack of housing options or housing options that are unsafe and or unfriendly to sensory difficulties. There are a few repeated reasons for the lack of housing: due to the need for intensive support, due to low income, and due to low income and sensory difficulties.
- The commonality in almost all of the negative housing situations is that the bricks and mortar alone, rarely produce successful, suitable housing..... a wide range of accommodating factors are required for sustainability.

- Thinking about age, choice and access to affordable, appropriate housing fit here. The difference is how few housing options there are for older millennials and younger autistics due to the housing crisis, staying at home with family.
- Access to Sensory Integration is still expensive and few individuals are practicing this. It is still an ongoing developing area of knowledge in this community. More education needs to occur at all levels of development. Schools are recognizing some families but I still see a mainly behavioural approach to ASD without considering sensory processing differences. We still have a long way to go. Sensory consideration in housing should be a must for everyone. It is not difficult or expensive to offer equipment to improve matters.
- Education in the housing realm in the structuring and training of staff is important. Being aware of sensory triggers and strategies to resolve the escalation would make a world of difference if it was part of daily routine in the housing world.
- Suitability is about finding the right place, right time with the right supports must seem insurmountable for autistic adults and anyone supporting them. Financial resources, appropriate support and control over space to alleviate sensory issues seems to be key.

Highlight stories

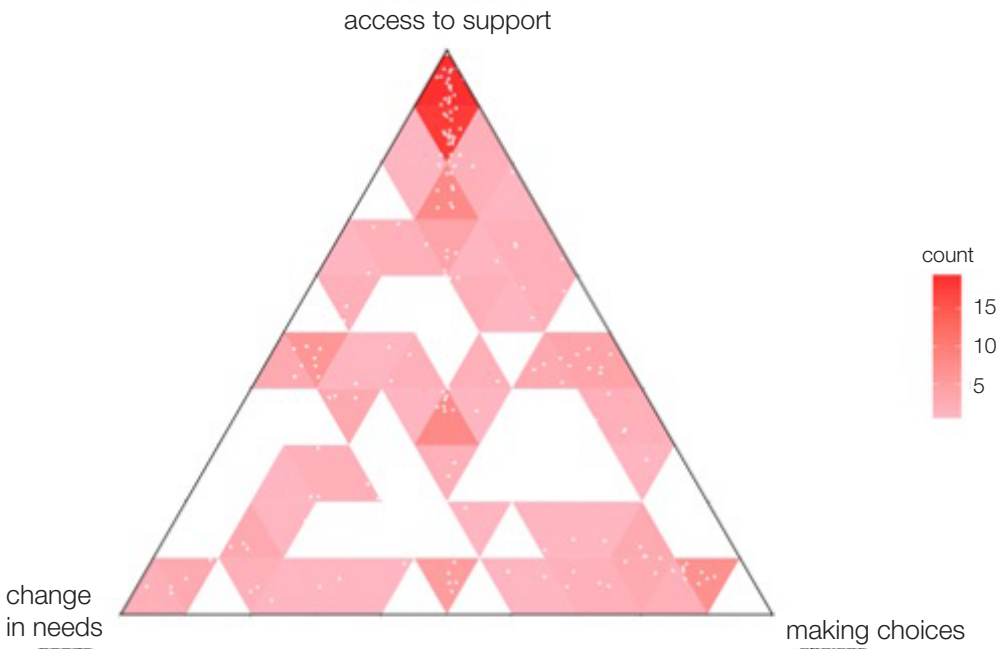
Everything is so loud. As someone with sensory processing issues, it seems like there are fewer and fewer "safe" places to live. When I moved into my apartment, I chose it because the soundproofing was excellent. But when a new management company bought the building, they replaced the wood flooring with plastic and now the sounds disturb me all day. Rental prices have been steadily increasing, moving apartments further and further out of my budget, while low-cost renovations drive down the quality of rental apartments. It seems like a lose-lose situation for people with disabilities, especially those on fixed incomes who can't keep up with the housing market.

One place I lived as a young person had months of renovation work, and the constant noise and dust made it hard to stay at home. A few years later I lived in a quiet residence with a communal setting, but where I had my own bedroom. I filled it with all my favorite books, and I was very happy. It would have been better if I did not have to share the kitchen, bathroom, and dining room, but at least it was safe and I had some space to myself.

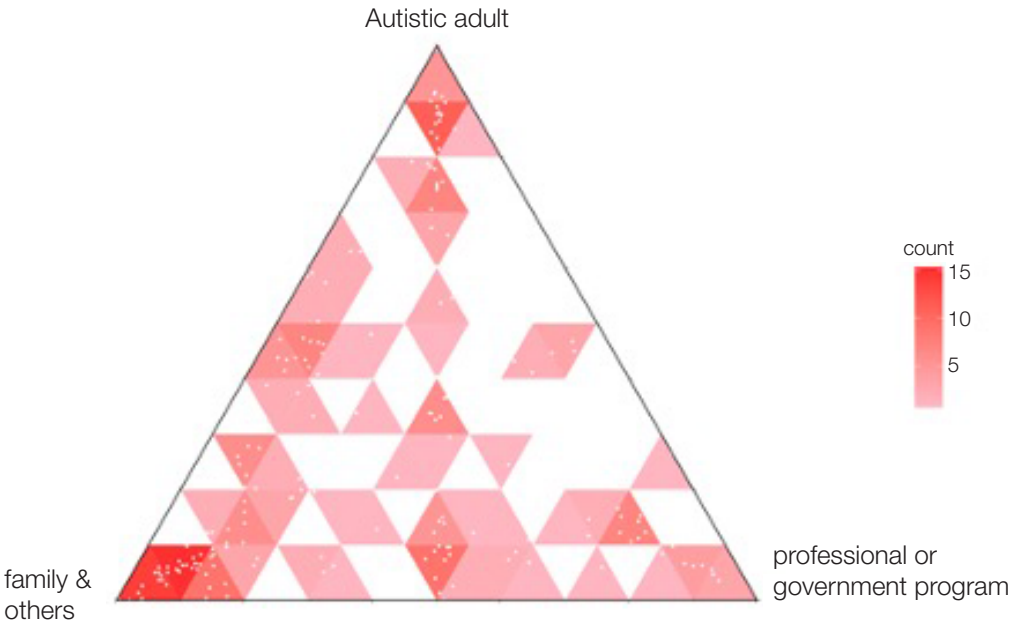
Pattern 7 – Access to Support (Paid and Natural) correlates with positive housing experiences

Support: Assistance is given to support daily living. Natural support includes the unpaid assistance given by family, friends, neighbours, or others in a personal network. Paid support includes paid assistance given by government-funded or privately hired staff.

Access to support was the most common issue amongst the stories (figure below). Effective supports helped provide a safe environment for autistic adults to build skills, deepen capacity and work towards living independently. Access to support increased autonomy, helped autistics secure employment, and reduced social isolation and mental health issues.



Our findings state the obvious—access to support positively correlates to housing outcomes, where the more support, the more positive the housing experience. In our stories, support was most often downloaded onto the individual family as opposed to government or public support services.



