‘It’s just my home, you know?’ Home-making and Belonging for People Labelled/with Intellectual Disability

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TITLE: ‘It’s just my home, you know?’ Home-making and Belonging for People Labelled/with Intellectual Disability

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Abstract

This master's thesis research focuses on the experiences of people labelled/with intellectual disability in their current homes and also what they want for their future home. Few studies in Canada have focused on specifically asking this population what their ideal home looks like and acknowledging the gap between this and what their reality is. Advocacy groups in Canada and the United Nations Convention on the Rights for Persons with Disabilities have been calling for years to better address the rights of people with disabilities and their place in the community, yet there has been little progress within Ontario towards this.

Using semi-structured interviews and an arts workshop, participants were asked to think about what their life is like now and what their aspirations are for their future. The research is based on a relational model of home as more than just a physical structure and expands the definition to include the neighbourhood, relationships, and support that participants experience, which shape their home and their feelings of belonging inside and outside of it. Findings show that, while there were opportunities for agency within their homes and relationships, there are many restrictions to attaining their ideal home, including funding constraints, long wait lists, and few choices for what type of housing they receive. The findings of this study have important implications for ideas of belonging and processes of home-making within geographic research, as well as for future policy based on housing for people labelled/with intellectual disabilities in Ontario.

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Chapter 1: Introduction

1.1 A note on language usage

In keeping with both person first and labelled person language, this thesis will be using the term ‘people labelled/with intellectual disabilities’ as a way of including both of these groups (Fudge Schormans et al., 2018). Often the literature in Ontario uses developmental disability to describe intellectual disability, which encapsulates an onset before the age of 18 and life long cognitive or adaptive impairment (Ontario, 2021). While all intellectual disabilities are developmental disabilities, not all developmental disabilities also include intellectual disability. Wherever possible, the language of intellectual disability is used to account for this discrepancy. In some cases throughout there are references to ‘learning disabilities,’ which is the term used for intellectual disabilities in the UK. It is important to note that many of the studies referenced disproportionately include people with mild-to-moderate intellectual disabilities, due to the complicated issues with gaining ethics approval for ‘severe’ intellectual disability (Santinele Martino & Fudge Schormans, 2018), which limits participation in research.

1.2 Research rationale

This thesis is concerned with the housing options currently available to people labelled/with intellectual disabilities in Ontario. However, at the outset it is important to situate these options within the broader history of housing for this population. The first purpose-built institution for the ‘feebleminded,’ the historical term for intellectual disability, opened in Ontario in 1876 (Burghardt, 2018). At its peak thousands of people were institutionalized, many of them children (Burghardt, 2018). The stated aim of these institutions was to provide a separate space for learning and training for the intellectual disabled, however the reality was that this stated aim did little to improve circumstances in institutions (Burghardt, 2018). In her book *Broken,* Madeline Burghardt interviewed nine survivors of Ontario institutions about their experiences (2018). The retelling of the conditions within institutions described by survivors is characterized by loss, abuse, and oppression (Burghardt, 2018). Each day was highly controlled and regimented to increase the efficiency of the institution and survivors lost all sense of self (Burghardt, 2018). Despite their deplorable conditions and growing public pressure beginning in the 1960s, institutions continued to operate well into the 21st century because of the efficiency of the model and the rise of the psychiatric profession. Low costs, maintained by unpaid labour from survivors, meant institutions required very little outside funding from the provincial government and so the government had little motivation to close them (Burghardt, 2018). The building of institutions additionally coincided with the rise of the psychiatric profession and the 'medical model' of treatment, based on the belief that disability was the fault and responsibility of the individual and intelligence could be tested and measured in order to separate the 'feebleminded' from the general population (Burghardt, 2018). This disproportionately affected low income, racialized groups, who were much more likely to be tested and institutionalized against the wishes of their family (Burghardt, 2018).

It is important to note that during this time, there were few alternatives for families in providing care to their family member with an intellectual disability (Burghardt, 2018). A lack of community care infrastructure, driven by medical opinion, meant that only those families with an in-built support system could continue to keep their child home (Burghardt, 2018). It was not until 2009 that the last institution closed in Ontario (Burghardt, 2018). The closure of asylums was largely driven by public pressure and these institutions have been replaced by a movement towards community care, with most asylum survivors returning to live with their families

(Ombudsman Ontario, 2016). The effects of this period continue to be felt today, with many survivors still dealing with the upheaval and loss of that period of their lives (Burghardt, 2018). It has also had a major influence on current conceptions of home for people labelled/with intellectual disability within government policy and practice as institutions were the only option for decades, and it was only recently that living in the community was possible (Burghardt, 2018).

In the last few decades, there has been a change in the understanding of how people labelled/with intellectual disability should be treated, medically and socially. Internationally, the most influential legislation on this has been the *United Nations Convention for the Rights of Persons with Disabilities* (UNCRPD) which was adopted in 2006 (United Nations, 2006), and ratified in Canada in 2010 (Stainton, 2016). Of critical importance for people labelled/with intellectual disabilities are Article 10 (right to life), Article 12 (equal recognition under the law), and Article 19 (living independently and being included in the community) (United Nations, 2006). This convention has become the benchmark within policy in Canada for understanding the rights of people with disabilities, seen in the *Canadian Charter of Rights and Freedoms* (Section 15, equality rights for persons with mental and physical disabilities) and the *Canadian Human Rights Act* (protection from discrimination or harassment on the grounds of disability) (Prince, 2009, ch. 1). It can also be seen at the provincial level, in legislation like the *Accessibility for Ontarians with Disability Act* (AODA), which works to remove systemic barriers in the public and private sector for people with disabilities (LCO, 2020), and the *Social Inclusion Act*, which has worked to shift towards more community inclusion for people with disabilities (Ontario, 2021). The nuance and implications of both these policies will be discussed further in Chapter 3.

The main trends within policy and literature, spurred by the UNCRPD and advocacy work have been self-determination, social inclusion, supported decision making, and person-centred planning for those labelled/with intellectual disabilities. Self-determination is "the product of both the person and the environment - of the person using the skills, knowledge, and beliefs at [their] disposal to act on the environment with the goal of obtaining valued and desired outcomes" (Wehmeyer & Abery, 2013, pg. 2). Social inclusion focuses on the active inclusion of people labelled/with intellectual disability in the community, specifically achieving this through employment, independence and community-based living (Ombudsman, 2016). Supported decision making is a “legal framework that recognises decision making as a shared process and gives formal standing to supporters” (Bigby et al., 2019, pg. 396). The emphasis on shared responsibility is important here, as it recognizes the ability of labelled people to make their own decisions rather than having them made for them. Person-centred planning is the practice of creating an inclusive document covering multiple domains like "education and employment, physical and psychological health, quality of life, housing and independence" (Wehmeyer, 2014; Wehmeyer & Gardner, 2013, as cited by Dew et al., 2018, pg. 402). The planning document is meant to guide the support network of an individual in understanding the short-term and long-term goals of the people they support, in order to foster independence (Dew et al., 2018). Each of these trends and practices are centred around the ability to choose where and how people labelled/with intellectual disabilities live their lives, although many efforts in policy and practice to achieve this aim often fall short of their intended goals (Ombudsman, 2016; Spagnuolo, 2016). The causes and consequences of this will be expanded on in Chapter 3.

Within advocacy for people labelled/with intellectual disability, work has focused on one key statement, “nothing about us, without us” (Santinele Martino & Fudge Schormans, 2018).

This encapsulates areas of policy, funding, research, and service provision, with advocates pushing for inclusion in all areas where they are being discussed (Santinele Martino & Fudge Schormans, 2018). Major advocacy groups, including the Canadian Association for Community Living (CACL) and People First of Canada (PFC), have put out statements highlighting the importance of the ability to choose where and how people labelled/with intellectual disabilities live in the community, with access to the supports they need to do so (CACL, 2020; People First of Canada, 2021). They have also emphasized a focus on person-centred planning, social inclusion, supported-decision making, and self-determination in future policy and funding decisions for housing, noting that these are currently absent or inaccessible for many (CACL, 2020). CACL argues for addressing the broader social context in which housing is situated, recognizing the linkages between “household, dwelling, structure, person, and neighbourhood” (CACL, 2020, pg. 2). People First further state that “[a] real home means a neighbourhood, a community, choices and opportunity” (UNCRPD, as cited by People First of Canada, 2021). This broadening of what the home means is important to better represent the ways in which people labelled/with intellectual disability actually experience home and what is important to them.

It is within this context that the current research study is based, following in line with the belief that people labelled/with intellectual disability have a right to equality and choice in how and where they live. Few studies have directly asked people labelled/with intellectual disabilities what this choice would look like for them and the gaps in service they experience (Verseghy et al., 2019). For this reason, it is important to ask how people labelled/with intellectual disability understand their home currently, and also how they envision their future, in order to better know what challenges they face in doing so and how the provision of housing, and allied community spaces, can better cater to their needs in the future.

1.3 Position statement

I come to this work as a white, cis, queer, able bodied person with an invisible disability. This position holds a privileged place within society, and more specifically within academia as I have no outwardly visible difference. My position, from within a science-based undergraduate and masters program with limited experience in qualitative, inclusive work, also informed how I chose my research methods and the form of the analysis of the work. While I have done by best in this thesis to present as much of the stories of the participants in as close to their words as possible and have reviewed this with participants at multiple stages of the research, there are inevitably gaps, as I myself am not labelled nor have lived experience of intellectual disability.

Chapter 2: Literature Review

2.1 Geographies of Disability

The work in this thesis is based within the broader geographies of disabilities, which draws on the relationship between disability and space (Chouinard et al. eds., 2010). While is it not possible to provide an exhaustive history, some of the contributions from the field will be highlighted here in order to situate the work and to identify its relevance to the broader study of geographies of disability.

The 'first wave' of geographies of disability began in the 1990s. Up to that point disability had largely been considered in relation to individual diseased bodies and where they are located, barriers to inclusion experienced in cities, and studies in mental health, all situated broadly within a medical model of disability (Chouinard et al. eds., 2010). As stated above, the medical model is rooted in individualistic definitions of disability and doesn't account for the "broader socially and spatially produced causes of exclusion" (Chouinard et al., eds. 2010, pg. 2). The social model of disability was developed as a counter-point to the medical model, positing that whereas impairment is a bodily state, disability is a "social process of oppression and exclusion" (Chouinard et al., eds. 2010, pg. 7). Critical geographies of disability in the 'first wave,' influenced by the social model, called for a shift towards understanding and challenging those social and spatial forms of exclusion and oppression (Chouinard et al., eds. 2010). Research in this period included work focused on the lived experiences of people with disabilities in space (Parr & Butler, 1999; Hall, 1999), the wider concerns with how research is conducted and how it may reproduce ableist practices (Chouinard, 1997), and calling for research done *with* instead of *for* people with disabilities (Chouinard et al., eds. 2010).

The ‘second wave’ of geographies of disability continued to look at the issues raised in the first wave, but in ways that are more nuanced and complex (Chouinard et al., eds. 2010). For example, researchers have focused on understanding how disability and space are relational and “bodies, things and spaces [are] interacting in various ways to produce shifting exclusionary and/or enabling arrangements” (Morrison et al., 2020, pg. 2; Wilton & Hall, 2017). Work has also expanded to include experiences of disability in the Global South (Chouinard, 2014; Counter, 2018). Within these broader trends, there are three that are of most relevance to the work in this thesis; research done *with* and *by* people labelled/with intellectual disabilities, geographies of home, and geographies of belonging. These will be discussed in more detail to give context to the analysis to come in Chapter 5.

First, within the ‘second wave’ there have been calls for the inclusion of people labelled/with intellectual disabilities. Hall & Kearns emphasized the absence of intellectual disabilities within geographies of disability (2001). They account for this absence by pointing to the social isolation of people so labelled, even after moving into the community following deinstitutionalization, and the lack of academic and political involvement that includes people so labelled (Hall & Kearns, 2001). They call for “an ethnographical approach to understand the experiences of people with disabilities by connecting the personal and the social-political context” (Shakespeare, 1996 as cited by Hall & Kearns, 2001, pg. 243) and research which centres people’s engagement with places and spaces to get at how they feel within those spaces (Laws & Radford, 1998 as cited by Hall & Kearns, 2001). In response to these concerns, and others within the field, work in the last few decades has seen an increase in research done *with* and *by* people labelled/with intellectual disabilities as opposed to *on*. For example, the *My Life in the City* project included participants leading researchers on trips around Toronto to identify how they interact with and feel within the city, as well as participating in a group workshop to create maps and art of their experiences (Fudge Schormans et al., 2018). It further included opportunities for participants to directly engage with the public, politicians and service organizations in the city, as well as producing a documentary of the project (Fudge Schormans et al., 2018). Another example of this work is the *Voices of Youth* project which had young people labelled/with intellectual disabilities as co-researchers on the project who were actively involved in deciding the form of the research and dissemination (Renwick et al., 2019). The project used video-based methods to capture non-verbal interactions between youths and their friends and family (Renwick et al., 2019). Both projects demonstrate the practices of engaging people labelled/with intellectual disabilities directly in research projects and bringing those experiences into the public consciousness.

The second aspect of geography studies within this period is on the geographies of housing and home. The home is a fundamental place within people's lives (Dupuis and Thorns 1996, Gurney 1990, Rakoff 1977, Saunders 1989, 1990, Saunders and Williams 1988, as cited by Imrie, 2004). Home has been conceptualized as complex and multi-faceted, being understood not only as a place, but also as a collection of feelings, and the relationships between the two (Blunt & Dowling, 2010). The home then exists as an important geographical site, while also extending beyond this to encapsulate an experience and a process (Blunt & Dowling, 2010). The home is further complicated in the context "of disabling built environments," for example people, with physical disabilities can be constrained by the structure of their home by being unable to leave or care for themselves without support (Imrie, 2004, pg. 749). While Imrie is directly connecting these constraints of the home with the experiences of people with physical disabilities, this context has relevance for the experience of home more broadly for people with disabilities and how conceptions of home can be complicated when the home is also a space for care (Imrie, 2004).

A third, related element of recent scholarship is the emphasis given to belonging in place (Kaley et al., 2021; Morrison et al., 2020; Power, 2013). Recent work has focused on the ways in which spaces foster feelings of (not)belonging, related to how people are able to be in that space. Work by Morrison et al. emphasizes that feelings of belonging are not merely about having ‘disability spaces’ because spaces designated for people with disabilities do not work to include all people with disabilities, all of the time (2020). In response to this, people with intellectual disabilities have in some cases moved to create their own spaces and their own forms of inclusion (Hall, 2004). Research by Kaley et al. on the ‘self-building’ of belonging by people with disabilities within their communities suggests this is done by “having meaningful information, choice and control about what to do with their day" (2021, pg. 13). Each of these trends and specific examples are examined further below in relation to the current study.

With this context in mind, the remainder of this literature review will turn to discussion of the current context of home for people labelled/with intellectual disabilities, drawing on access to housing and housing types, conceptualizations of home and home-making, and feelings of belonging in place to underpin the findings of the interviews and art workshops of this study and it’s overall conclusions.

2.2 Housing and People Labelled/With Intellectual Disability

As was noted above, the home is first a geographical location, a site where someone lives. It is then important to understand what kinds of housing are available for people labelled/with intellectual disability, in order to understand how they conceptualize home. This section discusses the general housing types available to people labelled/with intellectual disability drawing from a variety of national contexts. As was noted in Chapter 1, institutions were the primary source of care for people labelled/with intellectual disabilities until quite recently (Burghardt, 2018). In many Western countries, large scale institutions were only phased out in the last decade, specifically in the UK, US, and Australia (Bigby et al., 2017). It is notable that across the literature on intellectual disability and home, very little is focused on the geographic locations of *where* people labelled/with intellectual disability live (Wark, 2018). Beyond the categories of rural or metropolitan areas, most neighbourhood context is limited to the type of dwelling, i.e., group home, family home, etc. (Wark, 2018). As such, this section will detail each of these types of common dwelling, laid out as the family home, group home, and alternative models of housing. More details of the Ontario context for housing will follow in Chapter 3.

Family home. Following deinstitutionalization, living in the community has predominantly meant living in the family home as the default (Grey et al., 2015; Verseghy et al., 2019). While this is not necessarily a negative experience, as many people labelled/with intellectual disability and their parents enjoy living together, this trend also reflects constraints on the availability of housing, a lack of financial resources to live in the community, complicated and overwhelming planning processes, and a lack of consistent support (Grey et al., 2015; Isaacson et al., 2014). Families frequently defer future planning for their child labelled/with intellectual disability because it can be a stressful and expensive process, and difficult to know what resources are available to the family that is planning (Grey et al., 2015). The lack of available housing options means that it can take months if not years to find somewhere to live in the community, and this also means that placement will likely not be the one chosen if they had more available options (Grey et al., 2015; Verseghy et al., 2019).

Group homes. After the family home, group homes are one of the most common forms of community care and are considered better than the institutional care that came before it in terms of providing support to residents (Bigby et al., 2017; McConkey et al., 2016). A group home provides 24-hour support for between 3-8 residents (Laschewicz et al., 2020). Yet there are growing concerns over the experiences of people residing within them (McConkey et al., 2016). Group homes themselves are an increasingly unsatisfactory choice for individuals labelled/with intellectual disability because of their inflexibility in providing individualized care (Bigby & Wiesel, 2015; Wilton & Fudge Schormans, 2019), variable quality of life outcomes (Bigby & Wiesel, 2015), and limiting of personal choice (McConkey et al., 2016). The disconnect between need and availability means that residents in group homes can often also have conflicting interests, ages, and support needs (Roos & Søndenaa, 2020).

Alternative housing. In addition to the family home and congregate settings, a third category has emerged in the form of offering alternatives to them. Alternatives can take on many forms and often exist outside of form systems of housing support provided by the province, although some have become a rising alternative within them as understandings of housing for people labelled/with intellectual disabilities have changed.

Supported/Semi-Independent living. Originally conceptualized by Kinsella (1993), supported independent living is a broad term that separates housing provision from support, meaning that the two can be more flexible and tailored to the individual needs of the person (Bigby et al., 2017). The terminology changes in the literature, including supported independent living (Bigby et al., 2017), semi-independent living (Atack et al., 2019), and individual supported living (Isaacson et al., 2014) but the premise is the same. The person is able to live in their own space, while having varying levels of support provided in that space (Bigby et al., 2017; Isaacson et al., 2014). This may also include housemates as a form of informal support in that space (Isaacson et al., 2014). The supported living model has been shown to provide greater choice and control than group homes (Bigby et al., 2017) and to be more cost effective overall (Hole et al., 2015). A recent project, located in Toronto, utilized a version of this called the 'Friendly Housemates' model (Atack et al., 2019). The project paired college students with adults labelled/with intellectual disabilities to live as roommates in housing provided by the labelled person's family (Atack et al., 2019). Partnerships lasted from a few weeks to a full year (Atack et al., 2019). While not all of the partnerships worked out, many of them continued through the entire project (one year) and all showed both the labelled person and their family that they were able to live semi-independently or independently (Atack et al., 2019). The challenges of this project were that it was a very small sample size due to the high perceived risks of this kind of living situation (Atack et al., 2019). While it has the potential to increase independence and interpersonal skills, it also has the potential to be negative for either the labelled person or the student (Atack et al., 2019). It also requires a level of financial stability because the housing was paid for by the family of the person labelled/with intellectual disability and subsidized by the research project (Atack et al., 2019). However, despite these challenges the shared housemates model shows a lot of promise for facilitating greater independence for people labelled/with intellectual disability (Atack et al., 2019).

Home sharing. Another popular alternative housing model that follows the same principles is home sharing, which accounts for 50% of residential services for intellectual disability in British Columbia (Hole et al., 2015). It is characterized as a "living situation when one or more adults with an intellectual disability share a home with another person or unrelated family who is paid to provide residential and, at times, additional support as needed" (Hole et al., 2015, pg. 279). A home share operates outside of the persons family home and is built on pre-existing relationships between the person and the family or individual providing support (Hole et al., 2015). The benefits of this model of housing are that in its optimal application it provides residential services centred around the individual receiving care and enhances quality of life which has the potential to balance the relationship between independence and support (Hole et al., 2015). Positive home sharing experiences were connected to ‘a good match’ characterized by inter-personal skills like listening and trust, support that enables independence, and supported decision-making (Hole et al., 2015). Home sharing benefits from the policy landscape in British Columbia, which has the most advanced legal frameworks for supported decision-making in Canada, the *Representation Agreement* (Stainton, 2016). Some of the challenges with this model that have been identified are that there are a lack of safe-guards and standards of care currently in place, because of both the rapid expansion of the model and the fact that housing is spread out and there is a lack of inspectors investigating housing standards.

Intentional communities. An example from the UK and Ireland of alternative housing is ‘intentional communities.’ This model seeks to place people labelled/with intellectual disability in planned communities, mainly coordinated by independent charities, and of which there are roughly 73 existing in the UK (Randell & Cumella, 2009). Importantly, care workers are not financially remunerated for the care they provide but instead view their role as a way of life rather than a job, which changes the dynamic between them (Fahey et al., 2010). Research on intentional communities demonstrates that residents feel like they are a productive member of the community and feel a sense of belonging (Fahey et al., 2010; Randell & Cumella, 2009). This model has important implications for understanding how supported living can be communal as well as individual (Fahey et al., 2010).

Each of these projects highlight trends towards a focus on housing based around choice and self-determination, in keeping both with the UNCRPD and with position statements from advocacy groups liked PFC and CACL. These forms of alternative housing are needed in Ontario in order to better support people labelled/with intellectual disabilities, by increasing the number of options available to them and improving community connections and feelings of independence (Atack et al., 2019; Hole et al., 2015). While there are challenges with each, they represent novel models of housing beyond the default of living with family or in group homes. The types of housing that are available directly impact on how people so labelled experience and make their homes, and also what they believe is possible for them in the future. It is with this context in mind that the discussion now shifts to the literature on home, in order to understand how these types of housing shape conceptions of home for people labelled/with intellectual disabilities.

2.3 Geographies of Home

As was highlighted at the beginning of this chapter, the home has become an important geographical site of meaning and is fundamental in people's lives (Imrie, 2004). This is particularly true for people labelled/with intellectual disability who have historically been isolated within institutional form of housing and spend a large amount of their time there. It is thus important to understand how people so labelled conceptualize 'home.' To date, few studies have actually asked what conceptions of home are for persons so labelled, with some notable exceptions (Bigby et al., 2017; Laschewicz et al., 2020; Quinn et al., 2016; Robinson et al., 2018). Instead, the literature on experiences of home for people labelled/with intellectual disability is largely focused instead on the availability of, and quality of life within, different types of housing (Hole et al., 2015; Verseghy et al., 2019), the challenges experienced by parents in navigating the service system (Casale et al., 2021; Grey et al., 2015; Ombudsman Ontario, 2016; Roos & Søndenaa, 2020), or the experiences of support workers (Bigby & Wiesel, 2015; Pallisera et al., 2018), rather than actual experiences or needs of home from the perspective of people so labelled. However, from the existing literature some key themes can be drawn out about what elements of home are important to people labelled/with intellectual disability and the limitations to achieving these desired elements of home.

Control. One of the most consistent findings in the literature on home is the desire for control in the home, specifically the ability to leave and return to a dwelling when people choose to (Laschewicz et al., 2020). Home here is conceived of as having the control to "come and go" and "do as [they] like" (Reiter & Bendov, 1996, pg. 109). This control over decision-making also includes choosing what they want to do with their space and being able to decide who is allowed into it (Fisher et al., 2019). This aspect of control, and the emphasis it has on personal agency carry throughout research interviewing people labelled/with intellectual disability who feel a greater sense of self when able to decide what their lives will look like (Dew et al., 2018; Lashewicz et al., 2020; Robinson et al., 2018). However, this desire for agency is often linked to the limitations of achieving it in practice, given financial, legal, or support challenges (Robinson et al., 2018; Stainton, 2016; Verseghy et al., 2019).

Control also extends to having the ability to choose when to be alone. This includes having a separate space where a person is able to control the environment around them without others interference (Bigby et al., 2017; Quinn et al., 2016). The provision of privacy also facilitates the developmental of intimate relationships or friendships without the presence of others watching the interaction (Fulford & Cobigo, 2018). This allows the individual to choose when and how they interact with others and when they want to be alone. This can be challenging, as the presence of care workers consistently in the home can blur the boundaries between private and public spaces and complicate the dynamic of home by making it into a space of work (Dyck et al., 2005, as cited by Laschewicz et al., 2020; Quinn et al., 2016). Perceptions of vulnerability in intimate relationships may also decrease the possibility for privacy as support workers may worry about leaving the person alone (Quinn et al., 2016).

The language of control demonstrates the desire for agency, but not necessarily for independence. While many people labelled/with intellectual disability are capable of independence, there have been arguments to instead focus on *interdependence*. Andrew Power, in his chapter *The Geographies of Interdependence in the Lives of People with Intellectual Disabilities*, argues that people labelled/with intellectual disabilities exist in a nexus of care including family, care workers, social advocates, and are shaped by those relationships (2006). Rather than focusing on total independence as the goal, rooted in assumptions of the value of living alone and of paid work, Power advocates for a focus on the multiple and complex interconnections between people labelled/with intellectual disability and the people around them, allowing for both support and agency to play out together (Power, 2006). This connects to practices of supported decision making, seen in B.C., where decision making is viewed as a shared process among labelled people and their advocates (Bigby et al., 2019; Stainton, 2016).

Choice. A second and connected theme in the literature on home is choice. Choice is characterized by giving people labelled/with intellectual disability the power to make decisions in their life, and it is this concept that has underpinned much of the international movement for intellectual disability in the past few years, including that of the UNCRPD. Choice includes ‘big’ decisions of who to live with, where to live, and the level and type of support provided in the home (Bigby et al., 2017; Fisher et al., 2019; Verseghy et al., 2019). It also includes smaller day to day choices of what to eat or how to dress (Dew et al., 2018) and what they'd like to do each day (Quinn et al., 2016). These decisions are enabled or constrained based on the type of housing available, as well as the support available in facilitating choices, which can be limited by funding or knowledge constraints of family or paid workers (Bigby et al, 2017). The in/ability to be supported in these decisions directly shapes experiences of home and also of personhood.

In understanding what the conceptions of home are for people labelled/with intellectual disabilities, it is important to recognize that control and choice laid out here are often not the reality of housing for those so labelled. The housing landscape is still predominantly characterized by limited choices and the family home continues to be the main form of community care (Verseghy et al., 2019). While this is sometimes seen as the preferred choice of both the individual and their family, the absence of other accessible and affordable forms of housing means that there are few other options, and this may colour people's sense of what is possible. Often people labelled/with intellectual disabilities experience restricted choice, relating to the availability of housing, the funding available for housing, and the amount of support available for independent housing (Bigby et al., 2017; Wiesel & Fincher, 2009). Additionally, those with higher support needs are much less likely to experience the same range of choices available to someone with lower support needs because of the costs for creating alternative living arrangements with higher support requirements (McConkey et al., 2016). Those with higher support needs are then often left with the options of the family home, the group home, or in contemporary forms of institutional care, such as hospitals and long-term care homes (Spagnuolo, 2016; Wiesel & Fincher, 2009).

Additionally, the choices that person-centred planning focuses on relate to big life decisions of housing, life goals, etc. and leave out the small-scale decision-making that happens daily. Smaller scale decisions, such as what to wear or when to leave, have been shown to be just as, if not more, important than bigger decisions in building confidence for future decision-making (Dew et al., 2018; DuBois et al., 2019; Williams & Porter, 2015) yet are often ignored because of the pressures of providing care (Bigby et al., 2017). The language of choice disguises the fact that the choices available are often restricted and determined by the level of intellectual disability and available supports, which ultimately shapes the experiences of home for people labelled/with intellectual disability.

2.4 Home-making

Having addressed the types of housing available to people labelled/with intellectual disability and the conceptions of home, relating to control and choice, it is then important to consider how home is (un)made by people labelled/with intellectual disability in that context. The language of (un)making speaks to the ability for agency to be expressed, through having the control over and choice of making their home what they wish it to be, while also addressing the fact that this can be unmade by constraints on those choices and limits of control, evidenced above. Blunt & Dowling, in their 2006 book *Home* speak to the,

> relational geographies of home requir[ing] attention to what we term home-making practices. Home does not simply exist, but is made. Home is a process of creating and understanding forms of dwelling and belonging. This process has both material and imaginative elements. Thus people create home through social and emotional relationships. Home is also materially created – new structures formed, objects used and placed (pg. 23).

They are not speaking directly to disability in their work, yet the relevance is evident. For many people labelled/with intellectual disability, the home is the place in which they spend most of their time, and navigate relationships with family, friends, and support (Power, 2006). This quote also speaks to the iterative or emergent nature of home as made. It is not a static physical structure but a *process* through which meaning is made and feelings created. This recognizes that people labelled/with intellectual disability have agency in choosing what their home looks and feels like, while also acknowledging the influence of other people in the space in effecting feelings of being at home.

While home-making in many ways contains possibilities for choice and control, it simultaneously has the potential for isolation and loneliness. Laschewicz et al., in their study of the experiences of two young people labelled/with intellectual disabilities, present this idea as feeling ‘insideness’ and ‘outsideness’ within the home, based on the domestic structure itself and the relationships to people within it in creating and limiting choice, evidenced by the ‘insideness’ of one person living in a supportive family home, and the ‘outsideness’ of another living in a group home (2020). They compare these terms to feelings of belonging and non-belonging, whereby the family home made one person feel at ease, safe, and listened to, while the other person in the group home felt threatened and stressed. Laschewicz et al. connect this to the ways in which support needs, diagnoses, and training and availability of caregivers can shape those feelings of ‘insideness’ and ‘outsideness’ and shift how they feel in their dwelling. The process of making home then extends to the availability of good choices and the able to exercise control within their domestic settings and, by extension, the relationships and connections outside of that home in creating feelings of ‘insideness’ and ‘outsideness’ or (not)belonging.

Support. In relation to the processes of home-making it is then particularly important to consider the influence of other people in relation to people labelled/with intellectual disabilities, as they often share this space with family and/or paid support workers. As was discussed earlier, people labelled/with intellectual disabilities often live in the family home (Atack et al., 2019; Crawford, 2008; DuBois et al., 2019) and receive informal support from their family members (DuBois et al., 2019). It also falls to their family members to help navigate complicated support systems (Grey et al., 2015). Support by family members takes the form of emotional or instrumental supports. Emotional support is characterized by approving of and facilitating the inclusion of their family member in the community (DuBois et al., 2019). It also includes supporting opportunities for the independence of their family member (Dew et al., 2018). An example of this can be found in a study of life planning done by Dew et al. in Australia. Participants who had experienced attending college classes and been exposed to opportunities for growing decision-making, expressed the desire to continue to do so (Dew et al., 2018). The emotional support from families in facilitating these decisions is of critical importance for people labelled/with intellectual disability being able to achieve their goals (DuBois et al., 2019). Instrumental supports are things like scheduling events, coordinating transport, and overall increasing opportunities to be out in the community (DuBois et al., 2019). This also includes future planning practices, making plans for what future living arrangements will look like outside of the family home.

The extent of support and the form it takes are influenced by what the different families believe is ‘possible’ for people labelled/with intellectual disability (DuBois et al., 2019) and this is influenced by perceived vulnerability, for example in living independently (Verseghy et al., 2019). Research indicates that families are more likely to want the safety and security of a group home, which has staff available 24/7, compared to the relative risk of living in an independent or semi-independent arrangement (Curryer et al., 2015; Hole et al., 2015; Salmon et al., 2018; Verseghy et al., 2019). This is also due to a lack of information available to families about what services and support are available, as well as negative interactions they’ve had with the housing system in the past (Casale et al., 2021; Grey et al., 2015; Fisher et al., 2019; Ombudsman Ontario, 2016; Roos & Søndenaa, 2020). What is considered ‘possible’ can be further constrained by finances, as many of the alternative housing options discussed above require personal finances to cover all or part of them (Atack et al., 2019; Bigby et al., 2017; Verseghy et al., 2019). This constrains the ability for the individual and their family to look at alternatives as they are limited in their ability to plan for and find suitable housing.

In addition to family members, paid support workers also provide support in the home and can help with navigating both the home itself and the broader community (Laschewicz et al., 2020). Paid support workers provide the same forms of emotional and instrumental supports and are also influenced by beliefs about what is ‘possible’ for people labelled/with intellectual disability. Additionally, support workers can be a source of information in navigating supports available to the individual (Pallisera et al., 2018), helping to facilitate community participation with the person so labelled (Bigby & Wiesel, 2015). A study on community engagement by Bigby & Wiesel found that support workers are important for actively engaging and facilitating encounters with others in public space and people labelled/with intellectual disability, although the responses of the people they engaged with varied (2015). Additionally, person-centred plans, discussed above, are created with staff assistance and have been shown to increase the social inclusion of adults labelled/with intellectual disabilities in group homes (McConkey & Collins, 2010; Shipton & Laschewicz, 2017). However, support workers are limited by the mandate of their organization and/or funding and time constraints which can reduce their ability to foster engagement and supported decision-making (Pallisera et al., 2018).

Home for people labelled/with intellectual disability is thus shaped in part by these forms of support, and so it is important to understand how that support is experienced, and how it can enable and constrain feelings of control and choice. For example, it can support privacy and opportunities for agency (Laschewicz et al., 2020; Quinn et al., 2016), or can creating or exaggerate feelings of ‘outsideness’ or non-belonging because of beliefs of what is ‘possible,’ or because of limited supports (Laschewicz et al., 2020). The relations between the informal support of the family, and formal supports of paid support workers, are a key part of home-making and thus have the potential to shape how the home is perceived and experienced by people labelled/with intellectual disabilities.

2.5 Belonging

It was noted earlier that social inclusion has been emphasized within policy, both in Ontario, seen in the *Social Inclusion Act,* and globally, in the *UNCRPD,* as a key part of the lives of people labelled/with intellectual disability (Stainton, 2016; United Nations, 2006). However, some researchers have pointed to the fact that social inclusion in practice equates solely to finding employment and being independent, which are quite narrow requirements and do not create meaningful community involvement (Kaley et al., 2021). Another framework that has been suggested as an alternative to inclusion is that of belonging (Renwick et al., 2019; Morrison et al., 2020; Kaley et al., 2021).

Belonging is a difficult concept to pin down because it can often be taken for granted. The work of Antonsich is useful for this, in his work on belonging as an analytical framework (2010). Antonsich draws on Yuval-Davis for his definition that, “belonging as a personal, intimate, feeling of being ‘at home’ in a place (place-belongingness) and belonging as a discursive resource which constructs, claims, justifies, or resists forms of socio-spatial inclusion/ exclusion (politics of belonging).” (Yuval-Davis, 2006, as cited by Antonsich, 2010, pg. 645). Feeling ‘at home,’ and the ways this is experienced, are connected to five main factors: auto-biographical, relational, cultural, economic, and legal. Of most relevance to this work is relational, the personal and social ties of an individual in a given place (Antonsich, 2010). This has direct connections to home-making practices, in terms of the emotional relations in the home and their capacity to create the feelings of ‘insideness’ and ‘outsideness’ (Laschewicz et al., 2020).

The second element outlined by Antonsich is discursive, which relates to the broader practices of socio-spatial in/exclusion (2010). This is important for discussions of belonging because it points to the fact that beyond feelings of being ‘in’ or ‘out’ of place there are wider understandings of who belongs in specific places, which can shape those individual feelings, similar to the ‘insideness’ and ‘outsideness’ or Laschewicz et al. (Antonsich, 2010, Laschewicz et al., 2020). Bigby & Wiesel, in their work on encounters, note that community attitudes around intellectual disability can negatively shape interactions with the public and discourage future encounters (2015). Robinson et al. in their study of belonging for young people so labelled, highlighted the importance of feeling seen and valued as key to belonging, which was often negatively impacted by social exclusion (2018).

Much of the literature on home and home-making is linked to this idea of being ‘in’ or ‘out’ of place and the connections to both people and the environment around them. This idea of connection and the feelings of belonging it elicits are then rooted in how people make home. Work by Renwick et al. demonstrates that there is an element of interdependence in belonging that is important to people labelled/with intellectual disability, in their case specifically for young people so labelled (2019). This speaks to the fact that in contrast to notions of inclusion as being based on independence or ‘productive’ employment, as can be seen in Ontario policy, feelings of belonging are more nuanced than this and are about ‘finding a good fit’ of support for each individual that is based on changing and varied needs (Renwick et al., 2019), which connects back to ideas of interdependence in the home (Power, 2006). Kaley et al. notes this as well, saying “social inclusion policies—which are typically about placing people in the “right” sorts of settings, signify an inherently passive role for marginalised groups, such as people with learning disabilities. As a challenge to this, we suggest that self-building lives is about people with learning disabilities having meaningful information, choice and control about what to do with their day” (2021, pg. 12). Rather than there being one way in which to create belonging, by setting firm guidelines and specific spaces, belonging is created by each individual and often in spaces that weren’t specifically designed for it (Kaley et al., 2021; Renwick et al., 2019). This allows for more flexibility and complexity in creating spaces of belonging.

The work of Kaley et al. further discusses the nuance of this, by identifying the ways that feelings of belonging of an individual are connected to local organizations, community, and support networks (2021):

> For the participants in our study, belonging was about being able to spend time with friends as well as family, being an active part of the community, feeling welcome in everyday places and having the time to connect with other people and places. Belonging, then, is about both supportive and accessible contexts and the actions and experiences of people . . . feelings of belonging for the people in this study were about more than feeling attached to places where people can feel safe and accepted. Belonging was also about being recognised, understood and valued . . . people with learning disabilities are coming together to grant *themselves* belonging (Kaley et al., 2021, pg. 12) (italics from authors).

But it is also important to point out that there is a ‘structural fragility’ to belonging, that is a result of the complex context of austerity policies that make it more challenging “to meaningfully participate in their communities” (Kaley et al., 2021, pg. 13). They are further challenged by barriers in transportation and support that makes it harder to fully engage (Renwick et al., 2019).

Nevertheless, this work on belonging is important for understanding how people labelled/with intellectual disabilities interact both in their home and in their communities. While neither Kaley et al. or Renwick et al. focus specifically on the home as a space of belonging, they clearly outline how belonging is a result of processes of feeling safe and accepted, and connected to others, relating to the ideas of being ‘in place’ and ‘at home’ that echo those of home-making. It is these feelings of belonging that ultimately shape how people feel inside and outside of the home and thus shape their lived experience.

Chapter 3: Ontario Context

With the rationale for this research developed in Chapter 1, and having situated the research project within the broader geographies of disability, it is now important to understand the context of Ontario in which the research was conducted.

3.1 Housing in Ontario

The range of housing types for people labelled/with intellectual disabilities more broadly was discussed in Chapter 2, however it is useful to include some context here about the housing types within Ontario and Canada specifically. This relates to the policy and funding structures in place in the province and directly influences the choices of housing available to people labelled/with intellectual disability. It is important to note that the statistics used here are estimates, as there are no detailed records of how many people are diagnosed with an intellectual disability in Canada or Ontario. A report from the CACL says that this population is estimated to be approximately 1% of the population but that this is likely an underestimate (Crawford, 2008). This lack of data is problematic as policy around housing is based on the numbers of people so labelled and their housing needs, yet there are no clear statistics of what this looks like. This issue will be further discussed later in this chapter.

Family home. In Ontario, as in Canada, the majority of people labelled/with intellectual disability live with their parents (DuBois et al., 2019; Atack et al., 2019; Crawford, 2008) with only 18,000 of roughly 66,000 adults in Ontario receiving residential supports outside of the family home, for example in supported independent living or group homes (DuBois et al., 2019). This is in spite of the fact that recent statistics indicate that adults labelled/with intellectual disability increasingly wish to live more independently, with the number awaiting residential services in the province increasing by 50% from 2009-2014 but only a 1% increase in those being served (Ministry of Community and Social Services, 2016, as cited by Verseghy et al., 2019). While not every person labelled/with intellectual disability wishes to leave their family home (Crawford, 2008), these statistics show that many would like to have the opportunity and are limited in their ability to do so. A study by Verseghy et al. in Toronto interviewing people labelled/with intellectual disabilities, their families, and support workers, found that the main challenges to finding alternative housing are availability, affordability, and security (2019).

Group home. Following the trends internationally, group homes are the favoured alternative to the family home within Ontario, and they receive roughly 78% of the budget for residential services (Spagnuolo, 2016). However, this only services a small percentage of the population and the institutional structure of group homes limits the agency of people who live there. Moreover, group homes still remain underfunded and overpopulated to really support the needs of residents (Spagnuolo, 2016; Koenig, 2015, as cited by Atack et al., 2019). Group homes in Ontario have additionally been critiqued as being 'institutions without walls,' following a report by the Ombudsman in 2016, because of the regimented structure and limited freedom of residents to choose when and where they can go (Spagnuolo, 2016; Wilton & Fudge Schormans, 2019). Placements within group homes are also subject to repeated assessments, which means that qualification for a placement may change over time based on perceived support needs of the individual by the organization's staff (Spagnuolo, 2016).

The 'back wards.' An Ombudsman Report in 2016 also showed that many people so labelled end up 'institutionalized by default' in the 'back wards' of institutions, for example in hospitals, prisons, nursing homes, or shelters because their needs are considered too high or too risky to be placed elsewhere (2016). The Ombudsman report released in 2016 stated that roughly 250 individuals labelled/with intellectual disabilities reside in hospital or other institutions because they are unable to find a suitable residential option (Ombudsman Ontario, 2016). However the 2018 budget lists this number closer to 800 (MCSS, 2018). Treatment within hospitals and other institutions is reported as severely detrimental to health and relies on managing behaviours with medication and physical restraints (Spagnuolo, 2016). One of the stated goals of the funding increase in 2018 was to remove these institutional accommodations (MCSS, 2018), however it is not clear whether this has been successful.

Alternative housing. Alternative housing in Ontario can be separated by those created by the province, and those that are created by individual families or service organizations in response to the constraints of the system. Within Ontario, alternative housing includes the Housing Task Force and the Host Families program. The Housing Task Force, introduced by Developmental Services Ontario as a part of the funding increase in 2018 was created in response to the 2016 Ombudsman report (Housing Task Force, 2016). This program has funded 18 alternative housing initiatives for adults labelled/with intellectual disabilities within Ontario and many report being successful in promoting better community inclusion and independent living outcomes (Housing Task Force, 2016). These have ranged from fully independent to supported housing situations (Housing Task Force, 2016). However, many of these projects include only one or two individuals and it is not clear if more funding will be available for similar initiatives in the future or if they can be scaled up.

Another alternative housing program available through the Ontario government is the Host Family program. This program allows a person labelled/with intellectual disability to live with another family, members of whom act as caregivers and are remunerated for this service (Developmental Services Ontario, 2016). There is extensive vetting of the potential Host Family, who must be trained by a service agency (Developmental Services Ontario, 2016). This program focuses on set screening and matching processes to create matches between individuals and families (Developmental Services Ontario, 2016). Approximately 1,500 people live with Host Families in the province (Riordan, 2017). In 2016 new policy directives were implemented to better protect those living with a Host Family, following concerns over the unregulated nature of the program after a resident was found dead in his home (Riordan, 2017). There are no updated details on how successful this directive has been in facilitating better living standards.

Both the Housing Task Force and Host Family program are part of movement within the province towards more novel housing models. However, in spite of the added funding there are still limited choices for individuals labelled/with intellectual disability to move out of the family home, especially for those relying solely on government funding (Verseghy et al., 2019; Grey et al., 2015; Hole et al., 2015). Due to the limited choice, alternative forms of housing can have long wait lists, with many waiting as long as 22 years for a place within the province (Spagnuolo, 2016), which limits the ability to find alternatives within the provincial housing system.

Despite these constraints with provincial programs, many families in Ontario and in other provinces have worked to create novel housing solutions that have the potential to change the way home is conceived of by people labelled/with intellectual disabilities. These alternatives include some mentioned below, but also a vast array of unique housing situations, such as co-operative housing, finding housing with other individuals so labelled, or living with students who provide informal support (Verseghy et al., 2019). These living situations are driven by frustration or desperation on the part of families, who are unable to find appropriate housing through the government system (Verseghy et al., 2019).

The alternative then for many families in Ontario is to find housing opportunities outside of the provincial system. An example of this is the ‘Friendly Housemates’ model, fully outlined in Chapter 2, that was part of a research project by Atack et al. that matched people labelled/with intellectual disability with students as their housemates (2019). The researchers found this to be overall successful, though there were challenges in navigating the relationship as a housemate for both people (Atack et al., 2019). Yet this program required families to have enough financial stability to fully pay for the housing of the people labelled/with intellectual disability, meaning that this is only an option for those who can afford it (Atack et al., 2019).

Other alternatives are working with housing service organizations, such as LIGHTS in Toronto, supported by Community Living Toronto (LIGHTS, 2021). Originally created in 2010 by parents wanting to address citywide housing shortages, LIGHTS has worked with over 100 families to create person-centred plans and find housing arrangements that work for them (LIGHTS, 2021). This includes finding housemates for people labelled/with intellectual disabilities who share similar goals and want to transition to independent living (LIGHTS, 2021). However, volunteers still largely run this project, with the exception of two full-time facilitators, and it relies on private funding to operate which limits the number of people who can be helped at a given time (LIGHTS, 2021).

The types of housing available and the way they are allocated are directly linked to policy and funding in Ontario, as both of these enables or constrain different types of housing available to people so labelled, and also provide individual funding to those seeking housing outside of the family home.

3.2 Policy

Policy in Ontario relating to people labelled/with intellectual disability is mostly found within more general disability policy. The exception to this is the *Social Inclusion Act (2008)*, discussed in detail below. Laws in Ontario are broadly understood under the Canadian Charter of Rights and Freedoms, specifically Section 15, beginning in 1985, which "guarantees the right to equality before and under the law, and to equal protection and benefit of the law, without discrimination based on, among other grounds, physical or mental disability" and the "right to inclusion and participation, and advancing the principles of accommodation" (LCO, 2020). These are in keeping with the UNCRPD's Article 12 (equal recognition under the law) and 19 (living independently and being included in the community), discussed in the introduction.

Disability laws in Ontario fall into three main categories, as presented by the Law Commission of Ontario. The first encompasses laws that promote removing barriers for persons with disabilities, such as the Ontario Human Rights Code, the Ontarians with Disabilities Act, and Accessibility for Ontarians with Disabilities Act (AODA) (LCO, 2020). The second category covers access to benefits, supports, and accommodations for persons with disabilities, such as the Ontario Disability Support Program (ODSP) which is discussed in further detail below, and the Workplace Safety Insurance Program, as well as some tax benefits and programming (LCO, 2020). The third category are laws that restrict the roles, activities or decisions of persons with disabilities, based around ideas of mental capacity (LCO, 2020). The most relevant of these to intellectual disability is the *Substitute Decisions Act (1992),* based on the assessment of the cognitive ability of a person in order to ensure they understand their legal rights (LCO, 2017). Assessments of 'capacity' are based on IQ levels and medical diagnoses of disability (LCO, 2017). Policies on this subject encourage substitute decision-making by the friends or family of a person labelled/with intellectual disability when they have been found legally incapable (LCO, 2017). This highlights a tension between Article 12 (equal recognition under the law) of the UNCRPD and the interpretation Canada has of that document (Stainton, 2016). The CRPD Committee “has urged Canada to amend [substitute decision-making] laws and respect Article 12 of the Convention” (CRPD, 2016, pg. 1-2, as cited by Spagnuolo, 2019, pg. 52). However, while Canada has placed emphasis on supported decision-making, it has not ruled out the possibility for substitute decision-making, depending on the ‘legal capacity’ of the person in question (Stainton, 2016).

Within Ontario, the systems responsible for assessing legal capacity are decentralized and complicated to navigate, making it difficult for families and even for service agencies to understand (LCO, 2017; Linton, 2021). This has meant that the default is often to substitute decision-making, because there is no framework or guide in place for facilitating supported decision-making (LCO, 2017). The Canadian Association of Community Living has recently called on the Ontario government to make changes towards supported decision-making and has proposed a framework similar to the ones used in B.C. in the *Representation Agreement Act,* (1996) (Stainton, 2016). As of now there has been no moves towards this from the province and guardianship in Ontario is still predominantly decided based on medicalized assessments of capacity (Santinele Martino & Fudge Schormans, 2018).

3.2.1 Social Inclusion Act

Within Ontario, the main policy that relates specifically to intellectual disability is the *Social Inclusion Act*. The *Social Inclusion Act* is influenced by the UNCRPD and was originally passed in 2008 (Ontario, 2021). This Act replaced the 1974 *Developmental Services Act* and included more provision for independence and choice in community living, as well as laying out easier forms of assessment and simplified processes for accessing supports (Ombudsman Ontario, 2016). Under the Act, person-directed planning means the creation of services and supports that help people labelled/with intellectual disabilities in identifying their life vision and goals, as well as aiding in finding services and supports that meet their identified goals, with the help of their families or significant others of their choice (Ontario, 2021). This is in keeping with the global understandings of person-directed planning and self-determination. These changes are meant to roll out in stages but are not yet become fully operationalized so many of these elements are not yet in place (Ombudsman Ontario, 2016). The Act also created 'application entities' which are single access points for services in Ontario, who are responsible for determining eligibility for services (Ombudsman Ontario, 2016). These application entities, called Developmental Services Ontario (DSO) offices, operate as non-profits under the Ministry of Community and Social Services (MCSS) (Ombudsman Ontario, 2016). However, while meant to be based on principles of self-determination, the creation of 'application entities' in reality has resulted in arbitrary assessment practices and access to services that is determined by each individual service agency, with no province wide monitoring system (Spagnuolo, 2016). Assessment is further based on IQ and cognitive testing, which continues to follow the medical model of care based on perceived capacity and need (Spagnuolo, 2016). While purported to be based on individualized care and more independent housing for people labelled/with intellectual disability, the Act has been extensively critiqued for its focus on group homes and arbitrary assessment procedures (Spagnuolo, 2016).

Recent papers examining the application of the Social Inclusion Act shed further light on the inadequacies of this legislation. For example, "Supported Group Living residences and Intensive Support residences, which are owned or operated by a service agency" are able to be inspected without a warrant, including in semi-independent living spaces (section 28(3)), which limits the ability to have a truly private space (Butler, 2020, pg. 35). This is in spite of pushback from People First of Ontario on this issue (Standing Committee on Social Policy, 2008, as cited by Butler, 2020). The Act also does not contain any mention of rights for people receiving its services and supports, such as the right to appeal (Butler, 2020). The complicated provincial system has created "jurisdictional inconsistency" because there is no consistent oversight body and many institutional actors (Linton, 2021).