This is referred to as "natural support" and, therefore, depended on family financial and time capacity. We need to better understand how to develop policies, programs, and financial assistance models that support families and operationalize legislation at the federal, provincial, and municipal levels.

Sensemaking workshop content

- The negative experiences of these stories all seem to be tied to in part either one or more of the following three things: lack of money to afford supports and or proper housing, no support or inadequate support due to having more complex needs and the waitlists being too long, and lack of support because needs are not complex enough and or visually apparent along with there being a lack of accessible or event existing support.
- Many people with ASD go-to service providers who are not specialized in ASD therefore these providers cannot spot or know how to support the real issues at hand. People on the spectrum have a very limited number of connections, especially besides family. Most of the time they are in their own heads trying to figure things out as a neurodivergent in a mainly neurotypical world.
- Getting support for housing is downloaded onto the individual/family. What about those without families or those with families who cannot financially support them. This is an important piece for advocacy. From a policy perspective, any government involvement to support Autistic adults must focus on natural support. Need to understand what natural supports are composed of to develop policies, programs, and financial assistance to sustain natural supports.
- Times of transition are difficult, regardless of socioeconomic status. How can we design supports for times of transition?
- As autistics become adults and are not prepared, nor have the skills needed to move out, there is a terrible cycle: Poor independence skills, no one taking care, therefore, don't feel

valued, feel isolated which I believe leads to more mental health issues. Programming drops off after high school therefore connections decrease. Nothing to do, anxiety goes up even more. Difficulty finding employment, financial issues, more mental health issues. Terrible cycle.

- I think if autistics had ongoing support/mentor/ advisor that understood their issues and knew how to access support, many of these issues could be resolved with dignity.
- Again, the importance of having a variety of living options is highlighted here. What is shown more here is the importance of having effective and mutual options that work with the individual's degree of independence.
- There also seems to be repeated themes surrounding other people and sensory issues, roommates, affordable adequate housing, and styles of the housing affecting the autistic individual's living situation.
- So, all these stories are telling me that there needs to be autistic housing advocates to help autistic people deal with social and legal housing matters. These advocates need to communicate with the Autistic adult to find out what they are trying to say or do and then deal with the other people, organizations, or legal agencies that are a part of the situation on behalf of the Autistic person.
- We need to start building the natural supports and skills when individuals are in their teens. Assume competence is possible until otherwise shown. Mastering even small skills as they grow will enable the growth of self-confidence and independence.
- Difficulties that pop up across the stories tend to be either related to complex needs and a lack of support/care providers, or due to a lack of support to aid people in managing the executive functioning, adaptive living, and social interactions and relationships that are a part of daily independent living. This shows that for a positive housing experience there needs to be consistent, some of which are even minor, supports available, and or present, and maintained for autistic adults in specific areas of daily independent living.
- The independent daily living supports could incur minor costs for the government to set up, maintain and end up saving them millions in returns due to these supports enabling many adults with ASD to enter or maintain employment, and helping prevent crises caused by overload.
- This implicates that for more positive housing experiences to occur there needs to be more affordable supports and adequate housing, more housing with proper supports for those with complex needs, and affordable accessible supports for those with less complex and or visible needs need to be made available and exist.

Highlight stories

My brother can live autonomously, but he cannot manage his bill payments. He constantly doesn't pay his bills on time and gets angry that the bill increases every month (since he hasn't paid it). He is very lucky to have a landlord that accommodates him by paying his rent between 1 and 3 weeks late EVERY month. I wish he could have more help to manage basic life things—I worry he will eventually lose his housing and have such bad credit he can't get bills back in his name.

My experience is not with an autistic adult in housing, it's getting them to the housing stage. I have a 19-year-old who completed high school and is not motivated to do so. I live in a small town with zero activities for him to participate in. He hasn't got the skills to live on his own and the waitlist is extreme for support. His day consists of

lying-in bed playing video games and eating. He is overweight and his teeth are rotten. I don't have money to repair the damaged teeth. His psychiatrist has not been practicing due to covid, she is American and comes once a month to see patients, so it's been a year this month since he has seen her. We have asked for a referral to another psychiatrist but the waitlists 9 months long. He has days where he says he doesn't feel like living and I feel helpless. I wish for a day he could have his own place, but I am at a loss to get to that goal. He wants to be a heavy machine operator, but I don't know how this is going to happen. Please share your experiences so I can assist my son in achieving his goals.

Appendix 2 – Compendium of Promising Practices

For over 50 years the policy of deinstitutionalization has been changing the living situation for many autistic adults from large scale residential institutions to community-based living with the right individualized support. There is no one-size fits all solution for housing autistic adults, the right solution is as diverse as the autistic population itself.

We cannot talk about the right housing solution for autistic adults without including the right support. Support is an interictal part of housing solutions. A good housing solution sees housing and support options come together in a way that meets the individual needs of the autistic adult.

Supports must be able to flex and change over the life course as needs and possibly housing options also change. Support can be offered in many ways and in various combinations. The amount of support depends on need but also access to the financial resources (either publicly funded or private resources) to pay for these supports. Support types include:

1. **Natural support:** This type of support includes family members, friends, co-workers, neighbours and acquaintances to help with all aspects of daily living depending on need. Natural supports are unpaid and a critical part of the lives of all autistic adults and other disabilities. For many autistic adults, natural supports come from parents and family. When in place, natural supports can also come from Circles of Care or Microboards but for most, families it is a necessary complement or the only option when funding and finances do not allow for paid support options.

2. **Supported Independent Living (SIL):** This type of support is provided in an autistic adult's home. It can be provided by a staff person, paid for through government funding or private resources. A SIL worker either employed by an agency or hired independently helps people to live in their own space independently by offering guidance with shopping, housekeeping, cooking, finances, managing issues and relationships. SIL can be for a set number of hours or on an as needed basis.

3 **Congregate Living Support:** This support is provided in a group home or residence where an autistic adult will share a home with several other adults often with autism or developmental disabilities. Staff that offer support can be either publicly or privately funded. The home and the staff are often tied together. Staff will not necessarily live in the home but work in shifts for a 24/7 level of staffing. Congregate Living Support helps people with all aspects of daily living depending on need.

Section 1 – Promising Housing Models

Through a review of existing literature, we have selected eight different types of housing settings. These settings include:

1. **Remaining at home**
2. **Family living**
3. **Renting or owning a home/apartment**
4. **Co-housing**
5. **Intentional Communities**

And three specialized settings included:

6. **Residential Services**
7. **Transitional Housing**
8. **Homelessness/Dual Diagnosis**

There are many, many possible models inside each setting. Each housing model can vary by characteristic of the structure, size, and number of people in the household. The level of support in each of these models can be adjusted for individual needs from minimal independent living support to 24/7 assistance with personal care and activities of daily living.

All housing models regardless of the setting need a combination of three elements to be made possible, and to be successful over time. They require:

1. **Capital.** A capital investment (the land and/or building) can come from charitable donations, government contributions or usage of existing capital (parental home).