3.3 Funding

Studies interviewing people labelled/with intellectual disability have cited financial concerns as a key determinant in their ability to find housing (Verseghy et al., 2019; Bigby et al., 2017). Discrimination in finding employment (Dew et al., 2018) and a lack of accommodation from employers (Petner-Array et al., 2015) mean that many people so labelled must rely solely on government funding or family finances to pay for housing (Verseghy et al., 2019). With this in mind, the funding mechanisms in place in Ontario are also important to examine. The main forms of funding for people labelled/with intellectual disability are the Ontario Disability Support Program (ODSP) and Passport funding.

The Ontario Disability Support Program (ODSP) is the main mechanism that the MCSS uses to provide funding to people labelled/with intellectual disability for housing and other basic needs (Kerr et al., 2019). The maximum amount of funding available per month through ODSP as of 2022 was $1,169, accounting for both basic needs (food, clothing, etc.) and shelter allowance (rent, utilities, etc.) (Ontario, 2022). While this amount may be adjusted based on needs, it has been critiqued as being insufficient and restrictive (Chouinard & Crooks, 2005;

Smith-Carrier et al., 2017) and based on medical model conceptions of disability (Smith-Carrier et al., 2017).

The Passport program is the other main source of funding available to adults labelled/with intellectual disabilities in Ontario and is run by DSO (DSO, 2014). The person labelled/with intellectual disability is responsible for applying to the Passport program and funding is allocated based on high, medium, or low priority factors, such as medical or behavioural requirements, or other supports available (Ombudsman Ontario, 2016). A 2018 funding announcement from the province changed the qualification from needs-based allocation to inclusive funding, meaning anyone eligible will receive at least $5000 per year (MCSS, 2018). Passport funding can be used for expenses relating to community participation, activities of daily living (ADL), and person-directed planning with the stated aim of encouraging social inclusion into the community (DSO, 2014). It is based on a reimbursement system, meaning that families must first pay for services out of pocket (Verseghy et al., 2019). As of 2020, funding through Passport has temporarily expanded to include technology, home-based recreation, PPE, and behavioural support plans (MCSS, 2020) in response to the COVID-19 pandemic. Passport funding cannot be used for housing expenses, necessities covered by ODSP, or internet and cellphone payments (DSO, 2014).

In addition to the individual funding mechanisms, the majority of funding allocated for residential services is provided through the MCSS to the application entities set up by the *Social Inclusion Act*, known as TPAs (Transfer Payment Agencies), who received roughly 78% of the residential services budget in 2013-2014, equalling $1.16 billion (Spagnuolo, 2016). Transfer Payment Agencies “provide residential accommodations and supports” to people labelled/with intellectual disability, with the majority of this support taking the form of group homes

(Spagnuolo, 2016). In 2018 under the liberal government, Developmental Services Ontario received an additional $1.8 billion in provincial funding to improve the experiences of Ontarians labelled/with intellectual disabilities (MCSS, 2018). The stated goal of this funding increase is to create new residential support options for people so labelled in response to criticisms that the system is not flexible enough to accommodate individual needs (MCSS, 2018).

3.4 Critiques

As was alluded to earlier, ODSP has been critiqued in recent years as still being rooted in the medical model of care and based in 'denial by design' because of the heavy emphasis placed on impersonal assessments, the need for proof of diagnosed impairments, and extensive application paperwork (Fraser et al., 2003, as cited by Smith-Carrier et al., 2017, pg. 1578). This creates pressure on an individual seeking funding to prove that they are 'disabled enough' to receive the benefits (Lightman et al., 'Not Disabled Enough,' 2009, as cited by Smith-Carrier et al., 2017). The implications of this are that people in need of funding may be denied (Smith-Carrier et al., 2017). The restrictive and insufficient funding available means that those receiving ODSP are frequently still well below the poverty line (Chouinard & Crooks, 2005; Smith-Carrier et al., 2017).

A critique of the Passport program is that it still relies heavily on medical evaluations to measure service usage (Spagnuolo, 2019). It uses the Supports Intensity Scale – Adult Version (SIS-A) by the American Association of Intellectual and Developmental Disabilities (AAIDD), which MCSS pays a significant amount for training and use (Spagnuolo, 2019). In 2017, the MCSS paid $14M to the DSO, and two of the three funding streams were specifically for SIS assessments (Spagnuolo, 2019). The default for SIS is to have a support person there to help the person complete it, and this is waived only if someone isn't available or if the person has a ‘strong preference’ to represent themselves (Spagnuolo, 2019). The issue here being that support is the default rather than an option. The second issue is the amount that the MCSS is paying for this assessment. While the *Social Inclusion Act* does not explicitly reference IQ testing, people undergoing SIS assessment often require “an external psychological examination that demonstrates a level of incapacity,” (Spagnuolo, 2019, pg. 105) meaning that services received are still largely based upon notions of intelligence.

Passport funding is also critiqued as promoting an ‘economy of uselessness’ “wherein individuals are ranked according to their in/ability to model forms of independence that dominant groups (specifically those without an ID) identify as useful.” (Spagnuolo, 2019, pg. 90). The Passport program still requires administration through an outside agency to administer it and is based on the goal of *independence*, the nuance of which was discussed in Chapter 2 (Power, 2006; Spagnuolo, 2019). There is finally the issue of ‘direct’ funding language, which is problematic since funding is channeled through non-profit organizations and *then* to the individual rather than going *directly* to the individual (Spagnuolo, 2019).

The shift to Passport funding also has impacts on the people providing paid care to people labelled/with intellectual disability. The shift towards independent contracts means there is less data collection from personal support workers because they are considered to be independent of a regulatory body (Kelly & Bourgeault, 2015 as cited by Linton, 2021). There is also not enough money to pay for respite care and so care workers are often underpaid for their labour (Fernandes, 2020). They are also expected to take on more tasks, i.e., helping with paperwork, without any increase in hours (Fernandes, 2020). Care work funding, through Passport, is limited in scope and makes providing support more precarious to both those giving and receiving care (Fernandes, 2020).

It is therefore evident from these critiques that despite the messaging of self-determination and choice from the *Social Inclusion Act*, there remain many challenges in its implementation, rooted in the bureaucratic structures of funding and allocation of funds based on outdated ‘priority’ measures. The limited funding available for housing through ODSP means that those looking to live outside of the family home, especially in higher cost cities, are unable to afford it (Verseghy et al., 2019). Long wait lists for subsidized housing through the provincial support network mean that those wishing to move must wait as much as 10 years for a placement, with little option as to where and what that dwelling looks like (Spagnuolo, 2016; Verseghy et al., 2019).

Finally, as was noted at the beginning of this chapter, there are there are gaps in the available data for people labelled/with intellectual disabilities and this has a direct impact on the policy landscape and the services that they receive. Linton, in a recently published paper, noted that those residing in institutions were excluded from census data, effectively erasing them from larger data sets (2021). In the current model of decentralized care, the complicated system of service provision has meant that very little information is collected about how services are used and who might be denied by the system (Linton, 2021). Despite the stated aim of the *Social Inclusion Act* to create one, there is no current central data collection system in place in Ontario, meaning that there is no way to examine the ways in which people are using the current funding and service systems or what needs aren’t being met (Linton, 2021). This is deeply problematic for trying to understand how to improve the current service system or for finding out what proportion of the population is receiving supports.

These limitations of both policy and funding hold significant implications for how people labelled/with intellectual disabilities experience home, as well as shape the living arrangements to which they aspire. By limiting what kinds of home are available, for example through having the default to group homes and constraining the funding available for alternative models, people so labelled experience restricted choice and are more likely to stay in their family home (Verseghy et al., 2019).

Chapter 4: Methodology

4.1 Research approach and design

This research project was designed based on practices of participatory geographies, which are rooted in the need for social change while also de-stabilizing ‘academic-as-expert’ forms of knowledge (Askins, 2017, as cited by Fudge Schormans et al., 2019). Semi-structured interviews and an arts workshop, in a combination of in-person and virtual formats were used. At each stage of the project, participants were asked to check over their responses and make changes, to ensure their experiences were being represented in ways that felt right for them. The use of multiple research methods, particularly that of the art-making, allowed for participants to express themselves beyond just verbal answers to questions, and creatively think about what their future might look like.

While the forms the research took were chosen by the researcher, each was chosen to facilitate more meaningful participation of participants labelled/with disabilities throughout the project, the details of which are discussed further below. However, due to the time constraints of the masters thesis, the wider dissemination of research that is typical of participatory geographies, for example of presenting research to the broader public, was not possible in this project.

Ethics approval for this project was obtained from the McMaster Research Ethics Board (MREB), with an additional approval from the Associate Dean (Research) to conduct the arts workshops in person in the context of the pandemic. While many studies have noted the challenges in obtaining ethics approval for research involving people labelled/with intellectual disabilities because of worries about risk and vulnerability (Dee-Price et al., 2020; McDonald et al., 2017; Santinele Martino & Fudge Schormans, 2018), MREB had relatively few issues with the proposed research project.

This research project uses a relational approach to understand the ways that experiences of disability interact with social and physical environments. This follows the trend in geographies of disability towards thinking of a relational sense of space (Murdoch, 2006, Massey 2005, as cited by Hall & Wilton, 2017) whereby disability is a relational process “between bodies, objects, and spaces that combine to shape subjective becoming” (Hall & Wilton, 2017, pg. 731). In the context of this research, this means understanding the ways in which disability is experienced by an individual but also (un)done by the spaces in which people live and their relationships with others (Morrison et al., 2020).

4.2 Recruitment

Recruitment was accomplished by reaching out to service and advocacy organizations for people labelled/with intellectual disabilities in the GTHA. This was done by first reaching out to an administrative contact for the organization and asking them to circulate a letter of information about the study (Appendix A) or asking them to reach out to people they feel might want to participate in the research. At each stage it was emphasized that participation in the research was voluntary. Participants were given a copy of the interview guide (Appendix B) and informed consent form (Appendix C), both in plain language, in advance to review, and also read them with the researcher before each interview began. The researcher initially communicated through email or by phone with people interested to ensure they understood the research process and what they might be asked. If they agreed to participate, next steps were then discussed and a date set. An honorarium of $40 was given for each interview, and $80 for the art workshop, to recognize the longer amount of time for this piece. Participants were informed they could have a support person present with them for any of the stages of research, and five participants chose this option, with three parents present, and two support workers.

4.3 Participants

A total of 11 participants, four women and seven men, were recruited for this study. A chart with their details is included below. Ages ranged from late teens to late 60s and included participants from across the GTHA, with the exception of two participants living near Ottawa, Ontario. Participants were asked at the end of the project what their preferred pseudonym would be. Those who did not have a preference were assigned one at random.

Name	Description
Lily	• She/her • Early 30s • Paying rent in her parents home (mother, father) • Has previously lived outside of the family home both on her own and with a roommate • Lives in an urban neighbourhood
Timothy	• He/him • Early 30s • Lives in the family home (grandparents, mother) • Lives in a suburban neighbourhood
Oliver	• He/him • Mid 20s • Lives in the family home (mother, father, brother) • Lives in a suburban neighbourhood
Lear	• She/her • Early 30s • Lives in a transitional home for women • Has previously lived with a partner • Lives in an urban neighbourhood
Jack	• He/him • Early 30s • Lives in the family home (mother, father) • Lives in a rural area
Catherine	• She/her • Early 30s • Lives in two separate family homes (parents divorced)

	• Lives in an urban neighbourhood (for both)
Jonathan	• He/him • Early 30s • Lives independently in an apartment • Lives in an urban neighbourhood
Alejandro	• He/him • Early 20s • Lives in two separate family homes (parents divorced) • Lives in a suburban neighbourhood (for both)
Ruth	• She/her • Late 60s • Lives independently in an apartment (through Toronto Community Housing) • Lives in an urban neighbourhood
James	• He/him • Late teens • Lives in two separate family homes (parents divorced) • Lives in a suburban neighbourhood (mother), urban neighbourhood (father)
Alan	• He/him • Mid 30s • Lives in the family home (mother) • Lives in an urban neighbourhood

4.4 Data collection

Interviews. Two semi-structured interviews were conducted with participants, each ranging from 10-60 minutes. A week prior to the first interview, the researcher circulated the letter of information, interview guide, and informed consent, each written in plain language. Before the interview began, the researcher and participant went over the informed consent form and paused for any questions that might have come up. The first interview roughly followed the interview guide, with some prompt questions for statements that needed clarification. Following this, participants were sent a summary of their answers to review and suggest changes. Prior to the second interview, informed consent was again circulated as well as read with participants before the interview began. The second interview allowed for participants to clarify any of their responses and the researcher to ask any further questions that had come up, again with a summary being sent to participants after. This reiterative process was important for allowing participants time to think and reflect on their answers, and make sure their thoughts are being clearly articulated and understood. It also allowed participants to take time to fully express themselves, even if they became tired or overwhelmed in the first interview.

Art Workshop. Of the 11 participants, 8 took part in the arts workshop. Originally designed to be a group activity, the format of the workshop was changed due to the constraints of the pandemic and the associated health concerns and challenges of facilitating the exercise as a group virtually. Participants were given the option to meet in person one-on-one with the researcher to complete the artwork, or offered the option to meet virtually one-on-one, based on their comfort level. Four meetings were completed virtually, and four in person. Participants were able to request materials in advance and worked collaboratively or independently to complete their art – with one piece based on their current home and one piece of their ideal future home. Limited guidance was given in order to allow participants to choose what felt right for them, but prompts were offered around what felt important to them and what they felt encapsulated both their current home and their ideal future home. Participants could ask for whatever materials they wished for, and the researcher mailed them out in advance for those participating virtually, or brought them on the day for those in-person. Materials chosen included markers, pencil crayons, paint, photographs, and catalogues (IKEA was used for two of them). A number of the artworks are shown in Chapter 5, and the entirety of the art produced, as well as the chosen materials of each, can be found in Appendix D. The artwork demonstrates a diversity of thoughts and feelings about the home. An arts facilitator was offered in support participants who did not feel comfortable actually doing the art themselves, and one participant (Jack) used this resource. This was a shift from the initial planning of the project, whereby the researcher and facilitator planned to co-facilitate a group workshop. Instead, in-person meetings were collaborative between the researcher and the participant, working together to figure out what the final form of the art would be. Virtual meetings were adapted to have the participant complete the work alone (with support if needed) and the final artwork was discussed over Zoom with the researcher.

The choice of an arts workshop as the final stage of this project was informed by the recent emphasis within the social sciences on the use of art as a form of communication device. The use of both semi-structured interviews and arts-informed work in this project was designed to promote full engagement of participants by providing multiple avenues for involvement (Dew et al., 2018). Visual arts methods have been proven to be particularly useful as a more accessible research method compared to traditional interviews (Richards et al., 2019) because it relies less on verbal communication and participants can more easily elaborate on experiences that may be difficult to put into words (Dew et al., 2018; de Jager et al., 2016). It also puts participants on a more equal footing with researchers by putting the creation of data in their hands (Dew et al., 2018). Several participants spoke about the benefits of visualizing their ideal home in the alternate medium of the artwork.

4.5 Data analysis

Analysis was conducted following Braun & Clarke's thematic analysis approach (2006). Interviews and workshops were audio recorded and transcribed verbatim by the researcher, following which the data was coded using NVivo, where it was reviewed multiple times to ensure nothing was missed in the coding process. The initial codes were reviewed with her supervisor, and then themes were drawn from this, to again be reviewed and structured into the format and content of the analysis. The structure of analysis, which separates current processes of home-making from the ideal home, with sub-themes of the characteristics of home, household types, relationships, support, and neighbourhood, are discussed in-depth in Chapter 5. A discussion of COVID-19 is included as well, to acknowledge the impact this has had on participants' lives.

Following the write-up of the analysis from the research, a short summary of the overall findings of the research, along with the quotes used from participants, were sent back to them for feedback, in order to review what quotes had been chosen and ensure this was what they had wanted to say. Several weeks were given for participants to look over these findings to ensure they had time to review it, with the option of meeting virtually with the researcher to make any changes they wished for. This final review of the research by participants allowed for them to be fully in control of how their experiences were communicated.

4.6 Limitations

As was alluded to earlier, there are time challenges of the chosen method, both in terms of the actual data-collection, and the dissemination. This method of arts-based research takes longer than traditional interviewing practices. To account for this, participants were compensated $80 for their participation in the workshop in acknowledging the longer length of time it took for them to complete the activity. The dissemination of the research could have been much more substantial, including presentations in public or other media forms, however, the length of time available in the masters did not allow for more extensive research dissemination typically associated with participatory research methods (Fudge Schormans et al., 2018).

There were also limitations in the data collected. As this was the first time the researcher had undertaken a project of this scale, there were some elements that could have been further asked during interviews that would have been useful in hindsight, for example of asking more specifically about disability resources used and what organizations they receive support from to access it. The researcher did not ask for this from every participant and so it is only available from the participants who volunteered it. Additionally, this project only connected with people with mild-to-moderate intellectual disability, through selection of members by service agencies limiting people with higher support needs from participating (Wilton et al., 2017).

Additionally, the need for some participants to have support for participation (carers, researchers, etc.) reduces their control over the end product and their ability to communicate their own thoughts (Richards et al., 2019). While for many participants a support person was necessary to facilitate the interview, both to make them more comfortable and to help with answering questions they weren’t sure of, it did mean in some instances the support person spoke over the participant. Wherever possible, the researcher steered the question back to the participant but in some cases this was not possible.

The research also contained a small sample size. However, this is accounted for by the rich detail offered by the two interviews and art, to ensure that each participant had provided as much detail as the time allowed. This is by no means meant to be a representative sample of the population, but more to emphasize the need for future work in this area, particularly in asking people labelled/with intellectual disability themselves what it is that they want from their futures, and what they think the challenges are for this.

Chapter 5: Analysis

5.1 Making Home

This section will focus on how the participants of this study are currently making home. The conscious choice of the word ‘making’ rather than ‘experiences of’ alludes to the active process of creating home that participants are engaged in their everyday lives. This is not just a narrative of their house but an illustration of the understandings, feelings, and relationships, which are actively created and shaped by the participants that go beyond just a description of a physical space.

Drawing on the literature in Chapter 2, this analysis demonstrates how the home is fundamentally connected to both the material elements of the dwelling and the social and emotional relationships experienced inside and outside of it (Blunt & Dowling, 2006). While starting within the physical structure of a home, it also importantly includes experiences in the community, creating the feelings of ‘insideness’ and ‘outsideness’ used by Laschewicz et al. (2019). It is these experiences which can create feelings of (not)belonging, as outlined by Antonsich (2010), Renwick et al. (2019), Morrison et al. (2020), and Kaley et al. (2021). The nuance of this will be furthered in the discussion in Chapter 6.

Home is thus used here in a broader sense beyond just the bricks and mortar building in which people reside. Home extends to include the neighbourhood, social relationships, and networks of support that work together to create a feeling of being ‘at home’ (Blunt & Dowling, 2006). Home does not happen in isolation from what is around it: people move in and out of home space and are engaged with the people and spaces around them, and so this broader definition acknowledges the relational and spatially expansive nature of the home. This section will therefore cover not only the types of home that people live in, and the people they live with, but also the characteristics of the neighbourhoods around them, the people they are in relationship with both in and outside of their home, and the networks of support, both paid and unpaid, that help them. It will also speak to how people feel in their home, and what they are missing from it. Each of these elements influence how home is understood by the participants and shape the broader structure of their lives.

The experiences depicted here vary widely and cover a wide range of living arrangements. For a detailed chart of some of the characteristics of the participants of this study, refer to Chapter 4. Wherever possible this variety has been shown, while also connecting some of the key similarities across participants' experiences. Throughout the analysis, the artwork made by participants is included to further demonstrate or elaborate on points that were made in the interviews. Wherever possible, quotes from participants have been used to convey their own experiences spoken through what they said, rather than interpreted by the researcher.

An important consideration is that this research took place during the COVID-19 pandemic. This has in many cases drastically changed the way participants interact with their physical homes, and the spaces and people around them. To account for this, the ways in which COVID-19 has changed their home life will be discussed at the end of this section. Note that this has been done purposefully so as not to fully remove the agency of the participant by shaping every experience around COVID-19, however, given the impact that it has had on housing and services, it does still have a place within this discussion. We will now turn to how participants are actively engaged in making home.

5.1.1 Physical Home

It is interesting to note that, although the project asked about home, very few of the participants spoke at length about the actual physical space of the dwelling. The only times this came up was in thinking about their favourite and least favourite parts of home. In these, there are a wide variety of responses.

Some responses focused very specifically on physical elements of the house they liked and disliked, for example Catherine said she liked the downstairs bathroom in her home because “it’s private, like, there aren’t any windows, and the upstairs bathroom has a little window.” Her worry here is that “the neighbour next door can look in and see” in the case of the upstairs bathroom. For her, the physical construction of privacy in this bathroom space is important for feeling safe. Jack spoke about the gym in his house, which he uses daily, as his favourite part of the home, shown in the artwork below. The gym is an important piece of his health, as he works towards healing from an Acquired Brain Injury. Alan said his favourite part of his home is the kitchen and cooking, “that’s my favourite thing to do” and that he and his mom share the responsibility for cooking. This shared activity is what makes the space feel important for him.

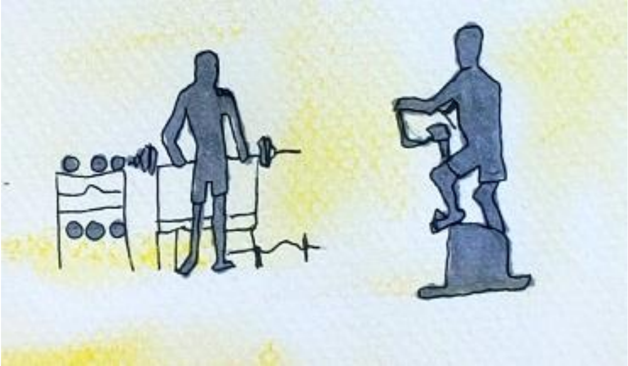

Figure 1. Jack’s artwork – the gym

Likewise, some least favourite parts of the home were features of the home itself, such as Alejandro’s dads’ basement, which has low ceilings he knocks his head on frequently, making it hard for him to navigate the space. Oliver also spoke about the basement, specifically the boiler room because “it’s loud and kind of hot. And it’s also where the freezer is, so that’s um, it’s kind of annoying to have to reach down and get it too. And it’s one of those like small freezers that have the open top.” Again, the layout and conditions of the room are what influences the feelings attached to it. In each of these examples, the physical construction of the home influences how that space feels to the participants, in these cases the way that a room is laid out or the objects in it influence how they feel there, both positive and negative.

Conversely, participants also spoke of more relational parts of the home when thinking about their favourite and least favourite parts, such as the people in it, rather than the physical features. Lear, who lived in a group home, spoke to the fact that she loved “being around the women [in her home] and going through, uh, uh, emotions with them. Just being with them, and learning about them, and being ourselves.” James’ favourite part of his house is being near his mom, saying “um, I like to sleep next to [her] because I love my mommy.” Conversely, Ruth liked the fact that it is only her in her space, saying she liked “being by myself in my apartment” and that this allowed her to go out when she wanted but also spend time alone. These examples speaks to the relational nature of home-making, as the social and emotional ties in the home are just as important as the physical structure itself. The people (or lack thereof) within the home shaped how participants interacted with that space, and with those people, shaping how they felt in their home.

5.1.2 Living Arrangements

With this in mind, this section will focus on the types of homes in which participants live and speak to what the experiences are within those homes, as who they live with, and what those relationships look like, is a meaningful component of home-making. The section will include a few broad categories, including the family home, independent living, and group home. In each of these categories it will examine the range of experiences within them and how this influences processes of home-making.

Family home. One of the most frequently represented types of homes that participants lived in was in their family home. Of the 11 participants, 8 lived in their family homes. This includes homes where participants lived with one or both parents, with siblings, and with extended family, such as grandparents. The size and shape of the homes themselves also varied but were exclusively single family detached houses. Again it is important to note that these experiences are not just guided by the material conditions of the home but are also influenced by emotional and social relationships, and by cultural expectations that shape participants' understandings of home and how they interact with it.

Five participants recounted overall positive experiences in their family home and expressed the desire to stay there. In some cases, this desire to stay at home was partly because of age. James and Alejandro (both in their early 20s) figured that moving out was a long way off and hadn't really considered what it would be like to live outside of the family home. Alejandro mentioned he didn't "plan on moving out [until he's] at least 30 or 31". As participants got older, it seemed like there was more pressure, either internally or externally, to move out of the family home.

In other cases, the desire to stay at home was because participants had lived already outside of the home and had moved back. Lily had previously lived both with a roommate and on her own and had moved home following this. She currently rents a room in her parents basement. She described this return move as "very therapeutic" and "so supportive, so loving." Although this move was beneficial for her, she noted that she "was losing somewhat of [her] independence" however, this was balanced with changing needs in her support, specifically in response to her dissociative disorder, which meant she needed more ongoing support in her home. Her dissociative disorder, a form of PTSD, means she can have episodes at any time, where "out of nowhere my brain sort of goes off into, like, somewhere else and I'm no longer, you know, I'm no longer me." This change in her support needs meant that she was no longer able to live independently, however she was quick to note this was not necessarily a bad decision for her currently.

Other participants noted that the family home was the only place they'd ever wanted to live, and they had no plans to ever leave. Alan, who lives with his mother, said repeatedly throughout both interviews that there was "lots of love in [their] house" and they were "happy to have [their] home." When asked if he had ever wanted to live on his own, the answer was a resounding no. Similarly, although Timothy was looking for another home, as he currently lived with his grandparents and mother, the future apartment would still be shared with his mother, and he did not want to live on his own.