2. **Sustainability.** A housing option to be successful needs the right, consistent support for the resident to live sustainably over the long term.

3. **Funding.** Financial contributions to the housing option for both the capital and the sustainability can come from government, charitable contributions, or private contributions.

Housing options for autistic adults or individuals with disabilities requires all three elements at varying levels to be successful. Housing for these populations is like a three-legged stool, without one leg the housing option will not work. In this document, the models may refer to adults with intellectual disabilities and not autism. The difference in disability does not impact the possibilities for autistic adults nor does it take away from the success of the housing model.

1 Remaining at Home

Why Wait Demonstration Project - Live-in Caregiver Model
York Region, ON

Launched in 2018 under the Ministry of Children, Community and Social Services (MCCSS) Housing development task force, the “Why Wait” demonstration project provided four housing models with sustainable, long-term support inside the housing situation.

For this document we are looking at two of the four models for the Live-in Caregivers. The Live-in Caregiver Model provided an opportunity for an individual and their family to develop a housing solution where the individual is staying at home with family but in a self-contained unit with the support they require.

Audience

The “Why Wait” demonstration project was aimed at individuals and families on the MCCSS housing wait list.

The approach requires a family to build a self-contained unit inside their existing property (or another dwelling or to purchase a property where a self-contained unit could be built).

The level of support needs varied and, in some cases, space was built for a live-in caregiver so they could provide evening and overnight support.

Program Description (including support)

In the first live-in mode—the person supported purchased a home and their housemate would become a co-owner through a rent to own approach. A live-in person was offered a free room in exchange for their presence and provided overnight support most night of the week.

The second live-in model—two people purchased their own modified and accessible home. There were two live-in support people to provide support.

The Why Wait Demonstration project ensured that housing models were to be created in a way the was sustainable and so as part of the model included:

1. Hiring an independent facilitator to support the implementation of their models, to build their personal networks of support and ensure individualized goals were achieved.
2. Creating a Microboard, to support the sustainability of the model over the long-term, in particular once the primary caregiver had passed away
3. Hiring staff to provide the daily support through a transfer payment agency.

Partner agencies that supported this initiative included Montage Support Services and YSSN. Montage provided trained staff and coordination to those families interested in the purchase of agency staff and YSSN provided the brokerage of MCSS funds.

At the time MCCSS put out a call for proposals for housing innovations. “Why Wait” Demonstration project was one of the projects that was funded.

This demonstration project relies heavily on the initiative and motivations of the government of the day. To date, the investment has not been repeated by the current government despite the positive outcomes.

Funding Model

This model was funded through the Government of Ontario’s Developmental Services Housing Task Force.

The base budget for “Why Wait” (which included supporting eight individuals) was $405,807 in year 1 and $571,754 in year 2. These costs did not include any capital costs, legal fees, mortgage or building/development costs. All Passport funding was used for day supports and ODSP was already deducted from individualized budgets.

With housing capital provided by the people supported (and their families), the project supported individuals with developmental disabilities using incorporated Microboards to ensure ongoing supportive decision-making; independent facilitator(s) to help increase informal supports, improve participants’ quality of life, change community perceptions and increase community capacity to include people in full citizenship; and Individualized Funding appropriately directed to support requirements.

Most families used their resources to purchase support services directly rather through a support agency. Hiring and coordinating support staff is recognized as time consuming and demanding for families, and assistance with managing staff, hiring & training is important while maintaining self-direction. Technology worked well to support some individuals, reducing need for 24-hour staffing support.

Measures of Success

- Sustainable, individualized, long-term housing options
- Each person living according to their personal vision for community life and in their preferred housing
- Each individual had a Microboard that managed the funding and interests for housing sustainability
- Increased choice for flexible supports
- Individuals choosing where and with whom they live
- Agencies providing support for identified needs
- Family as back up support only
- No chance for eviction

Would it work in Ottawa?

In consideration of the presented information, there is no doubt that “Why Wait” is a promising practice already in effect in different variations across the city of Ottawa and beyond.

However, this model is resource intensive and only available when the housing capital and the dollars for individualized support already exist.

Without these two components it is unclear if there would be the same level of success.

Recent changes to bylaws make it easier to build secondary dwellings in Ottawa.

Similar models

The Beat Goes On, Toronto, ON

Windsor-Essex Housing Collaborative, Windsor, ON

Additional Material

https://plantoronto.azurewebsites.net/HTF2/viewer/desktop/index.htm#page/32

2 Family living

Homeshare by Ottawa-Carleton Lifeskills

Ottawa, ON

Homesharing is the fastest growing residential option in British Columbia increasing 350% over the past 15 years with over 50% of individuals receiving residential support living in a homeshare.

Homeshare (also known as Lifeshare) is a very broad and flexible label that includes a wide variety of arrangements. With each Homeshare arrangement people share their lives for mutual benefit. The homeshare provider offers ongoing support, companionship and low-cost accommodation to an autistic adult. In turn the homeshare provider receives a steady income.

Although homeshare is offered through an increasing number of agencies, we are looking specifically at the model offered by Ottawa-Carleton Lifeskills (OCL).

Audience

In Ontario, the Homeshare program is accessed by individuals through Developmental Services Ontario. It is open to adults with autism or developmental disabilities who would like to live independently in their communities. Depending on availability, Homeshare providers can accept a wide range of needs, including more complex ones.

Program Description (including support)

In the OCLS Homeshare program compatibility between residents and the Homeshare provider and their family is an essential part of the program. To make sure a good match is made, the intake and hiring process includes evaluating several factors:

- the physical premises compared to the physical needs of the individual
- the location of the home
- the presence of a spouse or significant other, children and/or pets
- common interests and activity levels, Intensive Support and Supervision Program (ISSP) goals
- the Homeshare provider's experience in dealing with issues specific to the individual (medical, behavioural, communication, etc.)
- personality mesh

When OCL determines a match is possible, the Homeshare provider and the resident meet and start to develop a relationship based on short-term visits. As these visits continue, the Homeshare provider and the resident will spend more time together and participate in overnight visits before the resident moves in. Visits will encompass all members in the family home and other individuals who are also being supported in the homeshare.

The resident and their families participate in an annual Individualized Service and Support Plan (ISSP) meeting to set goals and develop strategies for reaching these goals. The Supervisor and Homeshare provider revisit this plan and documentation is kept showing follow-up towards attaining the goals which were set.

The program supervisor regularly visits each Homeshare residence. They meet with the Homeshare provider and the resident to continually assess the quality of service and the ongoing suitability of the match. The Supervisor carefully monitors changes to the household, including the addition of other persons, a move, family illness, birth of a child, introduction of pets, etc.

Each host family owns or rents their home. The host must house two individuals at the same time.

Funding Model

Homeshare spots are funded by MCCSS. OCL has funding for 15 homeshare spots which serves 30 individuals.

When a Homeshare spot opens up, OCL must notify the local MCCSS office, Developmental Services Ontario Eastern Region (DSOER). DSOER looks at who in Ottawa is a priority for a Homeshare placement and who is a potential good match with the host family and the individual already living with them.

The Homeshare host becomes a fulltime employee of OCL. They are paid a salary and benefits, and have monthly respite. The host family is also paid a flat monthly sum to contribute to household expenses (housing costs, food, transportation).

The two individuals living with the host pay the board and lodge portion of their Ontario Disability Support Program (ODSP) benefit to OCL and that money, combined with MCCSS funding, pays for the host's salary and benefits and the individuals' living costs.

Measures of Success

- A good match between the homeshare provider and the resident
- Sustainable, individualized housing options
- Each person living according to their personal vision for community life and in their preferred housing
- Ongoing support built into housing options
- Agencies providing support for identified needs
- Family as back up support only

Similar models

Ottawa-Carleton Association of Persons with Developmental Disabilities Homeshare

Community Living Brant

Community Living British Columbia Shared Living

Would it work in Ottawa?

Yes, it is currently working in Ottawa and it is a promising practice. However, this practice cannot be a long-term sustainable solution without diligent oversight and ongoing maintenance from a Transfer Payment Agency. This is not an option that can be actioned outside the system of Developmental Services and so only initiative and motivation from the Ministry of Community and Social Services can make this program grow in Ottawa.

It is also important to note that many autistic adults do not have access to Developmental Services and which immediately excluded from the possibility of Homeshare.

Additional Material

https://www.mcss.gov.on.ca/documents/en/mcss/developmental/LifeShare_Booklet_En.pdf

https://www.mcss.gov.on.ca/en/mcss/programs/developmental/serviceSupport/lifeShareFAQ.aspx

https://www.mcss.gov.on.ca/en/mcss/programs/developmental/serviceSupport/residential_supports.aspx#host https://www.mcss.gov.on.ca/en/mcss/publications/developmentalServices/hostfamilydirectives/Host_Family_ProgramPolicy_Directives_2016.aspx http://qamtraining.net/docs/english/DS-Host-Family-Operational-Guidelines.pdf https://mulpress.mcmaster.ca/hro-ors/article/view/2867

https://cic.arts.ubc.ca/home-sharing-exploring-the-experiences-of-self-advocates-home-share-providers-and-family-members/

3 Renting an apartment or home ownership

Renting an apartment either alone or with roommates where an autistic adult can live independently, or owning a home, with the right support, is a popular housing setting as it allows the autistic adult to live an “ordinary” life in the community.

There are many models under this setting. The following two models are quite similar with some key differences. Both models are new and have charitable developers involved in the project development. The Ottawa initiative is in a suburban area in a mixed income development and separate supports. The Calgary initiative is an urban development specifically for people with mixed vulnerabilities and light supports are tied to the apartment.

3A. Renting an apartment

Just Enough Support by LiveWorkPlay
Ottawa, ON

The Ottawa based, Multifaith Housing (MFH) initiative provides safe, affordable and well-maintained housing in inclusive and mixed communities. MFH is a charitable organization made up of a number of religions communities and partners coming together to act against homelessness and a lack of affordable housing in the city.

The Haven is a mix of 98 townhomes and two-low rise gold LEED (Leadership in Energy and Environmental Design) certified apartment buildings. Ten of the one-bedroom units were reserved for people with disabilities. There is a multi-use community space, an outdoor children’s playground, and a community garden that promotes healthy living environment and community engagement. All homes and indoor amenity spaces, in the Haven, are fully accessible.

To ensure the independent living success and sustainability of residents with intellectual disabilities, there is a partnership with LiveWorkPlay, an Ottawa-based organization for people with intellectual disabilities, autistic persons, and individuals with a dual diagnosis.

This housing possibility came together as a result of collaboration between LiveWorkPlay, Multifaith Housing Initiative (MHI) and Centretown Citizens Ottawa Corporation (CCOC).

Audience

The individuals are able to live alone with minimal support, most of the participants are using smartphones or tablets and using reminder alarms and online calendars to stay organized. To stay connected, and for remote problem solving they are using Facebook video chat or text messaging.

Program Description

LiveWorkPlay partnered with housing providers CCOC and the Multifaith Housing Initiative to secure apartments in this new affordable housing development. Individuals and their families or support networks developed a plan for transition to independent living and helped to build their capacity for an independent life in advance.

Support included both unpaid support from family, friends and neighbours as well as paid/ funded supported independent living provided by LiveWorkPlay

Funding Model

The total cost of construction was $19.3 million.

- Action Ottawa provided the land.
- Federal, provincial and municipal governments granted MHI $10 million for the construction of 98 units.
- MHI raised $1.2 million.
- MHI has financed the remainder of the cost through a long-term mortgage.

Support for housing was initially funded by the Ministry of Community and Social Services at approximately $100,000 per year for two years for the planning and transition to independent living.

Ongoing supports were provided through Passport funding, private resources and unpaid or volunteer work.

Measures of Success

The measures of success for this housing option included:

- Individuals moving into an apartment of their own
- Individuals engaging in formal and informal interactions with other residents
- Family members attend 4–5 days of plan development training
- Individuals and family members participate in and contributing to developing and independent living plan.
- Identifying neighbours at The Have who can help to provide natural, unpaid support
- A minimum of 12 neighbours living at The Haven will be identified and provide natural support

Would it work in Ottawa?

This model works is working well Ottawa and in other places in Canada.

However, the affordability of housing can limit or prevent this housing options from being a reality. Some form of rental subsidy is critical.

Additionally, adequate funding for support is also required through sufficient Passport funding or natural support volunteerism.

Similar models

All together housing, Belleville, ON

Additional Material

https://liveworkplay.ca/2015/01/19/inclusion-by-design/ https://www.multifaithhousing.ca/the-haven.html https://www.planningnetwork.ca/en-ca/Webinar/liveworkplay

http://www.barrhavenblog.com/barrhaven-multifaith-housing-initiative/

https://www.multifaithhousing.ca/tenants.html https://www.multifaithhousing.ca/uploads/1/3/0/4/13047577/2020agmwith2019report-final.pdf

3B. Renting an apartment

HomeSpace Downtown: Legacy on 5th,
Calgary, AB

HomeSpace is a charitable real estate developer, rental housing owner and property manager in Calgary. HomeSpace has approximately 30 properties throughout Calgary. For this document we are going to look at HomeSpace Downtown: Legacy on 5th.

Launched in 2018 and opened in February 2021, Legacy of 5th is 74 units of permanent rental apartments for single adults in downtown Calgary. All the units are dedicated to vulnerable Calgarians, 20 are specifically for autistic adults.

Partnership at all levels is key to the success of this housing option starting with key partnerships for building construction and partnership among social service agencies resident referrals, independent living support and community building. Legacy on 5th and other HomeSpace communities aim to provide safe, stable, sustainable and long-term housing for Calgary's vulnerable citizens.