Three of the participants who lived in the family home expressed wanting to move out of it during the interviews. When asked how he felt in his family home, Oliver said, "to be honest, like I've kind of outgrown it" and that he'd felt like this "for years." This feeling was linked to wanting to have his own space and the possibilities that are connected to that. These feelings are also linked to expectations of when to move out. For example when Catherine, when talking about how long she'd lived at home, said "and time to start thinking about moving out" as the next necessary step for her. She also spoke about how a friend of hers had moved out and that she'd like an apartment like her friends.' Jack, too, expressed frustration at not being able to move out, linked to needing to stay in the family home as part of his recovery from an acquired brain injury, saying his least favourite part of the home was "the fact that I'm so old and I'm still

– I'm still trying to recover this much" and that "someday I'm gonna walk out of here." For both Catherine and Jack their answers were linked to their age, both in their 30s, possibly referring to expectations they have of themselves, or beliefs linked to an 'appropriate' time to move out of the family home, in contrast to Alejandro and James, in their early 20s not really thinking about moving.

This range of feelings demonstrates that the home is not understood in black and white and is attached to many feelings and relationships. This also demonstrates the importance of the relationships to parents, and also to the family home as key in shaping the processes of home-making, and how those then shaped the participants experience in the home. The nuance of relationships with family will be discussed further later.

Living alone. Two of the participants, Jonathan and Ruth, live independently in apartment buildings and have a very different experience to those who live in the family home.

Ruth lives alone in a one bedroom apartment with a balcony and had been there for 17 years. She described the space as "not bad" and that "[she's] definitely happy where [she] is now." She spends most of her time there alone but stressed that she didn't feel lonely. Her daily routine consists of going out in the community using transit, although this has changed during the pandemic. She did not think she would ever move from where she was, mostly because of the restrictions on finding other housing that is similarly subsidized. While she spoke about a wish to live in a condo or similar building, she said that this will likely never happen because of the types of subsidized housing available, and the fact that she wouldn't be able to afford anything else. She also spoke to the fact that she had to wait 10 years to get into her current unit and didn't want to go through that process again.

Jonathan also lives in a one bedroom apartment and had lived there for 10 years. He commented that his everyday life is happy but also hard and has challenges, although the details of these were not clear. He sometimes has people visit his apartment and pre-pandemic spent most of his time during the day at CORE, which is an adult day program. He said he would like to move but didn't have many options and had a hard time navigating finding housing. In his art, he expressed the desire to move out of his apartment to somewhere closer to his family.

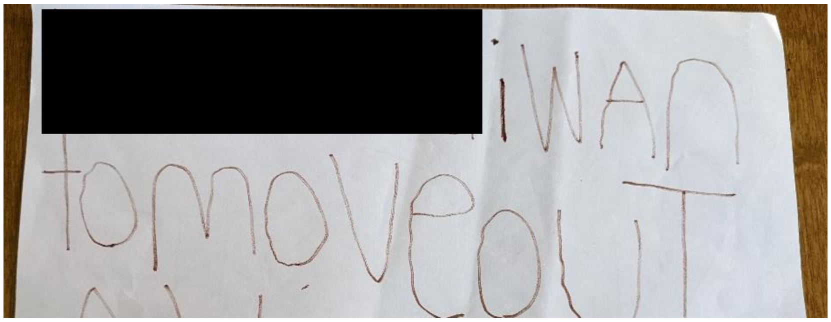
[redacted]

Figure 2. Jonathan's artwork - 'I want to move out'

In both of these cases, their space is influenced by how they feel within it and who is there, in positive and negative ways. For Ruth, the fact that she is alone in her space contributes to her feelings of being at home, whereas for Jonathan the opposite is true, and he wishes to be around people that he knows to feel more at home.

Group home. The final living arrangement that is represented by the participants is of a group home. Lear lives in a group home, specifically for women with mental health and addictions. The home has 10 women living there and she shares her room with a roommate. She described an overall very positive experience living there describing the ability to "think for yourself, uh, you can advocate for yourself, we can go out into the community and, um, learn from our mistakes." She said this has been better for her than her experience living at home because "it's a lot more independence." However, there was some worry that the current home she's in would soon be moving to a new space that would have less independence because "[the alternate living space] have a lot of rules in place for what I'm not used to and what I'm not, um, into right now. . . with curfew, and, um, yeah. I think it's more for people that are just getting out of hospital, and they need more level of care." This change is out of her control and other alternatives are currently out of reach stating that "I'll probably get [subsidized housing] in my 40s, yeah" and,

> Um, right now there's, I don't think there's anything for, I think there's L'Arche? Um, but that's not the care that I need, but I don't think there's something for the intellectual disability community, I don't think they've made any homes per se. They do have the roommates where you can go and live with them, that's what they started, but it's a little bit more expensive and our parents have to use their own money. So right now I'm looking for community living and I'm on the, uh, website for housing applications, so I'm in the process of that but they say it takes about 10-20 years just to get a one bedroom, basically.

Expressed within this is both a frustration with the options available to her and also a demonstration of the lack of flexible options available in general. It also speaks to the fact that the setting she is in currently, which she has had so much benefit from, is only temporary.

In each of the types of homes illustrated by the participants, there are both opportunities for agency and constraints of a broader system that limit their agency. In presenting both, the object is to show that in each lived experience there are feelings, expectations, and beliefs that play into the way home is created, no matter what shape the dwelling takes. These have important implications for the way home is perceived and goes beyond just the dwelling itself, but also the relationships within it and how those then influence experiences outside of the home.

5.1.3 Challenges in receiving support

Many participants are unable to move when or how they want because of a lack of available options. This means that even for those who are happy where they are for now, there is still an overarching restriction on what their options are. One of the issues pointed out was the complicated process of getting onto the waitlist for supported housing. When asked what the process of getting on the waitlist was like, Lear said “so I did that with my case manager three years ago, and she did most of the paperwork because I didn’t understand any of it. But, uh, they just said that, um, I guess for single mothers you would get a little bit more of a step up because, but my son I only have him on the weekends usually, so I, um, wasn’t able to do that so the one bedroom I have to stick with instead of a two bedroom.” This not only speaks to the challenges in being recognized as a mother by the funding system, but also her own struggles with understanding the process. She said that “I’m more in the backseat I just go along, yeah I’m not too much – I don’t really search for things on my own, my mom does it all and searches it.” In finding housing, someone else has to support her through the process, since it’s too complicated for her to be able to manage on her own.

This is echoed by Lily’s mom, who was present for her interview, explaining; “[u]m, [applying] was quite a lengthy process and it started just after Lily had just had this lengthy hospitalization, so she was still rather unstable. But she went through all the interviews and answered all of the questions. I mean she’s far better then now than she was then, five years later, so I think it will be time to revisit the application process and, um, she is on the list. As long as we’re able to continue to have her with us that’s fine but we’re both getting older, so we need to have a contingency plan in place in case of that emergency. And in that event if they were notified then there would immediately be – they would immediately step in . . . [a]nd the difficulty with the list is that they expanded the list to include people with learning disabilities not just developmental delays, so the list became so long, I mean there’s like 6000 people on it, so.” This worry of Lily’s mother, even though she is happy at home, is that they will only make progress on the waitlist if there is an emergency.

The other element brought up repeatedly was the length of time it takes to find a place. Lear said “[i]t is a long wait list, I wish it was shorter, but they said some people don’t even get in until they’re, like, 50 years old. It’s, yeah, it’s unfortunate.” Ruth, who had waited out that process already, said “[o]h yeah, I had to wait a long time, I think I had to wait, I think I had to wait, I don’t know maybe 10, 15 years? . . . [y]eah you’re on the waiting list for a very long time, you don’t get any easy- you start from the bottom and then you work your way up to the top . . . [because] there’s a lot of people on the waiting list, that’s the thing . . . [y]ou don’t get in fast, neither.” Lily echoed this, saying “I am on the list for subsidized housing and so, um, I’ve been on the waiting list, and it could take a long time.”

In addition to the waitlists there is also an uncertainty around where you might go when you do find a place; “I don’t- I don’t think I honestly think I’m going anywhere anytime soon. . . That being said the phone could ring tomorrow and be like ‘hey! You’re on! [O]h, a lot of uncertainty, but I also have the power I can say, you know, “no, that’s not, you know, that’s not where I want, you know, that’s too far away” or whatever, but then I know if I say no, then I- my names bumped.” There is also the element that if you say no, you will have an even longer wait period.

Beyond the constraints in finding a supported housing unit, there are also the current experiences of not having enough money even to cover it, or to have any other option. Catherine’s mom said, “[y]eah, Catherine is right, she has to have government funding or some kind of funding, because ODSP doesn’t go very far.” This worry was echoed by Catherine, who said “I’d like to try and have a job it’s just that I don’t have that much money, Sabine, like honestly I don't." In speaking about her own funding as she lives in a supported housing unit, Ruth said "I get $1562 plus the GAINS $83 but it's too separate cheques and I find it difficult cuz with the bills and stuff to pay and all that, I usually end up getting- getting- usually my cheque ends up gone in, um, in the middle of the month, like, uh, in, yeah- so that's the problem. It doesn't- it doesn't last long." This lack of money is reflected in her worry that "I don't have any extra funds to help me pay the bills. I wish I, uh- I wish there was an agency that would help me out, but- another agency, a different one, but, uh, I don't know if there's any around or not, I don't know." She said that she often has only enough money each month to cover her most basic expenses and this limits her ability to really engage out in her community with other people.

In each of these quotes a limitation is being expressed, created by the gaps within housing and funding support systems for people labelled/with intellectual disabilities, demonstrating the points made in Chapter 3. Despite wishing for a new space to move into or simply wishing for better supports, this is not available to many of the participants who need it or is only available many years in the future.

5.1.4 Relationships

As was alluded to before, home is constituted in part by the people who come in and out of it. For the participants in this study, this included relationships of family, friends, and paid support workers. These relationships are key in both processes of home-making and fostering belonging, as feelings of being 'at home' or 'in place' are shaped by how people labelled/with intellectual disability interact with those around them, as was illustrated in the Chapter 2.

Relationships for participants often include dimensions of support that can be difficult to navigate. It is this blurring of boundaries that has prompted the shape of this section, where the nuance of participants' relationships to those around them is depicted in ways that show both the elements of support given to them by others, but also the support that they themselves give to those around them, and the myriad of combinations in between. This draws on the concept of belonging set out by Kaley et al. (2021) and shows the ways in which relationships with others and in the community shape feelings of being ‘in’ or ‘out’ of place. It also speaks to the importance of these relationships to participants, as often one of the first things that came to mind in their discussions of current and ideal future home, something captured clearly in in the artwork of Timothy, Alan, and James.

Figure 3. Timothy’s artwork –people important to him

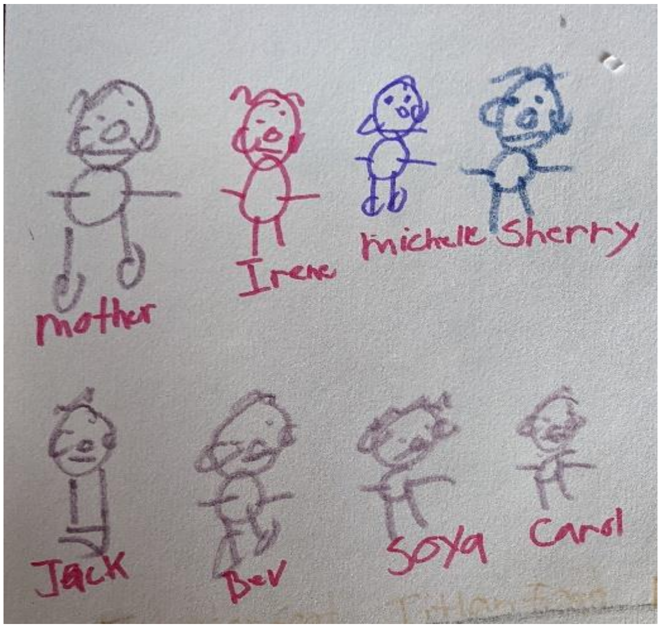

Figure 4. Alan’s artwork – people important to him

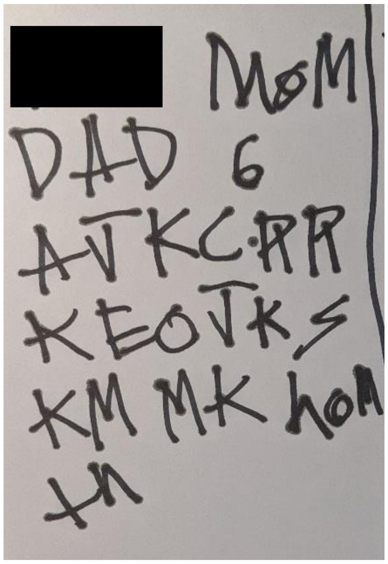

Figure 5. James’ artwork – ‘mom’ ‘dad’ and initials of people important to him

Family. One of the things that came out of this discussion of people was how important family is to participants. Alan described having a ‘good life’ in his interview, and when prompted on what that meant, he said that this was his family. “So your family is part of having a good life, yeah?” “Yes it is, yeah.” Similarly, during his interview Timothy was asked: “[i]s there anything else that stood out to you as really, really important to you for your life?" his answer was "[n]ot- just my family." Of these many familial relationships, two stood out as really important to participants, those of parents and of siblings. The parent and sibling relationships have been separated out from the broader family to focus on here.

Parents. The relationship with parents was discussed often by participants in thinking about their home, which is perhaps not surprising for those that live in the family home, but also remained true for those who lived outside of it. It is interesting to note that of the four participants who had a parent present or nearby for the interview, it was the mother who was with them. Of the three participants with divorced parents, it was the mother too who they were with at the time of the interview.

There is quite a bit of overlap between those with a positive relationship with parents and those who wish to stay in the family home. For example, Lily, who had moved back into the family home, said that "I'm forever thankful that I have both my parents, my parents have been unspeakably amazing" and that "I love being here. . . it's a great supportive environment." This is also reflected in James, who has no foreseeable plans to move, when he said, "I just like my home and my mom, everything we do together as a family." Again this is echoed in Alan, who doesn't ever wish to leave his home with his mother. When asked what was most important in his life, he said "[p]ut mother down, she's important in my life."

However, as with any relationship, there are also challenges that participants spoke of with their parents, especially relating to restricted agency in the home. Lear spoke to the fact that when she lived at home: "[t]here were a lot of rules . . . just because of my intellectual disability they were worried of, uh, people taking advantage of me, so I was restricted just a lot of doing things, so I was quite sheltered.” This speaks to a frustration of not being able to be as independent as she’d like to be when she lived in the family home.

Similarly, Catherine expressed the desire to go more places, like to the YMCA for swimming, particularly in the afternoons, but her mom said that she “has trouble sometimes about persuading her Dad about some of these activities.” The reason given by Catherine was “[b]ecause Dad’s kind of lazy” but also that her Dad didn’t want to use her Passport funding. This has impacted on Catherine’s ability to go out and do things, since she lives mostly at her Dad’s house. Her mom further said: “there’s other activities that- so her Dad keeps wanting to save the Passport funding for I don’t know what, but it is [name]’s money too.” To which Catherine added “[a]nd it needs to be- and the money needs to be spent because if I don’t spend the money then I don’t get any more money.” Here there is a clear worry that the decisions of her parents will impact not only on her ability to go into the community, but also to access funding.

Support. A key part of these relationships is the fact that many parents of people labelled/with intellectual disabilities act as the primary or sole support for them or provide some form of informal support to their child. This came up both from participants and from parents who were present during the interviews. Lear spoke about how her parents were the ones to find the transitional home for her, and her “mom has access to my bank account because money-wise and financial I just don’t get it.” Thinking of things she needed, “having [her] mom advocate for [her] and help [her] along” was a large piece of this. Likewise, Lily identified in her artwork that “[o]bviously the support, the main- the main support system is both my parents and my dog.” This support included many elements, one of which was also financial; “[m]y dad handles all of the accounting, he’s basically my financial assistant and he’s been like that since I moved out with my friend, he’s sort of taken on that role of making sure – like obviously I know how to spend my own money – but just helping manage all of that sorts of stuff.”

In both of these cases, participants had formal supports that augmented the support given by their parents, in the form of paid support workers, which is discussed in further detail later. However, in some cases, the parent was the only form of support that the participant had. Both Alan and James’ moms spoke to the fact that they were the primary support for them, largely because of the cost and challenges in finding outside support. When asked about additional support, Alan said “[l]et me think, um, well- my moms the one who, my moms the person who supports me.” His mother, on coming into the interview, confirmed that she’s “[name]’s primary care, uh, support person.” Likewise, James responded on prompting of other support “[n]o it’s just mom right now” and his mother, who was present for the interview, confirmed this. Often in these instances, this support relationship is necessary because there aren’t any other options for support, because of funding constraints, changes from the pandemic, or just because it’s easiest. This has the possibility of putting strain on family relationships (Curryer et al., 2015).

Giving support. Yet support in this context is not solely one way, and many of the participants spoke of how they give support to their parents, and their family more broadly. This is reflected in Alan when he said, “I take care of myself and we take care of each other, and, um, we have a house and we- we love our home, and we love each other, and stuff like that, yeah.” It’s reflected again when Timothy said, “a couple times when I was with my mom she had a, and I had a few sleepless nights because of [problems with his uncle] so I’ve been helping her, doing a lot of stuff for her.” He has also helped his grandparents, who he lives with, with technology,

> [y]es and I, yes and I am so good at technology I help my grandmother and grandfather with their iPads because they both have iPads as well, and they don’t- sometimes they

> don’t know what they’re doing so I help them find their old emails that they think that they might have lost or something. Or sometimes I- sometimes I help them with that, yep.

In both instances, the support given by parents and grandparents is complemented by support given back to them by participants. It is often the case that relationships of support can be characterized as unidirectional, with the person labelled/with intellectual disability being supported by parent. These comments complicate this notion and demonstrate that the participants of this study are not characterized only by the support they receive and are capable of agency and care of those around them.

Siblings. Another important relationship that emerged from the interviews was the one between participants and their siblings. This relationship can often be supportive and creates a close connection with the participant. One of the first things that Catherine said when asked about herself was that she was “very nervous and excited and stressed that [her] younger brother is getting married.” This was important to her and shows the connection that she has with her younger brother. This can also be seen in the artwork of Lily, who included a picture of her family doing the MS walk in support of her sister, “because my sister has MS, and she’s doing really well . . . but we walk in her, you know, in her honour.”

Figure 6. Lily’s artwork – her and her parents doing the MS walk in honour of her sister.

However, these relationships are also complicated by tensions, such as difficulties connecting with siblings and expectations of what their relationship should be. For example, while Alan spoke about his siblings and the fact that though they live close by, he “never heard from them but, um, they’re out of the picture? I guess, yeah.” He said he sometimes talks to them on the phone, but he doesn’t really see them.

Sibling relationships were also clouded by expectations about future living arrangements. Lear said her “parents want me to move closer towards, more towards my brother and sister which is the Upper Beaches, but I don’t know any Community Living there and I don’t really want to be close to them, so I don’t know yet.” She further said, “I don’t want to rely on my siblings because they have their families and I just, I don’t want to burden them so I would rather venture out and have that help on my own.” This speaks not only to expectations that siblings should take over support from parents, but also that the choice of this doesn’t seem to be offered to Lear to decide.

These sibling relationships can also be based on a desire to have what their siblings have. Jack continually pointed to the desire for “a family of [his] own to share with all my other siblings, because they all have families.” This goal of having his own family very much reflects the fact that this is set as the expectation, whether explicit or implicit, of his other siblings.

Children. An important counterpoint to these family relationships, which have largely been discussed in terms of the support provided, is that of being a parent and the relationship of care to a child. Lear spoke of her relationship to her son as something she’s limited in now, both because of the rules of her transitional home and her anxiety, but as something she’d like to have more of, she said recently she’d had him for the weekend, “but it didn’t go as planned and I had a panic attack and just didn’t have the help that I needed, that I usually have and so he did have to go home the next day. But I did feel proud of myself for having him for the whole day and night and just slowly getting back in there." She hopes that in the future she'll be able to be more involved with him, a point that greatly shapes her ideal future, discussed further later.

Friends. Beyond family relationships, another key connection is the one participants had with friends. While friends do not live in the home with participants, except in the case of roommates, which will be discussed separately, they are often visitors to that space, or draw participants out of their home space and into the surrounding environment. As such, friends play a significant role in shaping both the experience of domestic space and experience outside the home, which is so critical to the home-making process. Alan, when asked what was important to him, said "[y]eah, I've got good people in my life, too . . . I talk with them on the phone sometimes." Timothy, too, spoke to the fact that "I have several friends that live in [city] that I- that I arrange to meet people for a cup of coffee, or tea in the evenings, or sometimes we go out to supper it depends" and also "[l]ike I have a- like I have a friend I met through that's named [friends name] and me and him hang out together, yes and we talk on the telephone every week . . . and sometimes we go to sporting events together. Yes and- yes and sometimes we'll go out for coffee, I go out for coffee with him, and we hang out, we do a lot of stuff together."

After family, friends were the most frequently cited as important in their life. Jack included this as a key part of his artwork, saying he's "[g]ot bros around me, help me through this injury and everything yep." Friends in this case were shaped by being physically present in his life, and also of supporting him with his acquired brain injury, everyday of the week: "on Mondays I go to [friend's name (with gym)] in [city]. And Tuesdays I work out with I think [name of friend] here and online with [name of friend] at my own gym online and work out here." This continued throughout the week.

Figure 7. Jack's artwork – his friends around him

This speaks not only to the impact of these relationships in shaping their daily lives, but also the support that friends can provide. This is also echoed in Lily's workshop, where a friend of hers, when she was having a dissociative episode while out at a market, made sure that the area was safe and told the crowd around to "move along." This shows not only a knowledge and acceptance of her friend, but also an awareness of how to best support her during a dissociative episode.

Similar to the variety of ways participants are supported by parents and give support, participants spoke not only of the support given to them by friends, but also the support they give back to them. Alan, when speaking about his friends, said; "[b]ecause they are- I think they are very important in my life . . . [y]eah. Sometimes they ask- sometimes when they are feeling down or something, feeling stressed, then I will comfort them." He said that part of being independent was "helping people." Timothy also spoke to this idea of helping those he was close to saying he does it, "[b]ecause I like to help out people."

Roommates. Additionally, the relationships that participants had with roommates (both current and past) stands out as important, as this has a direct connection to the home-making process. When asked what she'd like in the future for support, Lear said "[f]riends would be nice, because I just met my wonderful roommates in here [the group home].” She spends a lot of time with her roommates, saying “we watch a lot of- the girls and I we- we’ve- we’re really become and family and friends . . . [s]o, um, on every Friday night, if I’m not at my parents house, we watch a movie and we each get to pick a genre.” However, she also noted that sharing a room has been hard, since her roommate likes to listen to really loud music and that “what I need to learn is to advocate for my feelings which are really hard.”

Another roommate relationship was one that Lily had while previously living with a friend. Despite challenges she experienced living there, related to her dissociative disorder, she said “I honestly can’t say anything really bad about my experiences living with my friend because, you know, she, she’s like, she’s now like a sister to me, so.” She spoke to the fact that it was her roommate who had brought up her episodes; “it was actually my roommate that approached my parents and just said, you know, this isn’t working, like I can’t, like this just isn’t- this just isn’t working . . . [u]m, because mentally it was just, it - I think at the time I think it was more of a struggle for her than it was for me.”

In each of these examples, it is evident that the relationships experienced by participants help to shape the homes they live in. All of the relationships explored here have demonstrated the wide variety of experiences that participants had, but also the common elements of them, particularly with regards to navigating parental relationships, both inside and outside of the home, and the friendships that they have outside the home that shape how they experience their homes. It is also important to recognize that while many participants experienced some level of support from family and friends, these relationships are not defined by that support, and that this support can also go both ways, with many participants supporting their friends and family.

Paid support. The final relationship explored here is that of paid support. The main form of support identified by participants was of individual support workers who, in varying ways, provide support in a paid position to participants. These forms of support help participants with tasks associated with making home, such as being going to the grocery store, paying rent, or going out into the community.

One of the main forms of support was with admin work, like budgeting and paperwork. Jonathan said that his support worker helped with "budgeting, yeah, budgeting, yeah, budgeting . . . [s]he comes to see me every once in a while, you know what, one day I want to prove, I want to be independent. One day, I want to prove I want to be more independent, some day. I want to prove Jonathan's life, yeah." Similarly, Ruth said that her support worker helps her with "just paperwork, just to see how I'm doing and that's about it, just general things, you know? And, um, help me with papers that come in- come in the mail and all that stuff, and then I call her and then, uh, I tell her I got a paper, and she- she comes, and she reads it and all that stuff." In both cases, this is particularly important as Jonathan and Ruth live on their own and do not have their family close by to help them with paperwork and so rely more on the paid support workers for assistance with this.

Oliver, who is hoping to move out of the family home, says that his support is; "[t]here's, um, there's a person that I usually go talk to every couple weeks and we're working on a plan to, um, actually look for sustainable housing and apartments and stuff. And he sends along resources that you can use to, um, find assisted living, such as finding someone to take care of your business, your banking, and your bills and stuff like that. And, um, stuff like setting your alarms for important dates and sending documents on time, that kind of stuff." This support for planning for his future is similar to that of Timothy, who has a facilitator who "helps me with planning my future. Yes and she helps me- she helps me- she's going to help me go to cooking- go to cooking classes and then, yep."

Support also took the form of going out with participants into the world. Lily's support worker took her on outings when her parents weren't available, often to do photography, something that Lily was interested in:

> [T]here are other times where we've gone to the conservatory, like various places where we take pictures of flowers or butterflies or, um, as of lately- as of recently we took pictures of the salmat run- the- the salmon run. . . [u]m, so just a very wide variety of different- different outings and activities. Sometimes it's not even to take pictures it's just to sort of get out and to not be confined within the house. . . But, yeah, that's a very- that's a big, um, component within my support system.

However, it is also important to note that within this nexus of paid support, there are limitations. These can stem from challenges in accessing support or not having support that is flexible to their needs. Ruth said that "my social worker- I don't think she really- I don't think she really helps that much." She would like more support "[h]elping me with my moods and helping me calm down and take a lot of stress off me" but that "Well I did but- I don't know. I'm taking medication, like I'm taking depression- but I'm not so sure that's really working but anyway I take it anyway." On prompting whether she'd had a therapist to support her, she said "[y]eah and she wasn't much of a help, like I can only see her for an hour and then once my sessions were done that was it, like my calls were closed basically." This lack of support for her mental health means that she sometimes can have negative interactions with people, saying "I can snap at any time, anybody says the wrong thing, I just snap at somebody" and also that "I talk about doing something to myself and all that stuff, and it got really bad" but that she doesn't have that support to really help with her low moods. Her experience speaks here not only to a lack of support from current paid workers, but also a lack of support from previous experiences of therapy. These constraints limit her ability to engage with people out in the community, because of a worry that she won’t be able to connect with them and means that she spends more time alone in her apartment.

5.1.5 Neighbourhood

Beyond the experience within their dwelling, and the relationships that exist in and around it, the neighbourhood was also an important part of their home; including where they like to go, how they get around, and their interactions with their neighbours. These dimensions can add or take away from a feeling of belonging in their neighbourhood and shape the way that they interact with people outside of their dwelling. A negative feeling about their neighbourhood may mean participants choose to spend more time in their home, or a positive feeling may mean they spend more time outside of it.

Location. Six participants lived in suburban neighbourhoods. These were all participants who live in their family home, which were single family detached houses. When asked about the location of the home, the consensus was that it was nice. Oliver said that “the location’s pretty good. It’s basically on the corner of two streets and it’s pretty quiet, so.” Alejandro, when describing his Dad’s neighbourhood said; “I love that neighbourhood because it’s so nice, and a lot of the people there are nice and it’s just like a kind of like serene vibe when you go up there because it’s like literally suburbia.” In both of these there is a sense of peace and calm, relating to the quiet of the area.

Four participants lived closer to the city centre, including the participant who lives in a group home and both who live alone. The experiences in these neighbourhoods were more varied. Lear, for example, spoke about her neighbourhood and some of the worries she has; “and even here- I’m living in [urban neighbourhood] there’s a lot of, um, police chases. There’s- we have a lot of people that come up and down out- like it’s quite dangerous but we kind of keep inside our bubble and we go out during the day, and we are just in bed by 9.” In the reverse of this, Ruth said that she likes her urban neighbourhood because “there’s lots of people around, lots of houses. Lots of kids around, and schools.”

In talking about their neighbourhoods, participants identified the places that they like to go to, creating mental maps of their neighbourhoods and what was important to them. These were often in relation to people they might see in those spaces. An example of this is places to eat, Alan mentioned this; “[w]e have so many restaurants just here, so . . . [i]t is nice, yeah” specifically in relation to meeting people in that setting, saying he’d gone recently with “my friend has her birthday already we went to- we went to a restaurant for her birthday.”

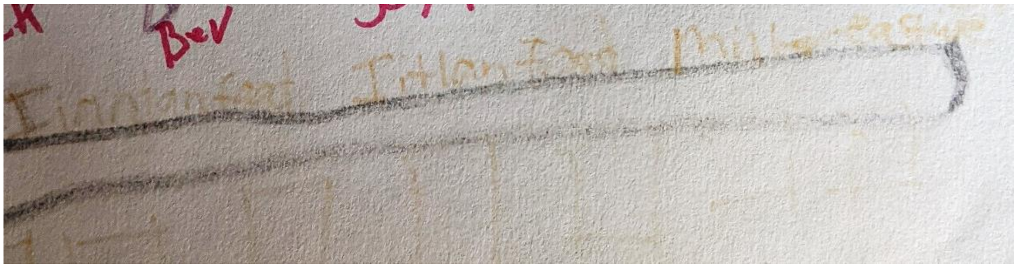

Figure 8. Alan’s artwork - Image reading ‘Indian food, Italian food, Middle Eastern food’

Ruth also used restaurants as an example, saying, “[o]h yeah I got a Tim Hortons, I got an A&W, there’s different kinds of restaurants around here, bars, like, yeah, taverns, bars, lot of stuff around this area” as something she liked about her neighbourhood. Catherine mentioned the importance of a favourite coffee shop to her in her neighbourhood. She said this was because the owner of the coffee shop “has a nephew who has autism.” Her mom furthered this to say “Catherine recognizes that someone in the community is very kind to her and knows that she’s autistic and doesn’t really hold it against her. So this family who owns this [coffee shop], and so Catherine is naturally drawn to something like that.” This speaks not only to the availability of places to go to, but also the nature of those interactions, with Catherine recognizing when someone is more accepting of her.

Another example was of shopping malls, Timothy specifically pointed out the benefit of being near a shopping mall, in comparison to his previous neighbourhood; "[y]es, I prefer this neighbourhood. It's- it's a lot more closer to the shopping malls, this neighbourhood." He says that:

> I like to go to the shopping mall; I go to every- almost everyone in the city . . . [y]ep. Cuz I walk around them, and sometimes- and sometimes I run into a lot of people, sometimes I run into some people, it depends . . . [p]eople that I know, yeah, yep. Since I know tons- since I know tons of people, yup.

Participants also spoke about walking and biking their neighbourhood as something they liked to do. When asked about how he feels about his neighbourhood, Timothy said "I feel good, like, I have a bicycle, a three wheel tricycle, an adult tricycle and I go for bike rides around the neighbourhood." Jonathan also mentioned biking, "[u]m, I like- I like going- going- going on the, yeah, bike, yeah, bike." Walking in their neighbourhood was also important, with Alan saying "[y]eah we always walk" as a part of his daily routine with his mother.

In each of these examples, an emphasis is placed on being out in their neighbourhood as a key part of their day and being able to freely walk around to the places near them is important. The other element in this are the connections to people that they have, either friends or acquaintances, as seen in Alan's trip with his friend, or Timothy's experience of meeting people at the mall. This speaks to the importance of positive encounters in shaping feelings of belonging (Bigby & Wiesel, 2015). Most of these examples were positive, however there were a few where participants spoke about being uncomfortable in their neighbourhood, particularly Lear who lives closest to the city centre, and feels unsafe being out at night.

Neighbours. Interactions with neighbours created feelings of belonging for some and exclusion for others, which impacted how much time they spent around their neighbourhood and how much they felt supported within it. Positive interactions worked to encourage participants to be out in their neighbourhood. Oliver said that “[l]ike, we have, um, neighbours that we talk to interact with, whenever we see each other.” This is also reflected in Alejandro’s interview. When asked what a good vibe in a neighbourhood might be, he said “A good vibe would be, like, the neighbours are friendly, the neighbours are nice to you” “and at least, like acknowledging that you’re there.” This is what he’d experienced in his Dad’s neighbourhood. In each of these is a positive feeling attached to interacting with those living around them, shaping how they experience their neighbourhood.

Beyond this, interactions with neighbours are viewed as closer than casual interactions and can be considered as friendships by some participants. Timothy said “we have really good neighbours that we talk to everyday and we, yep, yep. Yes and they offer- and they always said that if we need anything to let them know and they would be happy to help us.” Similarly, Alan said that some of his neighbours are friends too, and they talk on the phone sometimes.

This can extend to providing important support to participants in the context of home-making. Lily, for example, said that “I’ve been quite lucky because I have fantastic neighbours I’ve gained as part of the support system, they all know if they see me sort of dissociating, they know the best way to approach so its not intimidating and escalating.” This allows her to feel supported in her neighbourhood, knowing that if she were to need help, her neighbours would be ready and willing to provide it. In each of these examples, neighbours are able to provide care and support to participants, which makes them feel better about being out in their neighbourhood. However, this was not always the case in the interviews. Alejandro mentioned that “[a] bad vibe would be maybe if the neighbours weren’t super nice, if- and that unfortunately is kind of the current situation at my mom’s house.”

It is evident here that the relational components of a neighbourhood, here meaning the neighbours, are just as important as the physical components, like the businesses and parks. This speaks again to the nature of belonging, of feeling included in the areas that people labelled/with intellectual disabilities are in, that was illustrated in Chapter 2.

Transit. Another key factor described by participants was the location of the home in relation to access to transit. The benefit of transit is that it is able to connect participants to places further than their immediate neighbourhood, like taking the bus to shopping malls, or grocery stores, or to work. This extends the spatial extent of their daily routines , allowing them access to their city without the need for a support person to drive them or help them navigate. When asked about transit, Alan said “[y]eah I love taking the subway.” Ruth talked about how close she is to transit in her neighbourhood, saying “[n]o, no it’s right in the area because I can walk to the Greenwood subway station, I can walk across the lights and I’m there . . . and I travel by TTC because I buy a monthly presto card and put money on that presto card for the whole month.” This is important to her as part of her daily routine is to take the streetcar out into the city.

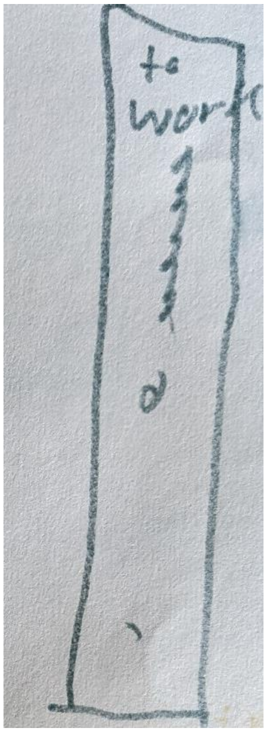

Figure 9. Alan's artwork – his subway ride to work

This is particularly true of services like DARTS and WheelTrans, which specifically support people with disabilities in getting around. Lily, who uses WheelTrans, spoke of transit as a form of freedom, saying "I had the freedom [in her former home] to go and see my friends when I wanted to, and I didn't have to worry about "will I be able to get a ride" or "will I not be able to get a ride" I just looked up the bus schedule and away I went." However, she also mentioned that WheelTrans, isn't available consistently in the city, and so she relies on being in an accessible location for it. This raised concerns for future housing because it might not be accessible to her.

Figure 10. Lily's artwork – WheelTrans logo

5.1.6 Disability Resources

In addition to individual paid support workers, participants also identified attending virtual and in person programming for people with intellectual disabilities, and also accessing other resources and supports. Many of these programs have changed during the COVID-19 pandemic, the ramifications of which can be found at the end of this section. As was alluded to earlier, accessing programming in the community can foster feelings of belonging, and gives participants a place to go where they can feel ‘at home’ (Kaley et al., 2021). This means the ability to not only be in the community but to feel as though they are a meaningful part of it, and are accepted in that space, is important for feeling that sense of belonging. This feeling is relational to other spaces, and so feelings of belonging outside of the home can shape people’s feelings of life inside of the home.

Programming. One of the examples of this is participants attending day programs for people labelled/with intellectual disabilities. Jonathan goes to [a day program], which supports opportunities for learning life skills: “I’m a chef, yeah, because I- I work at [day program], yeah.” Another example of programming that Jonathan attends is Best Buddies, where “[y]ou get a friend, you can find a friend- a friend, a best buddy, get a friend, yeah . . . [to go to] events, we do events together. Yeah, events? We did some, yes, we did some events together, yeah.” Timothy attends something similar in his city, saying “[y]es I belong to an organization called [disability organization] that helps out the disabled in [city]. . . [y]es and we- yes and they take me to like we go to special events every year with them, like a four course lobster dinner with them every year” and also “yes and I, yes now I belong to another group called [disability organization], and we meet on Zoom for the time being and then we’re going to go to events together like bowling or hockey games or movies or anything.” These resources are important because they shape the experience of community and support outside of the home, fostering a sense of belonging to a community, and have thus shaped the experience inside of the home because of the lack of them, meaning there is significantly more time spent in the home and less connecting with others because of changes in the pandemic.

Working. Another important element discussed by some participants was finding work specifically with organizations helping people labelled/with intellectual disabilities or people with disabilities more broadly. Alan, who works at a social enterprise which provides learning opportunities specifically relating to job skills for people labelled/with intellectual disabilities. For this role, "I do baking, sometimes I do- I do other things besides baking like, uh, doing-doing dishwashering sometimes . . . with, uh, with other partners too." However, he'd only recently been able to start working there again and was still only working "once a week . . . 12:30 to 3:30." Lear also has a similar work experience at her job, where she puts together gift boxes of local products, working with other neurodivergent people. She said this has been "really cool . . . and it's going really well," but mentioned it was only for a few hours each week and requires a long commute for her.

In these example, both Alan and Lear have found a position working within the community in a meaningful way, contributing to a feeling or purpose and sense of belonging and giving them somewhere else to go during the day which then shapes how they experience their home when they return. However, these positions have been drastically changed and shaped by the pandemic in the last two years, the details of which will now be explored more extensively.

5.1.7 COVID-19

The impacts of the pandemic have coloured all elements of day-to-day lives for participants. This means that no discussion of home can be complete without touching on what this has looked like for the people interviewed here.

Impact on resources. One of the most important differences that COVID-19 has made in the lives of participants is by limiting where they can go outside of the house, specifically meaning that it has altered the way that they access resources, go to work, go to school, see friends, or take transit, all of which have been discussed as important to their daily lives and to the process of home-making. Each time these activities were discussed, it was framed as either something they used to do, something that has been greatly reduced, or something they would like to do again soon.

Timothy, when talking about his new job, said "[y]es- yes and because of the new variant I'm not- I had to call them and said I'm not capable- I don't want to go out to the workplace and get this new variant that's going out." Alan's mom also echoed this reduced ability to be out in the world, saying "Alan has almost nothing to do now, he doesn't have work, volunteering, outside classes, etc. It's been stop and go with [his work]. This has changed a lot for us." Similarly, Jonathan hasn't been able to attend the day program he loves to go to, because "it's just that there's too many people, yeah, too many people . . . [b]ecause of COVID, yeah, because of COVID." In each of these, COVID-19 has limited the ability of participants in attending work or programming outside of the home.

Similarly, the experience of school has changed for the participants attending. James said, "I'm actually I'm doing homeschooling in COVID times," and the few times he did go to school, it was much harder to pay attention in class because of his mask. Oliver, when talking about his regular day, said “I wake up, class, do homework, go to more classes in the evening.” When prompted on whether these are online he said they were, and that meant he was in the house for most of the day.

Additionally, activities or interests from before the pandemic have been limited. Lily, when talking about using transit, which has been so important for her sense of freedom, said “well, not currently but before the pandemic I was getting around using Wheel-Trans.” Timothy, also speaking to things he used to do pre-pandemic, said “[y]es, like I go to the local community centre right up until when the COVID started I went to the community centre and since COVID is on right now I’ve not gone to the community centre. Yes and I go to every, I have tickets I go to all the CFL games I go to the hockey games and ever since COVID started I don’t go to them.”

In each of these, the places that participants used to go to outside of their home have become inaccessible, meaning that they have had to spend the majority of their time in their homes. This has limited their ability to experience agency and independence, which had been associated with their work, school, programming, or activities, all of which are important for creating a feeling of belonging (Kaley et al., 2021). This reduction is the ability to form meaningful connections and be out in the community has meant that many participants are limited to their home and have had to spend much more time restricted to that space.

Loneliness. Restrictions on where they could go and what they could do is reflected in feelings of loneliness and frustration that were expressed in the interviews with participants. This frustration is at the loss of activities but also at a loss of independence, as many are restricted in areas that they had freedom in before. James and his mom spoke about him going independently to the grocery store before the pandemic but “especially with COVID I go get the groceries. But when I bring them home, James takes the bags up and puts everything away and puts the bags back in the garbage . . . before COVID, James was just practicing going to the store from our house he went two times and knew what he was getting, and had money, and brought the stuff home."

The feeling of loneliness is reflected in the limitations of seeing friends and family. Timothy said that "sometimes I go out with friends for coffee when COVID is not on" but doesn't now. Catherine said that it's been challenging talking to friends because she usually does that "[i]n person, instead of just on the phone." It's also reflected in relationships with family, Catherine went on to say that being an aunt has been harder during COVID because she's not able to see her family. This was really challenging in particular for the participants who live independently, Ruth said "[y]eah it was mostly at home, and it was not fun at all" speaking to the fact that her daily routine had been entirely shut down during many points in the pandemic. Jonathan also spoke to this frustration, "I'm not happy about COVID-19, I'm not happy about COVID-19 . . . I can't- I can't go to work, you know? It's disappointing, disappointing. I can't go to work, it's disappointing." This was also harder for him to see people, particularly his family, "[w]ell, it's difficult because I want to change away, I want to change the way how I live because I'm a nice guy it's hard for me to live at [home] it's hard for me, you know? Because I miss going to Brampton and, yeah, I miss that, that's why . . . [b]ecause of COVID yeah, that's why." He has family in Brampton and the pandemic has meant that he's not been able to see them.

Focus on risk. In addition to the loss of daily activities and feelings of loneliness and frustration, there was also a hyper-focus on the news and risks associated with COVID-19 that came up throughout the interviews. This worry was linked not only to fear of the illness itself but also other health risks and meant that participants were less likely to go out into their communities because of the fear for health risks, meaning they were more often stuck in their home. Timothy said, in reference to attending his community centre, "no actually- uh, no actually I- no actually I- me and my trainer decided I'm not going to go back till once the COVID numbers go down, because they have their, right now they offer summer camp and they offer march break camp where there's full and full of kids, and then they offer after school program during the fall, summer, when schools on they offer that so I told them- so I made the decision I'm not going to go back until the COVID numbers are down . . . I don't want to catch something because I- I have a narrow oesophagus and I've had that; I've had that ever since 2000. Yep, yes and I- yes and I have- yes and I have a weak immune system ever since then and I don't want to catch anything off of them." This has also limited his volunteering, something he used to do a lot: "[i]t depends on- it depends on how the numbers are in Ottawa whether if I- whether if I need to google if I can volunteer or not . . . I did a lot more volunteer work before COVID hit." Lear also spoke about this worry around being out, saying "I'm a little nervous [about the pandemic] just because, um, since we live in a transitional home with other women we have to be extra careful. So I'm a little nervous bringing the virus back, even though we're all immune now, but I'm just nervous." In each of these sentiments there is a focus on the risks to themselves and to others, and a worry about what will come next.

Finding agency. However, in spite of the restrictions and worries that many participants have experienced over the two years of the pandemic, they also spoke about some of the positives of it and how they have found new forms of agency in their lives. It is important to note that this came mostly from those who live in the family home and the participant in the transitional home, and less so for those who lived independently. This speaks to the role that having resources and supports readily available within the home (in terms of parents or paid support) has on the ability for participants to respond to the pandemic in either positive or negative ways. One of the ways agency has been demonstrated is through increased online activity. Lily said that,

> COVID has not slowed down because I've been like *pause* not, uh, not been – I'd say not busy but it's the opposite, I've been crazy busy . . . I'm part of two different, um, [online] counsel, counsel groups so juggling between both of them it's like okay I can't like I gotta make sure that I'm not like double booking and I'm not – like I'm keeping everything separate, so, it's kept me busy.

Her mom further stated this point later, saying "as Lily's already stated, the time she's been home as been really therapeutic because she's had ongoing therapy and, interestingly, through COVID the amount of online activity she's had has really helped her expand her interests and her confidence. So, she's really kind of doing really well at the moment, which is good."

Another element of this has been increasing activities done within the house, by focusing on hobbies and interests. Alan said that "I have been cooking a lot during the pandemic . . . and I've been reading a lot, we also go for daily walks." Alejandro, too, said "I personally love cooking and like I've been, this whole quarantine, I've been like cooking and baking *laughs* and um, I love doing those things when it's not COVID times too, but I feel like I had a lot more time to kind of do that and, yeah, like I love cooking."

There have also been ways participants have adapted to the restrictions of the pandemic, for example Alan said that "we don't see people often, but we try to call them more." Lear also expressed the benefits from more time in her home, saying "[b]efore COVID happened we had to be out of the house from 11-3 to be, like go to work or part-time work, or just be out of the house. Um, I was coming from a bad place, so I didn't really have anything, so I really actually enjoyed COVID *laughs* so I got to learn a little bit more about myself again and find out what I like and yeah." She had also "started picking up, during COVID, knitting, um, and embroidery."

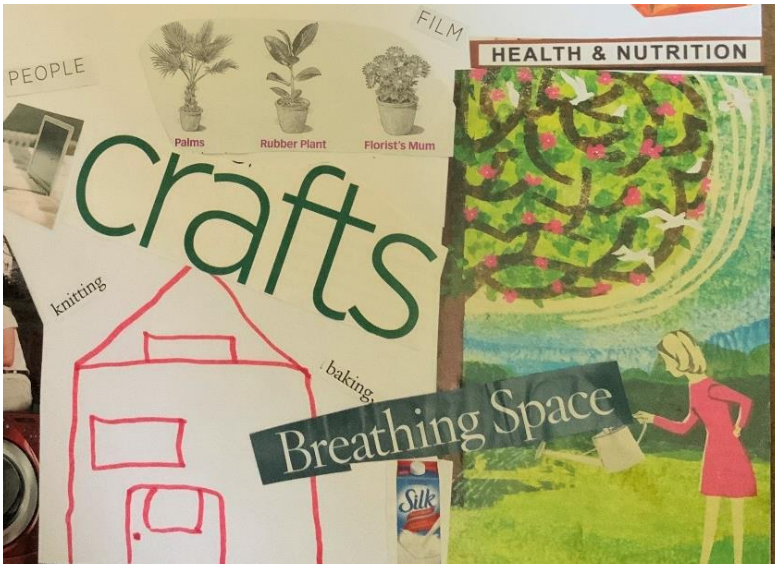

Figure 11. Lear's artwork - depicting some of her interests found during COVID-19, including crafts, knitting, gardening, baking.

In each of these instances, participants were able to continue to find agency in their homes by adapting to the conditions of the pandemic, through finding new hobbies or by increasing their online presence. Though this has been challenging in many unexpected ways and has continued to be frustrating and lonely, participants have been able to find ways around this and continue to live full lives in spite of it. This does not take away from the hardships experienced in the pandemic but instead is trying to demonstrate that participants are not being controlled by these circumstances and are finding ways to continue through.

5.2 Imagining Home

Having discussed the many aspects of participants' current homes, this next section will turn the focus to how the future home was imagined by participants. Imagine is a conscious word choice as the future home questions were meant to prompt thought not of the reality of their future home, but what their ideal is. This did not have any set constraints or beliefs attached; however, many participants spoke about their ideal in terms of what their reality is, often highlighting the constraints and challenges they will face, a point which will be expanded upon further. This demonstrates not only the perceptions of what is available to participants, but also identifies the gaps in housing and supports across the Ontario system in creating a full life for people labelled/with intellectual disabilities and encourages new ways to think about how support can be given.

At the same time, many participants expressed that they benefitted from talking about this ideal home in these interviews, because they hadn't really thought about it in great detail up to this point. Lily said that "it's fun doing this doing the interviews with you today because it's sparking that sort of thought that I had thought about quite a while ago and now sort of bringing those back fresh into my mind like 'oh okay well, this is really what I want things to look like in the future.'" This speaks to the fact that the concept of an ideal future isn't really something many participants are in a position to think about currently.

Again, this section adopts a relational conception of home, where the home is rooted in the relations participants have to the space itself, relationships with others they wish to have there, and relationships to the neighbourhood around the domestic setting. Each of these influence experiences within domestic settings and the ability of participants to create a feeling of home and belonging within themselves.

The level of detail given about the specifics of this ideal future home tends to vary depending on the situation of the participant, for example the participants who are not planning to move for some time or don't plan to move at all did not have as much detail to provide in terms of an ideal future. However, across participants it was clear that over the two interviews and the workshop, more thought had been given and their ideal homes began to take shape.

5.2.1 Housing & Household Type

This section will look at some of the physical characteristics that were discussed by participants with regards to their ideal home. The physical space of their ideal home was of much larger importance here than when thinking about their current homes and broadly included apartments and houses as their ideal future home, as well as an emphasis in some cases on a communal living space. Significantly, the discussion of the physical design of housing was inextricably linked to *who* would comprise the household, and so this topic has been included as well.

Apartment. Jonathan emphasized wanting to be in a newer apartment building, saying he'd like an "[a]partment, yeah, apartment, you can put a brand new apartment . . . you can put, um, brand new- a brand new beautiful home and you can say brand new chef kitchen, get a brand new kitchen and- and- and I want to get a home theatre, too." This is shown in his artwork, where a collage demonstrates the kitchen. He wants to live alone in this apartment, because this was an important part of independence for him.

Figure 14. Jonathan's artwork – 'brand new chef kitchen'

James didn't have a very clear idea of what he might like in his future, he was more focused on keeping the things he already has, and he didn't provide much detail other than he'd like to "be good and happy" in the future. However, his mom, who was present in his interviews, spoke to the fact that they'd thought about him living in a nearby apartment building and had drawn a rough outline of this: "I did a two bedroom for James because one would be where he sleeps with his stuff and the other room would be for the – what would you like to have in your spare room thinking of all these things?" to which James replied "[y]eah I know, a studio." The studio is important for "all the kinds of Youtube I do." He mentioned that he'd like to live in apartment "because this [house] is just too much for me" and "it's too much space because it's too big since dad left, yeah." His mom also mentioned a friend who might live with James but again this wasn't yet decided.