Audience

Residents of Legacy on 5th is for autistic adults ready to live independently. They can independently meet essential activities of daily living (e.g. grocery shopping, cooking meals, bathing, housekeeping, laundry and would be able to self-evaluate from the building without assistance in an emergency.) Residents would be able to access "light support", meaning that in-person support are on an as needed basis such as to answer questions, problem solve or provide community navigation.

The residents must also have a plan for how they pay their monthly rental fees, utilities and support costs as well as any added personal expenses (e.g. food, clothing, cell phone, entertainment, transportation).

Program Description (including support)

All residents of Legacy on 5th and other HomeSpace buildings are through a city-wide referral system called Coordinated Access and Assessment which is operated in collaboration with the Calgary Homelessness Foundation. Direct applications for housing are not accepted.

For autistic adults the Sinneave Family Foundation, Housing and Supports team are the entry point to housing and maintain the waiting list for this building.

Applicants contact the Sinneave Family Foundation and go through a quick screening and eligibility check to see if they meet the criteria for the building. Once the criteria are met a referral is made to Autism Calgary Association. Autism Calgary then discusses with the applicant the level of support needed and if the building is the right fit. If the applicant is accepted into a unit, then Autism Calgary connects the applicant directly with HomeSpace to sign a lease and plan the move in date.

Funding Model

Funding the construction of the buildings by HomeSpace is a result of many partnerships working together including the Government of Canada's Canada Mortgage and Housing Corporation, the City of Calgary and donations from philanthropists to the RESOLVE Campaign.

Funding the support staff

Light support is offered by Autism Calgary Association and Autism Asperger's Friendship Society and costs $60 per month. Purchasing this support is a requirement of tenancy for Legacy on 5th. The $60 is paid for by the resident.

Light support included monthly phone check in's and as needed, in person support visits to answer questions, help solve problems and provide community navigation. Autism Asperger's Friendship Society also offers monthly social opportunities with others from the building or the local community.

Rental Costs

Rent is fir $615 for a 360 sq./ft studio apartment to $740 per month for a one bedroom 500 sq./ft apartment. Residents must also pay $60 per month in utilities (including laundry) and the $60 for light support.

Total budget

The total project cost was $23.5 million (land at market value)

Measures of Success

The measures of success for this housing option included:

- Each person was living independently with light support
- The right tenant screened into housing
- Family as back up support
- Long-term, sustainable housing solution
- Safety
- No chance for eviction
- Low market rent

Would it work in Ottawa?

This model is working to a degree in Ottawa however, this model exists outside the need to be connected to Developmental Services or a Transfer Payment Agency.

HomeSpace is a charitable real estate developer, rental housing owner and property manager. Additionally, funding the construction of the building depended heavily on the philanthropic sector for its success.

HomeSpace and Legacy on 5th are a result of significant philanthropic capacity in the real estate development and land contribution. Ottawa does not have a comparable philanthropic landscape. Additionally, the referring agent is not necessarily connected to a government agency such as Developmental Services.

Similar models

Orchard Common, Allendale, NJ, USA

Horizon View (Glamorgan), Calgary, AB

Additional Material

https://homespace.org/

https://sinneavefoundation.org/wp-content/uploads/2020/11/Downtown-Info-Sheet-Nov-18-CD-1.pdf

https://homespace.org/wp-content/uploads/2021/02/Media-Release_Legacy-on-5th.pdf

4 Co-Housing

Terra Firma
Ottawa, ON

Co-housing is a Danish concept where a planned residential community is made up of private homes with some shared spaces. It has a set of core principles are participatory process, neighbourhood design, common facilities, resident management, non-hierarchical structure and decision making and not shared economy.[18]

Co-housing allows people to maintain a sense of private ownership in a residential neighbourhood design and encourages people to interact in shared common spaces such as gardens and kitchens. In cohousing arrangements, people may share meals and rotate daily living tasks such as gardening, grocery shopping and home maintenance among residents.

There is not an abundance of examples of co-housing in North America. There are currently 12 in Canada and 16 more forming because of a growing popularity and interest in the concept.

For an autistic adult co-housing presents an opportunity for the development of natural support and an opportunity to "age in place".

Audience

While few adults with autism live in cohousing, it is a housing model that could support residents who are able to live independently and could benefit from the natural supports (co-care) of the co-housing environment. Additional supports would have to be purchased privately.

Program Description (including support)

There are not a lot of details available for Terra Firma. It has been in place since 1997 and has 30 residents in separate homes. There has been very little if any turnover since its inception.

In addition to the advantages of co-care, there is the advantage of the community cluster from multiple homes meaning that supports (such as a Personal Support Worker) could be shared (like a Community Hub Support Model).

While there is little information about Terra Firma, and it is not an option with an abundance of housing opportunities for autistic adults, it is an important model to consider for its embracing of interdependence, co-care (natural support) and the opportunity to be part of community. It is a housing model in which people can perform some of the tasks at which they excel and trade off the tasks which they may not be able to do because of different physical, cognitive/neurological or economic capabilities.[19]

Urban cohousing emphasis on equality, participatory citizenship within the community, the layering of community within a larder resource-rich community and the intentional construction of shared living spaces and shared lives, along with independence and interdependent living.

18 McCamant and Durett, 1988

19 Basas, 2010

Funding Model

The exact funding for Terra Firma is not available.

Co-living arrangements are also difficult to finance since banks in Canada don't like this model of ownership. There is no real support for people who want to live in a collective context.

Co-housing is not subsidized in Canada and so participants need to be able to afford to buy their own homes and the cost is approximately market rate. There are additional fees for maintenance similar to in a condominium. For an autistic adult there would be additional cost for support if needed when support requirements are above and beyond what the natural support network provided by a co-housing can provide.

A new co-housing complex known as Kikekyelc is being built in Kamloops, BC. Kikekyelc is a 31-unit, culturally safe facility for First Nation elders and younger residents to live together with access to 24/7 wraparound services offered on site. This housing complex is $4.7million and backed by CMHC.

Measures of Success

Co-housing models are precarious and often disintegrated because the challenges are too much for a small group who may share compatible goals but are in different life circumstances. Nevertheless, some current research has been conducted by Rubin et al (2019) into the measures of success in intentional communities, specifically the satisfaction level of the residents. Findings from this study showed that measures of success included racial diversity and shared political intentions. However, overwhelmingly satisfaction was connected to the structural organization of decision-making.

Since its inception in 1997, no one has moved out, so turn over and opportunities to join this model are limited.

Other measures of success might include the financial responsibility and overall property maintenance.

Would it work in Ottawa?

Yes, co-housing is currently working in Ottawa and could work if there was an investment in this housing option.

Similar models

There are a number of co-housing models in North America.

Sweetwater Spectrum Sonoma campus residence in California is 2.79 acres and is located 4 blocks west of the city's downtown plaza, encouraging local community integration. The housing model is based on co-housing, and offers choice to its residents with individual, customized and flexible programs, supporting life skills training, continuing education, gardening, art/music, exercise and healthy lifestyles. The site was designed specifically to meet the needs of those with Autism and is environmentally sustainable where ever possible.

Convivum Cohousing is a new housing project for older adults in Old Ottawa East.