Catherine had also imagined an apartment space, saying she'd like, "a, uh, apartment, like a fairly new, like not old, fairly new apartment. Maybe not a condo, but a fairly new apartment, like a small, cozy one?" She compared this space to the apartment of a friend of hers, whose apartment is "small and cozy with like a small kitchen, a small living room, a small, uh, a small bathroom, a small bedroom *pause* with a balcony." She said she'd like a roommate who was, "[h]mm, just friendly, polite. Pretty quiet, well not too quiet."

Timothy, in describing his future home talked mostly about the amenities attached, saying he'd like "an apartment, cuz- cuz I like- cuz I- like I like having- like I like having a gym, like a weight room in the apartment. If there was a weight room I would use it every day . . . [y]es and if there was a pool I would use it everyday." There was less of an emphasis on what the unit itself looked like for him, and more on what else would be in the building. He would be living with his mother in this future apartment, who continues to be important in his choice of home.

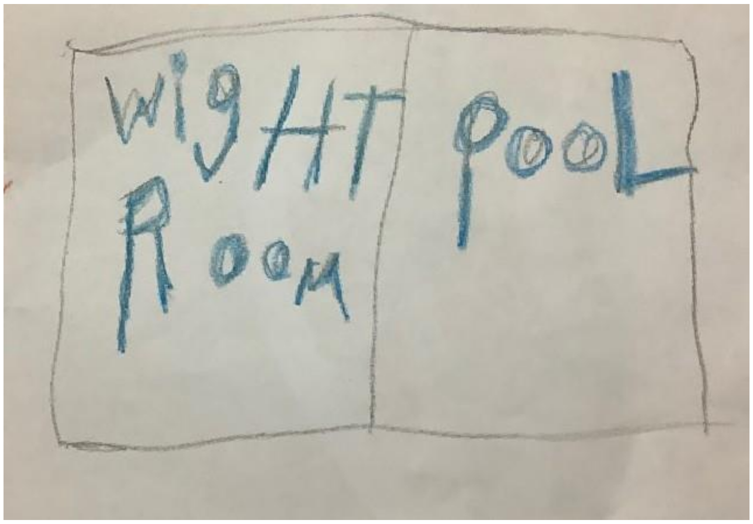

Figure 15. Timothy's artwork – weight room and pool in building

When asked what her ideal space looks like, Lily said: "a condo-like setting, um, the way I envisioned it, having like a condo setting where, you know, we all sort of live semi-independently but then have, you know, a giant, like, common area where we can all, you know, socialize and get to know each other and, you know, do activities, and all of that, you know, like all that sorts of thing." Further describing the unit itself, it included: "a lot of light, like a lot of natural light" and "a nice, open concept, um, nice, open concept sort of floorplan." These are shown in her artwork, pictured below, "then in my, like, my space, kind of have like a nook sort of similar to that where it has just a very warm, a very warm feeling." When Lily was asked about her home, she said "I guess, the big word that really comes to mind is equality." She also said "comfort . . . I think that that's really the big, um, uh, comfort, a loving environment, um, having the ability to have a dog." Other than a dog, she wouldn't like to live with anyone else saying, "if I had a roommate. . . I know when someone sees a dissociative episode, the first thing that they think of is 'I have to call 911.'" She also spoke to the fact that even in looking for those qualities in a roommate, she "[doesn't] have that control" in choosing who that roommate would be because they would likely be chosen for her. That's why she's in favour of the communal living space instead.

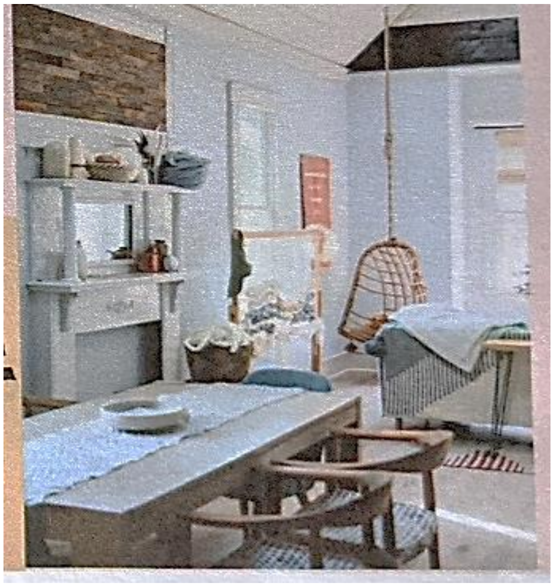

Figure 12. Lily's artwork – the 'nook'

Lear had a very similar vision of her future home, saying "having my own space so one bedroom little kitchenette, but also being able to, um, have another space and share that with other people and maybe we cook once a month and come together." Both Lily and Lear have focused on the element of community in their space, which is focused on more in the following section. Lear also included in her artwork the importance of having a space for her son to live with her, “I’d like to have my own place . . . [w]ith my son visiting, and then a bed for him . . . [b]ecause right now in my current home we can’t have anybody sleep over, um . . . [a]nd then a nice couch, where we can sit and relax.” In this future apartment she said she “really just want[s] to be supported and happy and comfortable.” She said she’d been thinking about “maybe I should get a house here with some of the girls I live with but some of them need more support and I know their living habits and I’m like do I really want to?” This speaks to the fact she’d thought about the dynamics of having a roommate and found that this was complicated.

Figure 13. Lear’s artwork – depicting bunk bed, child’s hand, ‘family’

Community space. In these last four examples, participants emphasized the importance of communal spaces within the apartment or condo building they imagined, which was important to them because of the opportunities it provides to be around people. When asked about what an ideal day in her future space looks like, Lily said:

> I think a lot of, um, a lot of interaction but then able to go back, uh, but then being able to go back into my own space, uh, and sort of have some, I guess, maybe almost to have like some me time and then, um, but to be able to have that freedom to, you know, be semi-independent but then also have the freedom to like go and like socialize, you know, to socialize with others because I think that that's, ideally? I think that when I look at it in the future, that's what I want, is I want the social interaction because thinking back to when I was living on my own with no social interaction I didn't like it.

She furthered this by adding; "an environment where I would love to be, is in the common area have, you know, kind of like a kitchenette sort of thing where, you know, you can kind of bake something and share, or even have, like, a baking, um, a baking workshops or something like that." In these communal spaces in the future building, she sees the possibility to connect with others in a meaningful way in this communal space, but also be able to have the agency to choose when she would like to be around others, and also have her own space to go to.

Figure 16. Lily's artwork – depicting communal areas

These ideas of communal space are echoed in Lear's ideal home, "[f]or the future, um, I would- just being immersed in a community, uh, congregate living I guess . . . being able to, um, have another space and share that with other people and maybe we cook once a month and come together. I really do cherish the community outlook on life right now, yeah." She said this form of living would be beneficial for her because "I tend to hide away a lot in my room and so being in a community with people knowing who I am they could be knocking down my door to see if I was okay, or- just having that, that space so, um, also ind- also by yourself but having people checking in on you, sort of." This again speaks to the ability to have her own space but also to be engaged with people in her building and share space with them.

Both Catherine and Timothy also express these ideas, albeit not as extensively. Timothy, on his future apartment, expressed the desire for "like if they had- like if they had a party room with special events I would go to them all the time, meets lots more people cuz I really enjoy meeting people." When Catherine was asked who she'd like to be living around in her future home, she said "[y]eah, [people] with developmental *pause* disorders . . . [b]ecause then they – because then those people understand . . . [a]nd don't make fun." She has previously experienced people making fun of her because of her intellectual disability, which is something she'd like to exclude from her future. In each of these quotes is the recognition of a desire to be included in a community within their future apartment building, a community that is accepting of who they are and able to provide interaction and informal support to them.

House. In contrast to the participants that wanted to live in an apartment in their future, five of the participants spoke about wanting to live in a house as their ideal home. The reasons for this vary but are important to consider in terms of what an ideal home looks like for them. Oliver, in thinking about his ideal home, said "[i]deally, it would be a two-storey place, um, modestly sized, decently expensive – not over the top but enough to justify the sort of space. Preferably a back yard, um, and a creative space, like maybe in a garage, or a workshop, something like that outside." Here it's the emphasis on space for living and working that's important to him in his future, however he also noted that this was subject to change for him. Oliver, in his future home, wanted to feel "[c]omfortable, safe, um, at peace." Oliver also expressed the desire to live on his own rather than with a roommate, based on wanting to be independent; "just because it's more so that I can um, have a sense of responsibility because it'll be just me, um, dealing with my life situation and not somebody else, which is what I don’t want . . . it’s kind of more like I’d rather live on my own, but if I had to have a roommate I will but again, that’s what I’d like to have first I guess is what I’m trying to say.” This speaks to a belief that independence is an achievement to reach, without support from anyone else but himself, and this is what he is working towards.

Alejandro also wants to live in a house in the future, saying “so like, um, so ideally I would like a place that’s not like an apartment because I’m not really, I don’t really like necessarily like vibe with apartments really . . . Like I, I really just want a nice house that has good floors, good, not, not too big of a house but like big enough that I can like move around and kind of do my own thing and I don’t feel like I’m bonking into anything all the time *laughs* yeah.” The reason for specifically wanting a house is that “I think like *pause* I think maybe it has to do with the fact that, um, I’m not necessarily anti-social but I do have social anxiety sometimes . . . [s]o I feel like some of it is based off of that, that I don’t necessarily want to be living with other people other than, like, a roommate? . . . So, I think like that’s a big reason and, I- I- I also have, like, height- I have, like, a fear of heights and, like, living on a high floor would kind of like freak me out, so.” The characteristics of a roommate were “a nice person I want an empathetic person, I want someone who is clean, and I want someone who listens very well because that would be really hard if I got someone who doesn’t listen really well, that would be kind of a hard, not so good relationship, so those are kind of the three main things I want, so yeah.” He also specifically mentioned that this would be a neurotypical person

Jack also spoke specifically about a house rather than apartment because his ideal is very close to what his parents house is, saying; “a [g]ym is very important. And, uh, I think, uh, the main floor, which is here, uh, it’d need to have a kitchen which is where I get my coffee in the morning- coffee or tea, yeah tea. And at the main floor, um, TV room with the couch and stuff." The main difference for him is "it's just I'm missing like I said before, a wife and kids of my own." For Jack the importance of a home is the people that are there with him, rather than the layout itself. His focus on family as key to an ideal home will be addressed in further detail later on.

Ruth also spoke about her ideal as a house; saying "[u]h, someday I'd like to have a nice bungalow house or have a condominium that's my ideal . . . because it's nice you've got 24 hour security and everything." Ruth's meaning of home is more rooted in security, "[h]ome means feels- I feel comfortable and cozy at home," when asked how she creates that she said, "[u]m, I don't know, I just come home and lock my door and just stay in and relax and keep to myself." She wanted "an alarm, alarm system in" and asked, "there's a lock on that door right?" saying that with that she'd "feel fine, safer." The locking of the door is important here and was reflected in her artwork, shown below. Her desire for a house, or a condo, which she also spoke of, is based on this idea of safety and security. However, she also spoke to the fact that she isn't actually planning to move and will likely stay in her current apartment for the rest of her life. This exercise for her was much more rooted in imagining than any of the other participants, who were actively thinking of their future.

Figure 17. Ruth's artwork - note the alarms on the door and windows, as well as the lock on the doorknob and pull chain lock.

5.2.2 Relationships

Echoing the discussion outlined in 'Making Home,' relationships to family and friends continue to be importance to participants in their imagined future. This speaks to the importance of feelings of belonging, as connections to others and a community shapes how they feel both inside and outside of the home.

Family. While in many cases, participants wanted to move out of the family home, their family continued to be an important part of their lives, and this is important to think about in terms of how it shifts the relationship between them. Parents continue to be a key relationship for participants in their future and help to promote connection to the broader community and facilitate support. What is evidenced in the ideal are the complexities of these relationships and how they continue to shape how participants viewed their future homes.

Timothy, who wants to continue living with his mom, also included his broader family within the future home; "[l]ike I'd like to spend more time with my- like through my family we're all going to stay- we're all going to spend a lot of time together in the future." He would also be in his future apartment with "[m]y- my mom will be in my unit myself." Alan also wants to continue living with his mom in the future, although this means staying in their current home rather than moving to a new space.

Lily spoke to the mixed emotions of leaving her parents home; "[a]nd so it was kind of- I guess in a way it was- especially putting together, like, my ideal future home- I guess it was- it almost was a little bit bittersweet . . . [b]ecause I love being here . . . [i]t's - it's a great- it's a great supportive environment and it's, I'm not gonna lie, it is absolutely terrifying to leave . . . [b]ecause this is like my, you know, this is my comfort bubble." The connection with her parents runs through her interviews, and the fact that she would be leaving in the future is mixed with these feelings of leaving them behind.

Jonathan, who lives on his own, mentioned this as something he is already experiencing, saying that in his future home he would be much closer to his parents than he is now: "[i]n, I – I want it, I want to move to Brampton because my family lives there right now. She's right, she's in Brampton right now . . . [m]y mom, my mom is, my dad is.” This is shown in his artwork, where one page is solely dedicated to moving to Brampton to be closer to his parents.

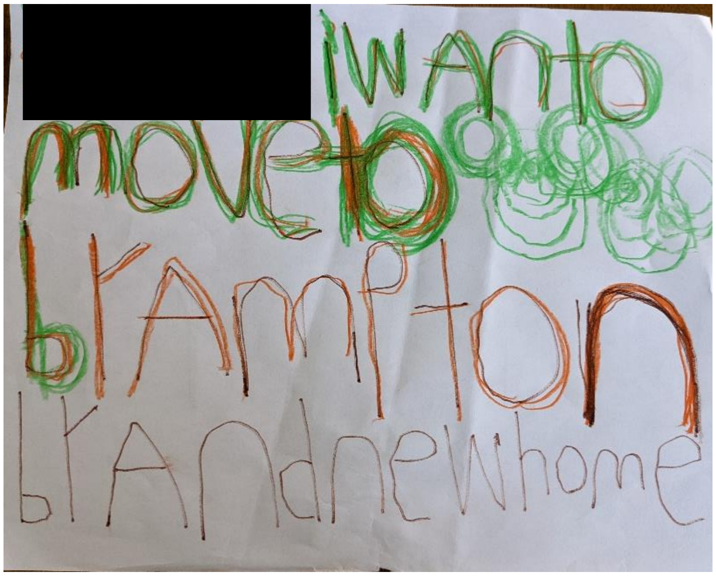

Figure 18. Jonathan’s artwork – ‘I want to move to brampton brand new home’

Future planning. One of the changing elements in the relationship with parents is need to plan for a future where they aren’t there or can’t provide the same level of support. The most specific examples of the idea of planning for the future came from quotes of parents present in the interview or when asking about the kinds of supports they might need in the future from family.

Alan's mom suggested for their future the possibility of intentional living. She and Alan have spoken about using the layout of the house, to accommodate another one or two persons, one possibly as a roommate and/or a tenant. The tenant could be part of the ‘intentional’ pursuit; they would be comfortable in a setting where one or another person might need some form of support. Alan would be the primary occupant of the house as his mom is considering developing the garage on their property, This would be self-contained she sees it as; close by, but independent and would nurture more independence for Alan and lessen his reliance on parental support. As well, she sees it as a ‘gentle’ transition for Alan (and herself) encouraging the establishment of his own space, schedule and responsibilities. It would nurture a necessary separation, allowing more freedom for both of them to pursue their individual interests. This not only speaks to a shared living space for Alan and a housemate, but also the lifting of some of the responsibility of support that his mom carries.

James’ mom also spoke to this idea of living separately in the future (but still close together), saying “it is his future, and this house is really even too big for me and him . . . [s]o one day I can see two littler apartments . . . you know, no young guy wants to live with his old mama.” These apartments would still be close enough that they could visit regularly, but her idea is that it would give some independence to James.

When participants spoke about future planning themselves, it was more often connected to things their parents or support workers had told them. Timothy mentioned that for the future his facilitator is going “to help me get a family group together that way- that way just in case anything was to happen to my grandmother or my uncle that’s very close to me, and those people would be able to help me.” Lear said something similar, that “in the future, when [her parents] pass on, [her mom] said [her support needs] will either go to my brother, or have somebody at the bank help me out, and I’ll also have a case worker who will also help me go to these appointments and help explain things a little more.” However she also said that "[m]y parents want me closer towards, more towards my brother and sister . . . but I don’t know any Community Living there and I don’t really want to be close to them, so I don’t know yet.” This speaks to a tension between what her parents might be planning for her future, and her own ideas about what she wants for herself.

There is an element of tension here between what parents have been thinking about for the future versus what participants spoke about. For example, Alan, in talking about his future, always included his mother directly in that space with him, whereas his mother spoke about them eventually having separate spaces and having some of the support responsibility shared with someone else. James' mother too had clearly been thinking more about this future than James himself. This reflects challenges in future planning which require difficult and ongoing conversations within families that are only slowly beginning to take place in many of these cases.

Wanting a family. A few of the participants, when talking about their ideal future, mentioned the desire to date and find a partner. While this question wasn't explicitly asked of all participants, it is an important part of their future home for those who brought it up, as this would be a person they are sharing their space with. In particular, Jack spoke about the importance of having a wife and kids, at multiple points throughout the interviews and workshop, one of which was "I'm always concentrating on, and my thoughts are always on, focused on bettering my future, um, Sabine . . . I'd like to get a wife- I'd like to- I'd like to marry a woman and have kids . . . [u]h, yeah, I guess- the biggest thing is family. Right? A family of my own to share with all my other siblings, because they all have families" and "[y]es and I just really want a family of my own too, like kids of my own." For Jack, his future home was entirely tied to this need for a family of his own, which speaks to some of the rooted ideas of a traditional family home that shape how he views his future. He also spoke specifically about living in a single-family home, further reflecting normative ideas about how and where a family should live. For example, he spoke of the key elements of home where he'd "make the kids breakfast, get them ready for school . . . fix dinner for the kids . . . then I'd, uh, maybe, um, say their prayer with them before they go to sleep." In each element of his day his wife and kids are there, fundamentally shaping processes of home-making. These also reflect some of the relationship he has with his siblings, included earlier, where he expressed wanting to have a family like they do, clearly shaping an expectation that he has for himself.

Figure 19. Jack’s artwork – his family

Lear also placed importance on family in her future, specifically of wanting a space for her son to be able to stay with her in her future home. She has struggled with this currently; “[s]o right now, so this house we’re not allowed to have visitors inside, so he’s mostly at my parents house and I go visit him there, so he comes to this neighbourhood, and we go to the park for an hour, and then he goes home.” In the future what was really important to her is “my son, so I’d love to keep- just because our situation is- he’s supposed to go to Brazil eventually, to live there. So I value our time together until then, so I want to make a living spot for us so we can spend time together.” As was shown earlier, this shaped her future apartment with the inclusion of a room for her son, and a space for them to be together..

Having spoken about the value of having a loving, comfortable environment, Lily said that “[b]ecause it’s- it’s not- it’s not the way I was- it’s not the way I was brought up, and it’s not, you know, it’s- if I happen to find a partner and we adopt or they- anything along those lines later on, like, hypothetically I wouldn't want that- I wouldn't to bring – like, even if it's not my own kid – I wouldn't want to bring a kid into a world without any of that." When asked further, she said she'd like "[m]aybe not necessarily, you know, a family, um, but definitely- definitely a partner for sure" in her future. This speaks to her ideas of a future life, where a partner would be involved in the experience of her home, although she recognizes that it would be much harder to have children if she doesn't have adequate supports in place in her future apartment.

Friends. Friends also continued to be important in the future. While not existing directly within the living space of the ideal home, friends connect people to people outside of the home and give meaning to those interactions. They can also continue to provide important forms of support and connection. Jack, when talking about his future home in the art workshop, wanted to include his friends, saying "[g]ot bros around me, help me through this injury and everything yep." James also, when thinking about his future neighbourhood, wanted "[t]o- to see [his] friends." Friends in the future continue to provide other kinds of support to participants as well, Lily spoke about the importance of this with regards to her sexuality,

> [y]ou know with being, you know, with being openly gay . . . [t]hat's also a big component, is, you know, obviously I'm not going to get an environment where it's going to be completely, you know, a-okay with, like with anything . . . [b]ut definitely have a core group- like a core group of friends who, if I am being gay-bashed, or if I am being teased for any given reason, I have friends who have my back . . . [a]nd vice versa. Which is also something that's really, really important . . . without friends, you've got nothing.

This speaks to the fact that friendship is not only about connecting with people and having support from them, but also a form of identity formation, where Lily's friends actively connect with her identity and protect her from others who may not share the same views.

Ideal support. This section covers what participants identified as their ideal support level, and also what they think their support needs might be. This is included with the relationships section because support workers are an important and complicated relationship for people labelled/with intellectual disability. Many participants spoke not only about what a support person might help with, for example with finances or cooking, but also what a support person might *be* like and how they would get along. An ideal home for many participants was based around having enough support to help them live outside of the family home, a tension that was picked up on in the 'Making Home' section, and this is reflected in their quotes.

Oliver spoke about his support needs as specifically around finances, saying: "[o]kay, well *pause* if I were to need supports I guess, um, just primarily just to, um, worry about some of the finer stuff, like, again finances, banking. I guess, um, shopping for, um, I guess customer awareness as well because, um, if you're living on your own you want to be able to maximize your, um, spending – you want to make sure that – you want to make sure you don't spend more than you make, and balance it with living expenses, transportation, etc. so . . . [s]tuff like that I feel would be the main source of support that I would need if I moved out."

Alejandro spoke about similar needs, although he also included help with cooking: "[u]m, I think yeah, um, I probably would need, like, a support worker for things like taxes, for, like, money things, for like knowing how much- how much I spent in a month, knowing, like, cuz I'm- cuz I'm good with the cooking but I'm not 100% great yet with the stove yet, still kind of like freaks me out a little bit. So that kind of stuff, and I think just, like, the general stuff in life that is a little harder, so I think it would be great if I could have at least, like, a support worker who would support me in, like, money situations and, like, knowing if certain things are safe, and, like, knowing what to get at the grocery store, so, and- and working with stoves and stuff, so." He also mentioned having a roommate who could also provide this kind of support, saying that a friend of his had something similar to this, where a housemate provided informal supports to them.

Lear, when asked what her ideal level of support would be, said; “we just talked about this last week with the staff, it would be having a case worker – I’m looking to having a case worker, for myself – but having a case worker come in maybe twice a week to help me with my finances, budget, check up on me mentally with my health and how I’m doing, um, and yeah, so that level.” This is similar to the situation she has currently, where there are staff available during the weekdays in her group home, but this ideal situation provides her with more freedom and less supervision.

Catherine mentioned a careworker providing verbal support, specifically; “[j]ust like verbal, ver- verbal reminders like *pause* so like specifically like, like with like shampooing my hair it’s like- like the reminders of the physical, of shampooing hair and- cuz I’m not very good at hand-eye coordination” and helping with “activities of daily living, I guess basically.” She said she’d be excited about; “uh, I guess just doing things with the caregiver . . . like having walks around the main streets, like the main street. Like going to coffee shops and going and exercising and riding a bike on bike share.” She mentioned that she would like this to be “Uh, like, basically a female too, like just not to sound sexist just cuz I feel uncomfortable like just cuz- like I- it’s not like- it’s a go out and see guys and meet guys.” This is different from her current situation, where her parents provide most of her support.

Lily, who as previously discussed has dissociative disorder and has more complex support needs because of this, spoke of her ideal support as “like I said to live semi-independently but maybe have like an aid worker come and check on me, you know, every other day or, um, every couple of days just to kind of check in” and “not have someone sort of looming over me but then just have someone there and then to also have someone on, like, backup." She said that "maybe that means having some sort of medical device that I wear that if like I'm on my own- like I don't even know if there's anything that like exists . . . [b]ut ideally having something on me that if I were to start, you know, freaking out or having, you know, something like that, that something sort of alerts someone else." This speaks to the fact that she needs flexible support because her needs can change each day and need to be addressed by someone familiar with her situation. She mentioned that the ideal characteristics for this support person would be "[i]deally, I think just having someone there, whether it be like a social worker or someone who, I guess someone who has, um, enough background or knowledge, uh, to deal with someone like me *laughs* who has almost like a medical background in terms of how to, you know, how to manage someone who has dissociative disorder. Because when it comes down to it that's what terrifies me the most is that, you know, will there be someone that will be able to manage without freaking out." She further went on to say that,

> unfortunately like I said there are support people out there who are like drill sergeants . . . [y]ou know, 'do this, do this, do this, do this' and that's not, um, I don't think that that's a very effective. . . [s]o have nice and polite, uh, nice and polite . . . I guess it would be, uh, sort of a happy medium between strict and pushover.

In each of these expressions of ideal support, there is an emphasis on having someone there *when they need them*. This speaks to a flexible, individualized care that is different from what is currently available to them.

5.2.3 Neighbourhood

Just as their current neighbourhood is an important piece of how participants experience home, the ideal neighbourhood is a key part of the envisioned landscape of their ideal home. This space around their home not only connects them to other people but also encourages participation in spaces outside of the home, thus shaping how they feel inside of the home as well.

Places to go. The places in a future neighbourhood that were important varied for participants but included things like natural areas and community centres and churches and practical places like the hospital and grocery stores. Lily mentioned that she'd like "a nice park, um, or some sort of, some sort of park that had, you know, nice seating areas, you know, some in the shade, some not in the shade. Uh, *pause* cuz who doesn't like parks right?" She added that she would also like "the element of being in the woods and to, you know, but having- having somewhere where, you know, there is a nice garden where you can, like, walk or, you know, have a picnic, or something like that, so that's what that- that's what that picture is . . . and just have, like, you know, nice places to sit . . . still have somewhere where you can sit, um, preferably picnic tables, um, cuz those are a little bit more welcoming." This relates to the image below, from her future home collage, where there are pathways to walk on, benches to sit on, and nature to sit with.

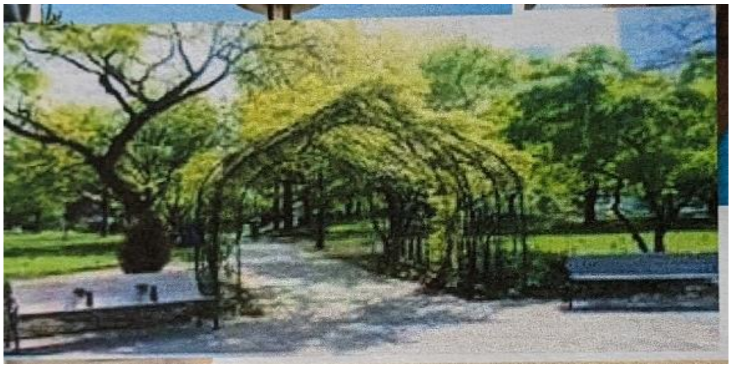

Figure 20. Lily's artwork – park space

Oliver included something similar, saying he'd like to be "close to a natural area as well, not so close to the suburbs [as his current house]." Alejandro also mentioned the benefit of park space, saying “maybe like a park because I like- I like going to parks when, like, I’m feeling, like, very overwhelmed or- or when, like, my anxiety is bad because going- weirdly enough, like, going to those areas kind of, like, helps me calm down because, like, I feel like I can sort of, like, collect my thoughts and like it- like the- the environment kind of makes me feel better . . . [s]o I like, I guess I kind of like going to- I guess I kind of like going to parks because they- they make me feel a bit less, like, stress-y and stuffy.”

Another piece that came up was the importance of places to gather, specifically churches or community centres. Lily mentioned that in her future neighbourhood she’d like “my co- my church- my- the- the, um, Anglican church that I’ve been going to, um, even before I was born . . . It’s- it’s my second- it’s my second family because it’s just been so important” so “[i]f I can get to my current church that would be . . . That would be- that would be fantastic. But if I can’t then, you know, at least let me be able to go to the [local church] . . . I think. Cuz that’s also- that’s also a church that is very welcoming to the LGBTQ times whatever letters they want to add.” The church in this instance serves not only for her to be in community but also is important for accepting her sexuality. Church was also important for Jack, who said he’d “like to live close to a church, or something I can take my kids, baptize them there, have them baptized and yeah, maybe go to church every Sunday or something, yes.” In this case, church is something that he would be able to take his future family to and is an important part of his life.

Lear also thought that her neighbourhood might include more communal events for her to attend, saying she’d like “to be in a nice neighbourhood. A lower income neighbourhood like Cabbagetown or Regent Park area so they can offer free amenities for the people that are in the low income, um, yeah” and also “to be around, um, community centres that are free and offer, because since we, we don’t really have a lot of money, and we’re on ODSP, um, our money is limited. So free programs, volunteer, just places close by around the neighbourhood, just basically?" Catherine included something similar, saying she'd like to be near; "I guess near a community centre, like, *pause* like the YMCA, or Variety Village, or near a hospital, or at least 2 or 3 cafes." The cafes came up multiple times as an important activity for her. Her mom also mentioned the hospital as important, "[b]ecause I think it helps her with her anxiety knowing something is close." This speaks to not only the desire for community and activity in the future, but also of making sure their needs are attended to, like being able to afford these services and access to healthcare.

Another element of their neighbourhood that was pointed to by participants was to have a grocery store or shopping closer to them than it currently was. Jonathan said that "I want to have- I want to have a shopping there, I want to have, um, um, yeah a shopping mall, and a grocery store, No Frills there, and Fortinos there." Similarly, Ruth said "I would like to have a nice, I would like to have a nice shopping mall around here . . . [t]hat'd be nice, but I don't think it's going to happen because there's too many- there's too many, uh, there's too many, uh, too many buildings and there's too many stores and all that stuff, and I don't think it would, I don't think it would work."

Alejandro said that he'd like "maybe, like, a grocery store, so- cuz in the- cuz in the last- in the last – excuse me – in the last few weeks . . . I've- I've been going alone to- to the- to the grocery stores near- near my parents, so like I- I just go with, like, what I want to get so it's like they- they let me get what I like and with- with the exception of getting, like, a few things but, um, but I would pro- I would also like to maybe be closer to a grocery store so I don't have to go too far just to get my eggs or, like, my breakfast or whatever kind of meal." The grocery store here is an important space for independence, of being able to buy his own food, and this was something he'd like to have access to in the future.

Many of these elements of an imagined home reflected the shortcomings of participants' existing housing living arrangements. For example Lear isn't very close to neighbourhood amenities where she is, and Ruth isn't close to a mall. There is also a worry here that in the future they might lose access to things they value in their current neighbourhood, such as Lily's church, or Alejandro's proximity to grocery stores that he can go to alone. This speaks to worries about what they have and what they would like may not line up in the future, and also speaks to the elements of a neighbourhood that they value.

Transit. Transit continues to be an important part of their ideal home in order to connect them to spaces outside of their immediate neighbourhood and provide a form of independence because they are able to navigate it by themselves. Oliver, when asked what he'd like to be close to, answered with "[w]ell obviously transit lines, to get around quicker." Timothy also, on what was important to him said "[w]ell, what's important is to be close to the local bus route, close to the local bus route because I enjoy, like I know- I know almost every bus route in the whole entire city and I go on lots of buses all the time and I know almost every bus driver." He further said that this was the only thing of importance in his neighbourhood "[n]o actually I don't care [what's there] as long as it's near the buses." Jonathan spoke about the importance of new transit opportunities that are coming to the city, as shown in his artwork below where he speaks to the new Eglington Crosstown LRT stop that he is excited to use in the future.

Figure 21. Jonathan's artwork – 'new 2023 Eglington Crosstown LRT'

Lear, on what was a key part of her future home said, "having the TTC there, access to the TTC" which was also reflected by Lily; "both the TTC and WheelTrans are both, uh, are both- are in both, um, pieces because that's obviously important." In their future, this is the only way for them to get around and so transit in this case offers a means to moving around the city independently of needing other people.

Safety. Safety is something that was emphasized disproportionately by female participants, with all four female participants mentioning it as compared with and only one of the male participants. This theme specifically revolved around the perceived threat of crime, but also included the safety related to other diagnoses. Ruth's comment on safety was shown above, where the house she drew in her artwork included locks on the windows and door, saying that this would make her feel 'safer.' Lear also mentioned safety in that she'd like to be "in a safer neighbourhood, um, definitely safety is a big concern so a good neighbourhood but also having the availability of programs for me, um, you know at Regent Park there's free swimming and there's a free gym. Something like that but like in a safer neighbourhood, quiet. I love quietness.” In this case the safety of the neighbourhood is not just about crime but also about the community around it.

Catherine echoed this idea of safety, when asked if she’ll be able to live in her future apartment, saying “[y]es, as long as it’s not too dirty and dangerous.” It would be dangerous, she said “[i]f, if it, if there’s crime. However, Catherine was also worried about danger to herself saying, “I’ve had independence before, but I’ve gotten in danger – Catherine has gotten in danger . . . [because] Catherine went out at night. So I have to make sure that, there’d have to be an alarm system where I can’t, I physically can’t open the door at night. Like even if I have a nightmare and I feel scared and I need to – Catherine needs to get out of the apartment – Catherine can’t get out of the apartment at night.” This is reflected in Lily’s future space too, where she spoke about safety mechanisms in her space to protect herself,

> what’s really scary and why safety is very, very important is because [a dissociative episode] comes on so fast and sometimes unexpectedly that when I’m in that state I need to have someone who understands and someone who knows how to, you know, someone who knows – [h]ow to respond in the best way and the safest way and without that its, you know . . I don’t want to say, like, constantly, like 24/7 on hand but just have someone that is readily available that knows, you know, if an alarm goes off or if my roommate, you know, sort of senses something they can call someone.

Oliver, on what a safe area meant, said “[w]ell pretty much what you would expect from the statement but, uh, quiet, um, minimal crime or no crime, preferably, and, um, good neighbours.” He was the only male participant who mentioned safety, and his worries about it are much less focused on fear for himself and more quality of neighbourhood, in the ways that we can see from the female participants, who spoke in more detail about their fears for their safety.

Safety here means many different things, including the safety of having support, the perceived safety of a low-crime neighbourhood, and the physical embodiment of safety through locks and alarms. In each of these there is a worry of what might happen if that safety was not in place, and the security needed to feel at home in their ideal future space.

5.2.4 Tensions between ideal and reality

How participants envisioned the steps to this ideal home varied and included things like the need to have a job, being more independent, selling their current family home, and the process of looking for an apartment. The timeline of when this would happen ranged from a few months to several years and reflected participants' current home situations and ages.

Finances and work. After discussing their ideal home, participants were prompted on whether this ideal matched with what they thought the future held. In response, participants varied on whether this ideal would be possible. A key component of this was a worry about finances or finding work, as provincial funding isn't enough to maintain a move, so finding a job was highlighted as a key criteria for many participants.

Catherine said she wasn't sure if this was possible "just cuz there's not that much other housing available . . . [i]n, in Canada" and that "[e]verything is taken." In closing the interview, she said "I would like to not be homeless" which expresses that this is a worry that she has. She said that she'd "like to try and have a job it's just that I don't have that much money, Sabine, like honestly I don't." Her mom went on to explain Catherine "had a job wiping tables and changing the garbage bags [at McDonalds], but then her anxiety and these panic attacks got so bad . . . they said they would need Catherine to sort of get help with that and- but, but unfortunately Catherine didn't get any therapy and it just sort of got worse. If you don't catch things, for all of us, if you don't catch things quickly they tally, they get- they get worse." Catherine has had a hard time finding a job since then.

When asked what would be needed to get to his ideal home, Oliver said: “[w]ell, for one, experience living on my own. Just to be able to, uh, create that mind set and responsibility. Second, definitely a job or a career to be able to pay for it.” He said further that he’d need help with this: “yes but it will take time. I’m currently going back to school for that very reason to be able to pick up something with a stable career so I can move out and get to that dream state.”

Jonathan, who would like to live closer to his parents as part of his ideal, says he also feels this is attainable, “[y]es, yes, yes . . . [at] some point, yeah, some point in the future, yes.” However, he also spoke about responsibilities he needs to take on for the future, such as needing a full time job, saying he’d need to do “want to get a job, full- I want to get a full time, paid job.” He said “I- I want to be an independent person, that’s why I- I want to be Jonathan I want to be Jonathan. You know?” In this case, Jonathan is referring to a desire to be an independent adult but hasn’t yet been able to feel that way because he’s waiting for people to support him to that.

Limited choice. Lear also wasn’t sure about the likelihood of her ideal, saying “I hope so? It would probably be in one of- it would probably be like outside of Toronto, um, in a quieter farmland area. Um, there are a few outside in Ontario but they’re quite far away from, um, everything? So, I hope maybe in the city but, yeah. It’s hard.” Again speaking to the lack of options available, “[u]m, right now there’s, I don’t think there’s anything for, I think there’s L’Arche? Um, but that’s not the care that I need, but I don’t think there’s something for the intellectual disability community, I don’t think they’ve made any homes per se.” This speaks to the fact that though she’d prefer to live in an inner city neighbourhood, close to transit and community resources, it seems much more likely she’ll find a space further removed from the city instead.

Lily also picked up on this challenge, saying “I hope so . . . [with] Community Living and so through, there’s a place called [name of home] for those who have developmental disabilities and so like I said before I am on the list, and so, um, I know eventually I’ll get a spot.” However, as was noted previously, she is also uncertain about when this might happen, since she’d been on the waitlist for approximately 5 years already with no sign as to when she might find a spot.

Ruth, who talked at length in the workshop about her ideal home, said in closing that “I wouldn’t be able to get into a condominium anyway first of all they don’t take people on government assistance, you have to be- you have to make a lot of money to get in to buy or to rent a condominium, you have to have a fairly good pay job and I don’t have that, so, I wouldn’t be able to get into a condominium anyway . . . [a]nd I wouldn’t be able to have a house anyway, those two things would be out of the question” because of funding constraints she experienced. In the case of Ruth, even when thinking about this possible ideal condo or house, she stated that this wouldn’t be possible in her position and that she’s “happy where [she] is” in her current apartment. Age is an important factor here, at 67 it feels much harder for her to move anywhere else, and her funds are limited to her apartment now. Her satisfaction with the apartment is likely tied to not having other options.

Staying with family. Participants who did not express as much uncertainty were those who expressed wanting to live with their family for the foreseeable future, like James and Alejandro. Alejandro said that “hopefully, like hopefully that can actually happen because that would be really great if we were somehow able, if were somehow able to make that happen.” However, he also felt that this would be many years in the future, when he is in his 30s. Additionally, while James and his mom spoke about an apartment in [town], his mom saying, “we could get an appointment to go look at the apartments they have, just to see what they’re like,” this seemed distant to James, who considers this far in the future, saying “I don’t mind, it’s up to you” rather than really thinking about this.

Alan, who is also planning to stay with his mother in their home, felt secure in this future. His alternate plan was to possible move to B.C. with his mother, but again they had the financial security for this, “[i]f we, um, if we- if me and my mother sell this home . . . [i]f we sell this home we can move [to B.C.] . . . [i]n the future. Or maybe we can rent it out, for example.” However, his mother pointed out that they don’t have the financial ability to live independently from each other, as combined their income is still below the poverty line.

In each of these cases there is a level of certainty about the future, or the fact that any planned move would be a long way off, and so there is less worry about what it might look like. It seems that the closer or less decided a move is, the more participants expressed worries that it wouldn’t work out or they didn’t really know what their options were.

Chapter 6: Discussion and Concluding Thoughts

6.1 Summary of findings

Overall the analysis presented in Chapter 5 has shown that participants' experiences of, and aspirations for, home are diverse, multifaceted and spatially expansive, involving much more than the material characteristics of the dwelling itself. By exploring not only the physical home, but also the relational ties to people and communities, this work demonstrates how people labelled/with intellectual disability strive for belonging both at home and in their immediate communities.

The ideas of home-making presented by Blunt & Dowling are evident within the analysis of this thesis, in terms of first the importance of home as made up of "material and imaginative elements," of "social and emotional relationships," and home as a process, which is constantly in flux (2006, pg. 22). In their current housing, participants demonstrated how their home is shaped by the material conditions of that space, such as the disliked basements of Alejandro and Oliver, and also by the social ties to others, like Lear's housemates. Participants demonstrated how the home shaped those feelings and how their relationships with others, for example family, friends, or paid support staff, contribute to feelings of being in or out of place. They also demonstrated their agency in shaping those conditions, such as choosing when they wanted to leave the home and where they'd like to go in their communities. Access to transit was a key component of this agency, as this allowed them to get around on their own. For example, Lily cited WheelTrans as part of her independence, because she could get around without getting lost.

Within the interviews, even among a relatively small group of people, there is a diversity of needs and aspirations, some of which affirm normative ideas of housing and some of which push against what an ideal future home is perceived to be. Normative ideas of a single-family home are seen in Jack’s case, where he wishes for a wife and children, to be in that home with him. This is possibly shaped not only by the example of his parents and siblings, but also broader societal understandings of what an independent home means.

By contrast, others aspire to more communal forms of accommodation, seen in the examples of Lily and Lear, who are pushing against a private, detached family unit in favour of a community-based, semi-independent living situation. This offers an alternate vision of housing based upon interdependence and supports that reflect changing and flexible needs. Both Lily and Lear have lived independently before and haven’t liked it, which might influence their desire for an alternative form of home. Yet these choices are not black and white, and there are a wide variety in between these two forms of living, for example in Jonathan’s desire for independent apartment living, or Timothy’s continuing wish to live with his mother in a shared space. This demonstrates that needs and aspirations for housing differ even among a small sample, and so the forms that housing and support take need to be flexible as well.

Belonging is also important for understanding these experiences, as laid out by Antonsich (2010) and taken up more recently in disability work (Renwick et al., 2019; Morrison et al., 2020; Kaley et al., 2021). In particular the idea of ‘self-building lives’ by Kaley et al. is useful here for understanding how people engage with networks, drawing upon relationships and resources to make home (2021). In this analysis, the feeling of belonging to a community was important to understanding the home, as relationships with neighbours, ability to access resources and places in the neighbourhood, and the opportunity to volunteer, work, or go to school were all emphasized as integral to current experiences of home, and imagined futures. Interactions in their neighbourhoods, or in places they go to, shape how participants interact with others more broadly and also encourages or discourages going outside of the home, based on how they feel during those interactions. For example, Lily spoke to the benefits of feeling safe in her neighbourhood because her neighbours can support her, and Timothy spoke about his trips to the mall or community centre as ways for him to see people he knows. This speaks to the importance of social encounters in shaping feelings of belonging, outlined by Bigby & Wiesel (2016), and the ways in which belonging comes from a feeling of community (Kaley et al., 2021). The (in)ability to access these activities and interact in positive ways changes how participants viewed their communities, demonstrated by the loss of many of these activities during the COVID-19 pandemic and the resulting feelings of loneliness and frustration experienced at home. However, it is also important to note the continued agency that was shown in the pandemic, particularly for people in their family home, in finding new activities that they enjoy, such as Alejandro's and Alan's interest in cooking.

Across each of the experiences discussed, an overriding theme concerned the challenges in receiving support, both in terms of paid support that meets their needs, and also in terms of finding subsidized housing options, which demonstrate the ways in which people so labelled experience restricted choice and limited ability to move into a space outside of their parents', reflecting the findings of earlier work discussed in Chapter 2 (e.g., Verseghy et al., 2019). It is seen also in the tensions between their ideal versus their reality. When asked whether their ideal home was possible, those actively considering a move replied with uncertainty, both Lily and Lear saying, "I hope so" and Catherine saying, "I would like to not be homeless" as her baseline, speaking to the fears and worries they each have for the future. Those who are not planning to move or were more financially secure, were more certain of the future. This reflects some of the constraints identified in Chapter 3, where the limited housing choices in Ontario were laid out, emphasizing the group home as the most funded community living option. The long wait lists for housing, and lack of choices within supported housing (Verseghy et al., 2019; Spagnuolo, 2016) are also reflected in the quotes from participants in this study, with Lily and Lear citing a 10 year wait list.

Yet in spite of these challenges and tensions, overwhelmingly the results of the interviews and art were positive. Participants were looking forward to their future and enjoying their present, despite the challenges that they experienced. It is important that this is acknowledged and understood, as often the narrative around housing for people with disabilities can be entirely negative, solely pointing out the flaws of the system and how poorly people are treated. While this is an important point to make, it is also important not to categorize people only by their hardships. While the lives of people labelled/with intellectual disability can be shaped by the conditions around them, for example funding constraints or attitudinal barriers, they are also able to exercise agency in how they interact with those constraints and their communities. For example, both Lear and Lily had had challenges in their previous homes, in navigating mental health diagnoses and other relationships. Yet both have also found ways to remake home in the context of their current living arrangements. Lear spoke about how much she loves "being around the women [in her home]" and Lily said that her experience in returning to her family home has been "so supportive, so loving."

6.2 Implications

For literature. This research project illustrated that the main form of housing for people labelled/with intellectual disabilities is still the family home (Grey et al., 2015), with 8 out of 11 participants residing with their parents and planning to remain there for some time. It also demonstrated the reasons why this is the case, specifically because of their limited ability to find housing, long wait lists, and a lack of housing options in the city (Grey et al., 2015; Verseghy et al., 2019). Findings also emphasized the fact that housing needs change across the life course. The age of participants exaggerated frustrations with wanting to move, seen in the case of Catherine, Jack, and Oliver, which was not present for the younger participants, Alejandro and James. Parents also expressed the need for future planning in view of their children aging, seen in the case of Lear and Alan. These changing needs emphasize the necessity of person-centred planning, discussed in Chapter 1, which creates a cohesive document detailing the persons short-term and long-term goals (Dew et al., 2018). Within this process there should be a reviewing of the goals every few years, to better account for the fact that needs and wants can change over time.

This research project also furthered work within disability studies focusing on the importance of belonging as a framework for understanding how people labelled/with intellectual disabilities experience their community (Renwick et al., 2019; Morrison et al., 2020; Kaley et al., 2021). It further connects this work to research focusing on the home, by demonstrating the ways in which the home, and the feelings attached to it, are fundamentally connected to experiences outside of it and the ability to connect to a community (Laschewicz et al., 2020; Quinn et al., 2016). This counters the prevailing trend towards *inclusion*, which focuses solely on paid employment or living independently, rather than the "many different ways in which people with [intellectual] disabilities can feel accepted, welcome or 'in place.'" (Kaley et al., 2021, pg. 7). Belonging offers a much broader means of understanding how people so labelled feel in their community, of feeling an 'insideness' and 'outsideness' in those spaces based on whether they feel like they belong or not (Kaley et al., 2021; Laschewicz et al., 2020).

The project also highlights the importance for geographic location in studies for people labelled/with intellectual disability, pointed to by Wark (2018). While his work was focused specifically on the rural/urban divide, this thesis demonstrates that the neighbourhood context (in cities and rural areas) is critical for understanding how people labelled/with intellectual disability understand their home. Where they live includes not only what type of dwelling they reside in, but also the places they can go to, the people they are able to see, and the supports they can access (Wark, 2018). Each of these shapes the experience both within and outside of the home, seen in Lily being able to use transit in her city to get around, thus giving her access to activities like attending church, going to choir, or seeing her psychiatrist. These connections can only be understood if geographic location is included in the research.

The findings of this thesis also further support trends within geographies of disability towards inclusive research practices, with research done *with* and *by* people labelled/with intellectual disabilities (Chouinard et al., 2010; Wilton et al., 2018; Renwick et al., 2019). Having the voices of people so labelled directly drawn on in the research, as well as ongoing plain language communication and summaries of both interviews and analysis, were used here in keeping with those practice and demonstrate the value of them both within research and for participants themselves.

The use of an arts-based method as an alternate accessible form of communication was informed by other work in disability studies (Dew et al., 2018; Richards et al., 2019). Those who participated in the arts component of the research expressed the benefits of it for thinking about their home, and also just that they enjoyed the activity. Lily in particular mentioned that she enjoyed going through photos to create her collage, as photography is a hobby of hers. The availability of an arts facilitator was particular useful for Jack, who struggled to complete the art himself due to limited mobility, and so this provided a way for him to participate in an alternate way. The use of multiple mediums (pencils, markers, paints, collage, photography), provided participants with the opportunity to express themselves in the ways they wanted to. This ranged from an activity done by the participant alone in advance of the meeting, to a collaborative one in which researcher and participant worked together to create the finished piece.

For policy and practice. It has been demonstrated here, in line with calls from the Canadian Association for Community Living and People First of Canada, that there needs to be a better understanding of home beyond just a physical dwelling (CACL, 2020; People First of Canada, 2018). In their position statement on housing, CACL state that "individuals with an intellectual disability and their families continue to be presented with options that do not support lifestyles of choice, and instead assume that people with an intellectual disability will stay indefinitely in the family home or move into group home programs or other institutional environments" (CACL, 2020). They call for "a rights-based approach to housing and community inclusion, facilitated by access to adequate and affordable housing, individualized supports of one's choosing, and separation of housing from disability related supports" and to "[e]xpand the traditional approach to analyzing housing development to include five domains of housing inclusivity - household, dwelling, structure, person, and neighbourhood - addressing both the social and broader ecological context" (CACL, 2020). People First of Canada further this broadening of the definition of home in their own position statement, stating "[a] real home means a neighbourhood, a community, choices and opportunity" (UNCRPD, as cited by People First of Canada, 2021). They also state that "[e]very person should have control over where and with whom they live" (People First of Canada, 2021).

The experiences captured in this research demonstrate that home is made up of more than just the immediate material conditions of the dwelling, encompassing the emotional ties to that space, the social relationships both within and outside of it, and the broader neighbourhood setting, resonating with these statements from CACL and People First of Canada. This has implications for the ways that housing is understood in policy in Ontario and other jurisdictions, which currently only looks at living in the community as either in group homes or independent living, with very little variability. Instead, a focus towards housing based around choice and control is needed, with flexible options available for support, catered to the needs and aspirations of the individual, specifically those with complex support needs. This work has also shown the importance of finding more novel housing designs, such as semi-independent living (Atack et al., 2019; Bigby et al., 2017) or shared housing (Hole et al., 2015), that move beyond either private living or group homes, and which are funded by the province and better able to create feelings of belonging – creating the opportunity for "community, choices, and opportunity" (UNCRPD, as cited by People First of Canada, 2021). Having alternative housing models has been shown to improve well-being for people so labelled, and can increase feelings of independence (Atack et al., 2019; Hole et al., 2015; Randell & Cumella, 2009).