Solterra Co-housing is a shared housing option in Port Carling, ON for senior, people with disabilities, students and anyone else who wished to create an intergenerational home.

Cambridge Co-housing has 41 units from town houses to studio apartments and a large common house with many amenities. It also included several green spaces. Cambridge Co-housing is a group of people of diverse ages, backgrounds, abilities, professions and lifestyles with the goal of supporting each other through all kinds of life events both positive and challenging.

Additional Material

Co-housing communities

5

Intentional Communities

Reena Community Residence
Vaughan, ON

The Reena Community Residence (RCR) is an intentional community, made up of sixty housing units. The RCR follows in the footsteps of countries such as the Netherlands and the USA, intentional communities have been used for quite some time to house individuals with developmental disabilities.

Audience

RCR is best suited to individuals transitioning from another housing type to independent living with a diverse set of ongoing support and services.

Most residents at RCR have developmental disabilities, autism and/or physical disabilities. Some also have dual diagnosis and a partnership with the Local Health Integrated Network means that residents with complex needs can also live at RCR and have their needs met.

Program Description (including support)

The intent of RCR is to be able to assist residents in a way that is seamless but brings in diverse agencies and partners to provide the support and services required for residents to live independently.

Even though residents may be supported by different organizations, the organization are required to overlap their services so that calls for help can be answered immediately by a staff member and the resident can receive care as soon as possible.

In addition to individual units, there are some cluster units build into RCR. Cluster units are three-bedroom apartments, there are two of these units on each floor and act as congregate living arrangements within the building.

In addition to paid supports, Circles of Care are developed provide natural, unpaid support networks for the residents.

The residents of RCR are tenants of their own private units which are regulated by the Ontario Landlord/Tenant Act.

Funding Model

Funding for RCR comes from a mix of sources including the Government of Ontario, the Reena Foundation, other charitable donors and fundraising.

The current market rent for a unit in the RCR is an average of $1,155. Approximately 18% of residents are paying full market rent. Resident data from Reena shows that of residents paying full market rent, more than half are supported financially by their family or by an insurance provider (57%). Other residents who pay market rent support themselves independently through employment, potentially combined with ODSP benefits (21%). For the remaining 21% of residents paying market rent, it is not clear how they support themselves financially.

82% of residents at RCR are paying an affordable rent rate or rent assist rate between $475 and $500. More than half of all RCR residents are currently receiving Ontario Disability Support Program (ODSP) benefits and/or Passport funding from Development Services Ontario (DSO).

Many of the supports offered are a fee-for-service model allowing for flexible support options so that residents do not have to opt-in to a complex building-wide model.

Measures of Success

The RCR model has five design principles for success including:

- Promoting independence by emphasising the tools (including design, tenancy model and supported independent living) for maintaining successful tenancies in the resident's private apartment.
- Reinforcing service consistency by having consistent staffing from various agencies working collaborative to create a consistent presence in the building.
- Fostering belonging by having a common meeting place and creating a neighbourly culture
- Creating community connections by engaging with close amenities such as neighbours, community centres, grocery stores, restaurants etc.
- Enabling personal growth by working with residents to build and fulfil individual plans and offering opportunities for skill building and personal development.

Would it work in Ottawa?

If such a facility existed in Ottawa it would likely be attractive to some members of the autistic community.

A charitable donor for the extensive capital costs to build such a facility in Ottawa do not exist at the moment.

Similar models

Anand Vihar Facility, Toronto, ON

Prairie Housing Cooperative Prairie Housing Co-op was formed to allow households with a physical and/or intellectual challenge live independently in a supportive environment.

The Co-op owns a turn of the century building converted into three independent suites, sixteen suburban family homes and a converted warehouse of twenty-eight suites.

Field of Dreams, Elmira, ON

Additional Material

http://www.reena.org/wp-content/uploads/2018/06/REE02S-Housing-Model-Evaluation-Accessible-Report-June-6.pdf

http://www.reena.org/wp-content/uploads/2020/09/2019-2020-Reena-Annual-Report-FINAL-Digital.pdf

https://www.reena.org/about/reena-community-residence/

6

Residential Services

Kerry's Place
Toronto, ON

Kerry's Place Residential Services (KPRS) is the largest service provider to families with children, adolescents and adults with autism in Canada. KPRS has approximately 90 homes in the Dufferin, Peel, Wellington, Waterloo, Toronto, Durham, and Hastings regions of South-Central Ontario. The homes have multiple residents and staff members who provide 24-hour support. They aim to provide an environment that reflects a home and facilitates residents' community involvement. Each residential setting is individually designed to meet the needs of the residents.

Audience

KPRS is specific to individuals with ASD who require 24-hour support. KPRS is also able to provide support for adults with dual diagnosis. Staff at Kerry's Place are an interdisciplinary team that includes behaviour therapists with front line staff. Increasingly KPRS is focused on older residents 50 and above.

KPRS is open to individuals eligible with Developmental Services Ontario.

Program Description (including support)

KPRS has been in existence for a long time (nearly 50 years) and have in this time worked to acquire, modify and lease homes to providers of services to individuals with ASD based on the needs identified by the service provider. The support provided is in person and available 24-hours a day. In the residential program, the houses are owned or leased by Kerry's Place.

KPRS' aims to provide an environment that reflects a home and facilitates the residents' community involvement with full support services. Supports include staff serving as the primary liaison person for the adult with ASD and their family, medical, educational, leisure and recreational contacts. Residents are supported and coached with social skills, communication and leisure activities. They also help to find solutions to good quality of life for the adult with ASD.

Funding Model

KPRS is a Transfer Payment Agency meaning residential placements are funded by the government of Ontario. Close to 90% of the funding comes from the Government of Ontario. KPRS holds assets of approximately $10 million dollars.

Measures of Success

Measures of Success for Kerry's place include:

- Using the science of Applied Behaviour Analysis, members of the Clinical team conduct specialized assessments, provide intervention/treatment for the persons supported within their residential sites/residential treatment centres, and delivered behavioural training to enhance capacity of staff
- Psychiatric Clinics are held in each region at a minimum of once per month
- Quality initiatives include goal achievement through Individual Support Plans / Person Directed Plans development, Advanced Care Planning, and staff education/training related to quality indicators
- The nurse practitioner supports the teams by monitoring and following up on health care needs for the people supported within the residential services. She is the lead of their Infection Prevention and Control (IPAC) committee to ensure public health guidelines and COVID practices are followed for both persons supported, families, and staff.
- Kerry's Place will be surveyed by Accreditation Canada (AC) in 2021. Practices are being reviewed against five AC sets of standards: Leadership, Developmental Disabilities, Governance, Medication Standard and Infection Protection and Control

Would it work in Ottawa?

In recent years, KPRS has taken significant steps to increase its capacity to purchase houses and has significantly increased the number of houses. However, the growing demand being experienced by Kerry's Place Autism Services and other service providers for residential services for individuals with ASD outstrips our ability to finance, purchase and modify houses.

With an increased demand for this type of housing solution and changes in funding to the Ontario Autism Program, it is not likely that this publicly funded model, while successful, would work in Ottawa.

The model is successful and needed, however an alternative funding model would be required.

Similar models

Centre Miriam, Montreal, QC

Hello Housing, various cities in the US

7 Transitional Housing

First Place Transition Academy
Phoenix Arizona

The First Place Transition Academy, operated by the Southwest Autism Research & Resource Center (SARRC), is a structured two-year program designed for adults with autism that helps build crucial independent living and career-readiness skills. Within the supportive environment of First Place–Phoenix, participants can maximize their capacity to live more independently through our Learn4Independence® curriculum and individualized services.

Audience

First Place Transition Academy is aimed at adults (18+) moving out of home for the first time. The academy has strict criteria for participation. The individual must able to complete basic self-care independently and function safely in their apartment or community without direct supervision. The individual must not have a history of addiction or serious mental illness, they can communicate and has no history of aggression or self-injurious behaviour that requires one-on-one interventions.

Program Description (including support)

First Place® Phoenix is an apartment complex with built in services and a floor for their partnered independent living transitional program. The First Place Transition Academic is operated by the Southwestern Autism Research & Resource Centre and is a two-year program designed for adults with autism that helps build crucial independent living and career-readiness skills. Within the supportive environment of First Place—Phoenix, participants can maximize their capacity to live more independently. There are 32 participants annually who live independently on site and transition to off-site year two.

To become part of this program there is an application process which includes a review to ensure ability to meet financial resource requirements. There is a complete clinical assessment and a determination of participation in the program. At that point, the participant can sign their lease and move in. During years one and two of the program, participants live at First Place–Phoenix in one of the four four-bedroom suites as they progress to more independent living.

Funding Model

Tuition for First Place Transition Academy is funded directly by the individual and their families. Tuition includes the apartment lease, utilities, community college tuition and instruction, and employment and clinical services.

The current annual tuition fee for the Transition Academy Is $66,000USD ($5,500USD/month) which includes the apartment lease, 24/7 support and amenities, utilities, and tuition fees.

Measures of Success

The transition academy has measurable results of becoming employed, living independently of parents, feeling satisfied with the number of friends the individual has, a reducing in the cost for needed supports, ability to cook a meal, ability to manage medication and ability to maintain a savings account.

Would it work in Ottawa?

If such a facility existed in Ottawa it would likely be attractive to some members of the autistic community.

Similar models

Community Living Options, Evanston, IL, US

Peterborough Transition-Aged Youth Transitional Housing Pilot Project, Peterborough, ON

Reach Toronto, Toronto, ON

Additional Material

https://www.firstplaceaz.org/ https://www.firstplaceaz.org/wp-content/uploads/Apartment-Pricing-Sheet-11.06.20.pdf

https://www.firstplaceaz.org/wp-content/uploads/FP-PAD-2162-Booklet_ONLY_al_11.06.20.pdf
https://greatnonprofits.org/org/first-place-az

https://www.indeed.com/cmp/First-Place-AZ/reviews

https://www.bizjournals.com/phoenix/news/2020/11/28/q-a-denise-resnik-autism-housing.html
https://inbusinessphx.com/growth-enterprise/first-place-autism-housing-network-release-a-place-in-the-world-report-to-advance-neuro-inclusive-housing-community-development#.X6MO_1NKgWo

8

Homelessness/Dual Diagnosis

Bridges to Housing
Toronto, ON

This cross-sectoral collaboration will offer a multi-disciplinary, integrated, approach to provide housing and supports to individuals experiencing homelessness, who are identified with developmental disabilities with complex health needs, and reduce the reliance on other costly provincially funded services, and providing needed primary medical care, housing supports and case management support. Gaps in housing and support will be identified.

The partners included: City of Toronto: Seaton House, Streets to Homes; Community Living Toronto, Inner City Health Family Health Team; Surrey Place DSO Toronto Region; and St. Michael's Hospital and CAMH (Centre of Addiction and Mental Health).

Funding Model

Ontario is provided $730,000 in continued support for the City of Toronto's Bridges to Housing project, including $465,000 in annualized funding beginning in 2018/19 to continue the project and maintain supports for individuals currently housed; and $166,000 in 2017/18 and $99,000 in 2018/19 in one-time funding to support implementation of the project.

Program Description (including support)

The Bridges to Housing team initially expected to provide clinical and housing supports to 25 shelter inhabitants with developmental disabilities. Ultimately the team assessed over 75 individuals, 45 of whom were confirmed as having dual diagnosis. The remaining individuals were too complex for this project; thus, a new health team was assembled to connect them to the appropriate medical and behavioural supports.

Sustainability of housing and adequate supports to remain in the housing: housing stability achieved for 25 people, deep affordability was addressed with housing allowances; people faced some discrimination due to lack of references and some social discrimination depending on housing type. What is acceptable to the person and importance to people to still feel a sense of connectedness was key. Created Collaborative of the Willing: Informal, ad hoc advisory group to engage in cross sector information sharing, problem solving and idea generation to meet the unique needs of this population. Shared ongoing learning from the gaps and challenges identified in housing supports.

Measures of Success

1. Improved screening practices in shelters achieved using the innovation of the Rapid Assessment of Residential Supports (RARS)
2. Shorter timeframes to DSO to better support individuals who are experiencing homelessness with suspected Developmental Disability.
3. Ongoing development of an integrated, multidisciplinary approach to support and services for those with developmental disability and multiple diagnosis such as mental health, acquired brain injury, and health issues complexities resulting from years of post-traumatic stress, substance misuse and chronic homelessness.
4. Raising cross-sectorial awareness of developmental disability and homelessness, which continues with increased collaboration between the shelter system and DS sector, as well as between Ministries.

Would it work in Ottawa?

Yes, this model would likely work in Ottawa. As with all models, the funding and will needs to be available locally to put this into action.

Additional Material

https://www.planningnetwork.ca/en-ca/Webinar/Bridgestohousing

https://plantoronto.azurewebsites.net/HTF2/viewer/desktop/index.htm#page/1

https://news.ontario.ca/en/bulletin/46858/ontario-expands-support-for-the-city-of-torontos-bridges-to-housing-project-for-adults-with-developmental-disabilities

Section 2 – Promising Support Models

Support is an interictal part of housing solutions so we cannot talk about the right housing options for autistic adults without including the right support. A good housing solution sees housing and support options come together in a way that meets the individual needs and is able to change over the life course as needs and possibly housing options also change.

Support needs and services are varied in their forms and intensity depend on people's needs which often change. They can include both clinical and non-clinical services that help people to remain stably housed. Examples of supports can include, but are not limited to counselling, personal care support, case management, income support, assistance with medication, meal preparation, financial support and accessing other services.

Support can be offered in many ways that may be offered in various combinations. The amount of support depends on need but also access to the financial resources (either publicly funded of private resources) to pay for these supports. Supports and services can be paid (from an agency or worker) or unpaid (from family, friends or neighbours).

Whatever the housing option and no matter what the needs of the autistic adult support services need to be:

- Flexible,
- Promote and support independence, personal growth, and dignity,
- Delivered in the most effective way possible, and
- Connect people with their communities and promote inclusion.[20]

There are innovations in offering support beyond having staff attached directly to the provider of a housing options. The following are some innovations to help provide the right support for an autistic adult regardless of their housing option.

1 Supported Independent Living

Supported Independent Living (SIL) is ideal for adults that require minimal and individualized support in areas such as finances, home management and developing community connections. SIL is based on the needs of the person and can be offered daily, weekly or monthly. SIL can be offered by an agency as part of their programming, as a fee for service or it can be purchased from an individual worker.

2 Community Hub Residential Model

The Community Hub Residential Model provides a predetermined number of hours of support along with spontaneous support on a 24-hour basis for people in numerous housing locations within a 20km radius of the hub.

The model is ideal for people requiring higher levels of support than the typical supported independent living. It also suits those who do not require medical monitoring or 24-hour onsite supervision that would potential be provided in a group home or long-term care home.

20 http://www.mah.gov.on.ca/AssetFactory.aspx?did=15988

Supports are comparable to SIL and could include financial management, assistance with daily living activities, managing a home, developing community connections, and linking and coordinating all relevant community services.

3 Smart Support – Technology Enabled Services

Smart Support provides adults with individualized technology solutions that are customized according to their goals, needs, preference, lifestyles and available resources. Computers, tablets, and other technological devices can be used to convey step-by-step instructions for daily tasks and needs, including scheduling reminders to leave for work or to take medication facilitating visual contact with family and friends. Smart support uses various applications to increase independence and reduce reliance on others. Participants and direct support networks will be provided comprehensive training in using the appropriate technology.

4 Developmental Service Workers Co-op

Developmental Service Workers (DSW) Co-op is a support model that provides nimble, community-based, person-directed supports to adults with developmental disabilities/autism in whatever their chosen living situation to facilitate their participation in all aspects of their home and community life.

The workers are owners in the co-op and can set their own schedules, find compatible clients and families and share in profits. Families use direct funding or personal resources to purchase the services they want.

Section 3 – Promising Practices in Affordable Housing

Most of these practices come the document “Promising & Innovative Practices in Affordable Housing” prepared by Randalin Ellery for the Guelph Wellington Local Immigration Partnership[21]

1 Secondary Suites

Secondary suites are typically a self-contained living space with private kitchen, bathroom facilities and sleeping areas located within or on the same property as a single-family home. They can be located in a home or on the property, above a laneway, garage, in a basement, on a top floor or in a coach house.

City approvals are required to build a secondary suite and are only allowed within certain land use districts. Units must demonstrate that they meet fire code building code requirements, by-laws and a building permit is required.

Secondary units must also be registered with the municipality ensure the suites have obtained all necessary permits and have been inspected to meet health and safety requirements.

21 http://www.guelphwellingtonlip.ca/wp-content/uploads/2019/04/GWLIP-Promising-and-Innovative-Practices-in-Affordable-Housing-2019-Final-Report.pdf

ADVANTAGES

- Increase the supply of affordable rental housing
- Increase affordability of home ownership
- Provide more housing while retaining neighbourhood character

CHALLENGES

- Costs associated with bringing secondary units into compliance with building and safety codes
- Increase people-to-space density

https://www.ontario.ca/page/add-second-unit-your-house

2

Canada Housing Benefit

The Canada Housing Benefit (CHB) is a commitment from the federal government to provide affordability support directly to families and individuals in housing need.

The CHB must work with existing provincial, territorial, and municipal housing programs and is a portable benefit in the form of a monthly subsidy provided to low-income households to assist with housing costs. The benefit is tied to the household and in Ontario it can be used to help pay rent anywhere in the province.

In Ontario, the CHB is administered by the province and managed by the municipalities. The benefit amount will be reviewed every year. Municipalities also determine priority groups for CHB.

ADVANTAGES

- Flexibility and increased choice of where to live
- Provide direct assistance with housing costs
- Targets individuals and households who need emergency assistance

CHALLENGES

- Does not improve housing supply, in particular the supply of social housing
- Risk of losing portable benefit with change of government

https://www.ontario.ca/page/affordable-housing-ontario

3 Inclusionary Zoning

Designed as a regulatory tool, inclusionary zoning is a provincial planning tool that enables municipalities to secure affordable housing in a new development over a certain size. Affordable units may target particular income groups or serve a range of incomes. Additionally, the resale price of the affordable units is restricted for a number of years.

New inclusionary zoning regulations came into effect in Ontario in April 2018 that allow municipalities to mandate that affordable housing units are included in new housing developments.

ADVANTAGES

- Production of affordable housing at little cost to local government
- Creation of mixed-income communities

CHALLENGES

- Mandatory inclusionary zoning can result in resistance from developers and costs associated with enforcement.
- Voluntary inclusionary zoning requires considerable incentives for developers to participate

4 Community Land Trusts

A Community Land Trust (CLT) is a private non-profit corporation created to acquire and hold land for the benefit of a community and provide secure affordable access to land and housing for community residents. CLTs offer a means of meeting the affordable housing and community development needs of low- to moderate-income households. They acquire land in the community—either by purchasing land directly or through donations of land, land and buildings, or money to purchase land. This land is held in perpetuity so that it can always be used for affordable housing. Access to this land is often limited to low- and moderate-income households and the non-profit organizations that serve them.

ADVANTAGES

- Preserves the affordability of housing, regardless of market changes
- Can provide home ownership opportunities for those that would otherwise be locked out of the market

CHALLENGES

- CLTs are dependent on a sustainable business model to maintain affordable rental rates while covering ongoing operating costs.
- Municipal policies and zoning regulations may act as barriers to the start-up of a CLT

Ottawa Community Land Trust

5 Housing Trust Fund

Distinct funds to receive dedicated public revenues that can only be spent on housing.

Sometimes called a Housing Trust Fund or Housing Reserve Fund, housing funds are distinct funds established to receive dedicated public revenues, which can only be spent on housing. The key characteristic of a housing fund is that it receives ongoing revenues from dedicated source of public funding, such as taxes. However, sources of funds can also include gaming funds, land sales, development levies, and more.

ADVANTAGES

- Designed locally to take advantage of unique opportunities and address specific needs that exist within a community.
- Establishes a clear role for the municipality in contributing to development of affordable housing.
- Provides flexibility to contribute to projects as they arise.

CHALLENGES

- Depending on the amount committed and the means in which funding is collected, it can take a significant amount of time to build a balance substantial enough to make an impact.

Appendix 3 – Summary of Relevant Legislation and Associated Resources

The *Summary of Relevant Legislation/resources* is attached under a separate cover. It contains a review of most relevant legislation and related resources, which are organized by level of government, starting with federal and proceeding to provincial statutes and municipal bylaws. Summaries and information links that are provided reflect legislative references and URL's as of April 2021 and may be subject to change.

Appendix 4 – Sensor micro-story collector

The Sensor micro-story collector is attached under a separate cover.