Additionally, there is a need to change the outdated policy within the province based in the *Social Inclusion Act (2008),* which heavily focuses on individual diagnoses and cognitive assessment, towards interdependence and supported decision making, which better represents the relationships between people labelled/with intellectual disabilities and their support network (Power, 2006). There is also a need to change how funding is given in the province. The default to the family home or group homes has left limited funding for alternative living arrangements, which have been shown to better cater to individuals labelled/with intellectual disability yet are often not feasible without adequate funding (Bigby et al., 2017; Atack et al., 2019; Hole et al., 2015). This leaves a gap between the diverse needs and aspirations of people labelled/with intellectual disabilities and what is available to them, reflecting outdated understandings of housing needs. The changing needs of people labelled/with intellectual disability have yet to be understood by the province, in spite of the work of advocacy groups for change. In this the vestiges of institutionalization are still evident, seen in the practice of transinstitutionalization for some people labelled/with intellectual disabilities with higher support needs who end up in hospitals and long-term care homes (Burghardt, 2018; Spagnuolo, 2016), and in the continuing emphasis on cognitive assessments and diagnoses as a basis for care, rooted in the medical model of disability (Spagnuolo, 2019). This demonstrates that the history of institutions is still influencing housing for people so labelled in both policy and practice (Burghardt, 2018) and continuing to constrain what is believed to be possible for their future.

6.3 Limitations

As was outlined in Chapter 4, there are a number of limitations with this study, in part related to the limitations of the masters. This includes a limited amount of time for the participatory research methods, which reduced the opportunity for participants to choose the forms dissemination took (Fudge Schormans et al., 2018), as well as limitations of the interviewing ability of the researcher herself. The small sample size means that this research is not able to be representative of the varied population and experiences of housing, for example it was not able to reach anyone with moderate-to-severe intellectual disabilities, but the multiple interviews and art have been used here to try to present as accurate and detailed account of the people interviewed here as is possible.

The conditions of the COVID-19 pandemic also played a role in limiting the form that the methods took, and the ability for participants to feel comfortable with the researcher over Zoom or phone calls. The researcher had initially planned to have the arts workshop take place in a community space with a group of participants working collaboratively on what was important to them, with an arts facilitator there to help. Changing conditions in the pandemic meant that this shifted to an individual activity, only some of them were in person, and only one using the arts facilitator to help with their art. The majority of the interviews and workshops were online, making it more challenging to foster open and comfortable discussion between researcher and participants. Technical issues played a role in this, with the audio or video sometimes cutting out, or the researchers cat sitting on the recorder. The technical component also made it more essential for some participants to have a support person with them to set up the call, which while beneficial, also meant that they spoke over or contradicted what the participant said. Wherever possible, the researcher steered the question back to the participant but in some cases this was not possible.

6.4 Future directions

As has been pointed out above, there is a need for further research to be done on how people labelled/with intellectual disability understand their homes and what that means for how housing services operate within the province. This could include quantitative data on the types of housing available within the province and how many people are using them, what kinds of service organizations are most used, and identifying gaps experienced in the community, in terms of accessibility or attitudinal barriers. It could also include more qualitative, arts-informed research on what home feels like, and how this can create feelings of (not)belonging both in the home and in the community, on a larger scale than this study.

There is also a need to understand the geographic locations of people labelled/with intellectual disability, with a focus specifically on what the neighbourhood context is for where they are living and how this influences their ability to navigate their communities (Wark, 2018). As Wark pointed to, the location of home for people labelled/with intellectual disabilities directly relates to their ability to access services, supports, transit, as well as connect with friends (2018). Further work in identifying geographic location is important for understanding where gaps in access are and how this shapes conceptions of home and community.

What is also clear is that future work needs to directly involve people labelled/with intellectual disabilities in the research, in keeping with some more recent examples (Fudge Schormans et al., 2018; Renwick et al., 2019). By including people so labelled actively in the process of research formulation, collection, and dissemination, their voices are being heard where they have historically been ignored or deemed too vulnerable within academic research (Dee-Price et al., 2020; Santinele Martino & Fudge Schormans, 2018; McDonald et al., 2017).

In keeping with policy such as the *Representation Agreement Act (1996)* from B.C., there is an opportunity to move towards supported decision-making and away from the substitute decision-making still in practice in Ontario (Stainton, 2016). This would shift the way that we understand housing and the rights of people labelled/with intellectual disabilities in the province, moving away from issues of capacity towards interdependence and trust between people so labelled and those supporting them (Stainton, 2016). Research looking at how supported decision-making can be achieved in practice is needed to better understand how this can be applied to policy in Ontario, in both small and large decisions, to replace outdated substitute decision practices (Stainton, 2016).

6.5 Concluding thoughts

The work in this thesis has shown the myriad ways in which people labelled/with intellectual disability are actively engaged within their homes and communities in creating and sustaining social relationships and emotional ties to the spaces they inhabit. The ideas of home-making and belonging have been useful for understanding the stories of participants, emphasizing the relational nature of agency and support, and the ways in which they intersect with the home and community.

By asking what an ideal home looks like, we can see the ways in which participants are engaged in the process of imagining and creating bright futures for themselves, based on flexible support systems and a diverse range of living spaces. These lived experiences show the importance of community both in the present and in the future, and also the aspirations of people labelled/with intellectual disabilities to be full members of their communities. It also shows the influence that beliefs about housing have in enabling or constraining what they feel is possible for that future.

While this thesis has only scratched the surface of what has proven to be a nuanced and complex relationship between people labelled/with intellectual disability and their home, it will hopefully lead to other similar studies and help to shift the way that housing has been perceived up to this point. A house is more than just a physical dwelling, citing People First of Canada again, “[a] real home means a neighbourhood, a community, choices and opportunity” (UNCRPD, as cited by People First of Canada, 2021). Hopefully this will eventually become the benchmark within Ontario.

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Appendix A. Letter of Information

A STUDY ABOUT EXPERIENCES OF HOME FOR PEOPLE WITH INTELLECTUAL DISABILITY

What is this study about?

- This project will explore how people with intellectual disabilities navigate housing and create home.
- We want to learn about what is important to you when thinking about your home and what your ideal future home would look like.

Who are you?

I am Sabine O’Donnell, and I am a masters student in the School of Earth, Environment, and Society at McMaster University in Hamilton, Ontario. I am working with Dr. Robert Wilton, a professor at the School of Earth, Environment and Society. You can learn more about Rob here: https://www.science.mcmaster.ca/ees/component/comprofiler/userprofile/wiltonr.html?Itemid=351

What do people do as part of this study?

There are three steps in this study.

Step 1 will be an interview with me, either via Zoom or phone based on your preference. I will ask you some questions about your experiences of home in the past and your ideal future home. Some example questions would be:

- What is your favourite/least favourite part of your current home?
- When you think about the future, what does your ideal future home look like?
- What would you need in order to create your ideal home? (For example, help, resources).

If you agree, I will record what you tell me on an audio recorder. I want to make sure I don’t forget any of the important information you share with me. I also want to make sure that I understood it correctly. This interview will take about 1 hour, and we can take breaks if you would like.

After the interview is finished, I will write a summary of what you told me and send it to you.

In step 2 we will meet either by Zoom or phone again to talk a little bit more about some of the things you said or finish answering any questions we didn't get to during the first interview. This will take about 45-60 minutes.

In step 3, I will invite you to take part in a workshop with other participants in the project. This stage of the research will take place in early 2022 and more detail on the workshop can be found in my second information letter.

*You may include a support person in any or all of the steps of the research if you like.

Where will the study take place?

The first two steps of the project will take place virtually, so you can choose a space that feels comfortable for you to take the call in. This may be a room in your home or a private room at a program or organization you are part of.

It is important to note that Zoom is an externally hosted cloud-based service. A link to their privacy policy is available here (https://zoom.us/privacy/). Whilst this service is approved for collecting data in this study by the McMaster Research Ethics Board, there is a small risk with any platform such as this of data that is collected on external services falling outside the control of the research team. If you are concerned about this, we can conduct your interviews over the telephone. Please let me know if you have any concerns.

During any interviews on the Zoom platform, I will only record audio data using a digital voice recorder. The audio recordings from interviews will be saved to a password-protected local computer and then stored on a secure university server. They will not be stored on an external cloud-based service.

Will I be paid for taking part in this study?

Yes, you will be paid a maximum of $160.00 for participating in this study.

- $40 for completing step 1 (the interview)
- Another $40 for step 2 (the follow-up meeting)
- $80 for taking part in step 3 (the workshop)

If for any reason you want to stop during an interview, you will still receive the money for that step of the study.

Will anything bad happen if I participate?

It is very unlikely that anything bad will happen if you choose to participate in the study. However, you might feel uncomfortable answering some of the questions that I ask you. You do not have to answer questions that make you feel uncomfortable or that you do not want to answer.

You might also be uncomfortable with some of the topics that are discussed. You don’t have to share any personal information you don’t want to share. You don’t have to participate in uncomfortable conversations if you do not want to.

At the end of the study, I will be writing reports and making presentations about what you and other participants told us. I will not use your name when we talk about your experiences. However, there is a chance that people might be able to identify by the stories that you tell.

What good things could happen if I participate?

Participating in this study will not change your life or change the services you receive. However, it will give you an opportunity to tell other people about:

- Your opinions about and experiences of home as a person with an intellectual disability.
- Opportunities and barriers you’ve faced in creating a home.
- What your ideal home would look like.

This will help other people (service providers, family members, members of the public) to understand more about what home can look like for people with intellectual disabilities.

What do you do with the information I share with you?

I will listen to everything you and other participants tell me. I will then write a report about the opinions and experiences of all the participants. I will also make a presentation on the research as part of my masters thesis.

Remember that the research is confidential. This means that none of your personal information will be attached to these reports or presentations.

I hope that by sharing what you told me in these ways, other people will have a better understanding of the things that are important for creating home for people with intellectual disabilities.

Will my information be kept private?

You can tell anyone you like about the research, but I will not tell anyone you are participating. I will also treat anything you say or draw as confidential. No one else will be able to see or read it. I will not use your name in any presentations or reports unless you want me to.

The information I gather during the project will be kept private. The data will be stored on a secure computer, that only I can access. When the study is finished, your name and contact details, audio files, and transcripts will be destroyed.

What happens next if I want to participate?

If you would like to participate, you can get in touch with me, and we can arrange a time to meet for an interview.

Before the interview we will review the information provided here and you can ask more questions. Then I will ask you give your consent to participate; this means you have had a chance to review this information and that you are willing to take part in the research.

What happens if I don't want to participate or if I change my mind later?

It is your choice to be part of the study of not, no one else can make you participate if you do not want it.

If you decide to participate, you can decide to stop at any time:

- Even if you already given consent,
- Even if you are already part way through the study,
- You can also refuse to answer certain questions if they make you uncomfortable.

If you decide to stop participating, the information you have shared up to that point will be destroyed unless you say otherwise. However, we will not be able to remove the information you have provided to us if we have already put the information in a final report or a presentation. For this reason, the last day to withdraw from the study is February 1, 2022.

What happens when I am finished participating in the study?

After you have finished participating in the project, I will write my report. You and the other participants will be asked to review the report to make sure I got it right.

I will also prepare a summary of the project and the things we learned from you and the other participants. If you want, I will send a copy of the longer report and/or the summary to you once they are finished.

Can I contact you if I have more questions?

Of course! You can contact me by email at odonnels@mcmaster.ca or call me on the phone at (905) 317-8485.

Thank you!

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster University Research Ethics Board
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
email: ethicsoffice@mcmaster.ca

Appendix B. Interview Guide

A STUDY ABOUT EXPERIENCES OF HOME FOR PEOPLE WITH INTELLECTUAL DISABILITY

1. Can you tell me a bit about yourself? Prompt on things like where are you living, what kinds of activities do you like to do, etc.

2. What kind of home do you live in now?
   a. family home
   b. group home
   c. by yourself
   d. with a roommate

3. How long have your lived in your current home?

4. How do you feel when you are in your current home?
   a. For example, mad, happy, sad, supported, etc.

5. What is it about your home that makes you feel this way?
   a. For example, the people in it, the physical space, location, etc.

6. What is your favourite/least favourite part of your home? (ask these as two separate questions)

7. Have you lived in any other kind of home? If so, did you feel differently about that home?

8. When you think about the future, what does your ideal future home look like? Topics to probe…
    a. Who would be there?
    b. Where would it be?
    c. What would the home look like?
    d. How is it similar or different compared to your current home?
    e. How do you feel in this future home?

9. What would you need in order to create your ideal home?
    a. For example, help, resources, etc.

10. Do you think you will have the opportunity to live in this future home?

11. What challenges have your experienced in finding a new home?

12. Is there anything else you'd like to tell me?

Thank you so much for your time!

Appendix C. Informed Consent

Oral Consent Script Interview One

Introduction

Hello, my name is Sabine O'Donnell. I am a student researcher based at McMaster University in the School of Earth, Environment and Society.

I am conducting research on experiences of home for people with intellectual disabilities and I am looking for people to take part in a series of interviews about their experiences of this. I want to learn about what is important to you when thinking about your home and what your ideal future home would look like.

What will happen during the study?

Step 1 will be this interview with me. I will ask you some questions about your experiences of home in the past and your ideal future home.

If you agree, I will record what you tell me on an audio recorder. I want to make sure I don't forget any of the important information you share with me. I also want to make sure that we understood it correctly. This interview will take about 1 hour, and we can take breaks if you would like.

After the interview is finished, I will write a summary of what you told me and send it to you.

In step 2 we will meet either by Zoom or phone again to talk a little bit more about some of the things you said or finish answering any questions we didn't get to during the first interview. This will take about 45-60 minutes.

In step 3 we will hold an arts workshop with other participants in the project. This workshop will take place in early 2022 and be held in an accessible room in Toronto/Hamilton or via Zoom, depending on the state of the pandemic. More details will be given closer to the scheduled date of the workshop.

*You may include a support person in any or all of the steps of the research if you like.

How long does it take to participate in this study?

Step 1 (the interview) will take about 45-60 minutes to complete. Step 2 (the follow up interview) will take about 45-60 minutes. Step 3 (the workshop) will take about 2 hours to complete (either in person or virtually).

Will anything bad happen if I participate?

It is very unlikely that anything bad will happen if you choose to participate in the study. However, you might feel uncomfortable answering some of the questions that we ask you. You do not have to answer questions that make you feel uncomfortable or that you do not want to answer.

You might also be uncomfortable with some of the topics that are discussed. You don't have to share any personal information you don't want to share. You don't have to participate in uncomfortable conversations if you do not want to.

At the end of the study, I will be writing reports and making presentations about what you and other participants told us. I will not use your name when we talk about your experiences. However, there is a chance that people might be able to identify by the stories that you tell.

It is also important to know that Zoom is an externally hosted cloud-based service. While this service is approved for collecting data in this study by the McMaster Research Ethics Board, there is a small risk with any platform such as this of data collected on external servers falling outside the control of the research team. If you are concerned about this, we can conduct any of the interviews over the telephone.

What good things could happen if I participate?

Participating in this study will not change your life or change the services you receive. However, it will give you an opportunity to tell other people about:

- Your opinions about and experiences of home as a person with an intellectual disability.
- Opportunities and barriers you've faced in creating a home.
- What your ideal home would look like.

This will help other people (service providers, family members, members of the public) to understand more about what home can look like for people with intellectual disabilities.

Will I be paid for taking part in this study?

Yes, you will be paid $40 for completing Step 1 (the interview), and another $40 for completing the follow-up interview. If you want to stop during an interview, you will still receive the money for that step of the study. You will be paid $80 for taking part in the workshop.

Who will know what I said or did in the study?

You can tell anyone you like about the research, but I will not tell anyone you are participating. I will also treat anything you say or draw as confidential. No one else will be able to see or read it. I will not use your name in any presentations or reports unless you want me to.

The information I gather during the project will be kept private. The data will be stored on a secure computer, that only my supervisor and I can access. When the study is finished, your name and contact details, audio files, and transcripts will be destroyed.

What happens if I don't want to participate or if I change my mind later?

It is your choice to be part of the study of not, no one else can make you participate if you do not want it. If you decide to participate, you can decide to stop at any time - even if you already given oral consent, and even if you are already part way through the study. You can also refuse to answer certain questions if they make you uncomfortable. If you decide to stop participating, the information you have shared up to that point will be destroyed unless you say otherwise. However, we will not be able to remove the information you have provided to me if I have already put the information in a final report or a presentation. For this reason, the last day to withdraw from the study is February 1, 2022.

What happens when I am finished participating in the study?

After you have finished participating in the project, I will write my report. You and the other participants will be asked to review the report to make sure I got it right. I will also prepare a summary of the project and the things I learned from you and the other participants. If you want, I will send a copy of the longer report and/or the summary to you once they are finished.

Can I contact you if I have more questions?

You can contact me by email at odonnels@mcmaster.ca or call me at (905) 317-8485

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster University Research Ethics Board
Telephone: (905) 525-9140 x23142
c/o Office of Research Services
Email: ethicsoffice@mcmaster.ca

Consent questions:

- Do you have any questions or would like any additional details?

- Do you agree to have the interview audio recorded?

- Do you agree to participate in this study knowing that you can withdraw at any point up to February 1, 2022, with no consequences to you?

  [if yes, continue]

  [if no, thank the participant for their time]

- Do you agree to be contacted about a follow-up interview, understanding that you can always decline the request?

- Would you like to remain anonymous in this study?

- Would you like to receive a summary of the study's results? By email or by mail?

Oral Consent Script Interview Two (plain language)

Introduction

Hello, my name is Sabine O'Donnell. I am a student researcher based at McMaster University in the School of Earth, Environment and Society.

I am conducting research on experiences of home for people with intellectual disabilities and I am looking for people to take part in a series of interviews about their experiences of this. I want to learn about what is important to you when thinking about your home and what your ideal future home would look like.

What will happen during the study?

In step 1 we met to talk about some of your experiences of home.

In step 2 we will meet again either by Zoom or phone again to talk a little bit more about some of the things you said or finish answering any questions we didn't get to during the first interview. This will take about 45-60 minutes.

If you agree, I will record what you tell me on an audio recorder. I want to make sure I don't forget any of the important information you share with me. I also want to make sure that we understood it correctly. This interview will take about 1 hour, and we can take breaks if you would like.

After the interview is finished, I will write a summary of what you told me and send it to you.

In step 3, I will invite you to take part in a workshop with other participants in the project. There will be 5 participants altogether.

This workshop will take place in early 2022 and be held in an accessible room in Toronto/Hamilton or via Zoom, depending on the state of the pandemic. If in person, we will be working together to draw pictures of what your ideal future home looks like, and then discussing together some of the key ideas you have. If virtual, I will ask you to prepare a drawing ahead of time and meet to discuss during the call. There is no pressure to be 'good' at drawing in this activity, this is meant more to engage with what you feel is important to you. In both cases we will be working with an arts facilitator who is available to help you with your images.

*You may include a support person in any or all of the steps of the research if you like.

How long does it take to participate in this study?

Step 2 (the follow up interview) will take about 45-60 minutes. Step 3 (the workshop) will take about 2 hours to complete (either in person or virtually). You can take breaks during the workshop.

Will anything bad happen if I participate?

It is very unlikely that anything bad will happen if you choose to participate in the study. However, you might feel uncomfortable answering some of the questions that we ask you. You do not have to answer questions that make you feel uncomfortable or that you do not want to answer.

You might also be uncomfortable with some of the topics that are discussed. You don't have to share any personal information you don't want to share. You don't have to participate in uncomfortable conversations if you do not want to.

At the end of the study, I will be writing reports and making presentations about what you and other participants told us. I will not use your name when we talk about your experiences. However, there is a chance that people might be able to identify by the stories that you tell.

It is also important to know that Zoom is an externally hosted cloud-based service. While this service is approved for collecting data in this study by the McMaster Research Ethics Board, there is a small risk with any platform such as this of data collected on external servers falling outside the control of the research team. If you are concerned about this, we can conduct any of the interviews over the telephone.

What good things could happen if I participate?

Participating in this study will not change your life or change the services you receive. However, it will give you an opportunity to tell other people about:

- Your opinions about and experiences of home as a person with an intellectual disability.
- Opportunities and barriers you've faced in creating a home.
- What your ideal home would look like.

This will help other people (service providers, family members, members of the public) to understand more about what home can look like for people with intellectual disabilities.

Will I be paid for taking part in this study?

Yes, you will be paid a maximum of $160.00 for participating in this study. This includes $40 for completing Step 1 (the interview), and another $40 for completing the follow-up interview. You will be paid $80 for taking part in the workshop. If you want to stop during an interview or workshop, you will still receive the money for that step of the study.

Who will know what I said or did in the study?

You can tell anyone you like about the research, but I will not tell anyone you are participating. I will also treat anything you say or draw as confidential. No one else will be able to see or read it. I will not use your name in any presentations or reports unless you want me to.

The information I gather during the project will be kept private. The data will be stored on a secure computer, that only my supervisor and I can access. When the study is finished, your name and contact details, audio files, and transcripts will be destroyed.

What happens if I don't want to participate or if I change my mind later?

It is your choice to be part of the study of not, no one else can make you participate if you do not want it. If you decide to participate, you can decide to stop at any time - even if you already given oral consent, and even if you are already part way through the study. You can also refuse to answer certain questions if they make you uncomfortable. If you decide to stop participating, the information you have shared up to that point will be destroyed unless you say otherwise. However, we will not be able to remove the information you have provided to me if I have already put the information in a final report or a presentation. For this reason, the last day to withdraw from the study is February 1, 2022.

What happens when I am finished participating in the study?

After you have finished participating in the project, I will write my report. You and the other participants will be asked to review the report to make sure I got it right. I will also prepare a summary of the project and the things I learned from you and the other participants. If you want, I will send a copy of the longer report and/or the summary to you once they are finished.

Can I contact you if I have more questions?

You can contact me by email at odonnels@mcmaster.ca or call me at (905) 317-8485

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster University Research Ethics Board
Telephone: (905) 525-9140 x23142
c/o Office of Research Services
Email: ethicsoffice@mcmaster.ca

Consent questions:

- Do you have any questions or would like any additional details?

- Do you agree to participate in this study knowing that you can withdraw at any point up to February 1, 2022, with no consequences to you?

[if yes, continue]

[if no, thank the participant for their time]

- Do you agree to have the interview audio recorded?

- Do you agree to be contacted about the arts workshop, understanding that you can always decline the request?

- Would you like to remain anonymous in this study?

- Would you like to receive a summary of the study's results? By email or by mail?

Oral Consent Script Arts Workshop (plain language)

Introduction

Hello, my name is Sabine O'Donnell. I am a student researcher based at McMaster University in the School of Earth, Environment and Society.

I am conducting research on experiences of home for people with intellectual disabilities and I am looking for people to take part in a series of interviews about their experiences of this. I want to learn about what is important to you when thinking about your home and what your ideal future home would look like.

What will happen during the study?

There are three parts to the study. In steps 1 and 2 I asked you questions about your experiences of home and what your ideal future home would look like.

In step 3, I am inviting you to take part in a workshop with other participants in the project. There will be 5 participants altogether.

This workshop will take place in early 2022 and be held in an accessible room in Toronto/Hamilton or via Zoom or telephone, depending on the state of the pandemic. If in person, we will be working together with an arts facilitator to draw pictures of what your current home, and your ideal future home looks like. We will then be discussing as a group some of the key ideas you have about creating home and the challenges you face in doing so. You will be reimbursed for transportation to the workshop if needed. This workshop will take about 2 hours, and we can take breaks if you would like.

If virtual, I will ask you to prepare a drawing ahead of time of your current home and ideal future home, either on your own or with the arts facilitator. Any arts materials you require will be delivered to you before this. We will meet as a small group to discuss your image during a Zoom call. There is no pressure to be 'good' at drawing in this activity, this is meant more to engage with what you feel is important to you. The small group discussion will take about 45-60 minutes.

I will be recording the audio of the arts workshop whether it is in person and virtual. I want to make sure I don't forget any of the important information you share with me. I also want to make sure that I understood it correctly. This workshop will take about 2 hours, and we can take breaks if you would like.

After the workshop is finished, I will write a summary of what you told me and send it to you. With your permission, I will keep a digital copy of your images to use in my research and return the originals to you.

We can also provide reimbursement for transportation to the workshop, should it take place in person.

After the workshop is finished, I will write a summary of what you told me and send it to you.

*You may include a support person in any or all of the steps of the research if you like.

How long does it take to participate in this study?

Step 3 (the workshop) will take about 2 hours to complete (either in person or virtually). You can take breaks during the workshop.

Will anything bad happen if I participate?

It is very unlikely that anything bad will happen if you choose to participate in the study. However, you might feel uncomfortable answering some of the questions that we ask you. You do not have to answer questions that make you feel uncomfortable or that you do not want to answer.

You might also be uncomfortable with some of the topics that are discussed. You don’t have to share any personal information you don’t want to share. You don’t have to participate in uncomfortable conversations if you do not want to.

If you choose to take part in the workshop, you will be sharing your experiences and opinions with me and other participants. We will ask everyone to respect each other’s privacy, but we cannot promise everyone will do this. For this reason, you should think carefully about what you want to tell us.

At the end of the study, I will be writing reports and making presentations about what you and other participants told us. I will not use your name when we talk about your experiences. However, there is a chance that people might be able to identify by the stories that you tell.

It is also important to know that Zoom is an externally hosted cloud-based service. While this service is approved for collecting data in this study by the McMaster Research Ethics Board, there is a small risk with any platform such as this of data collected on external servers falling outside the control of the research team. If you are concerned about this, we can conduct the workshop over the telephone.

What good things could happen if I participate?

Participating in this study will not change your life or change the services you receive. However, it will give you an opportunity to tell other people about:

- Your opinions about and experiences of home as a person with an intellectual disability.
- Opportunities and barriers you've faced in creating a home.
- What your ideal home would look like.

This will help other people (service providers, family members, members of the public) to understand more about what home can look like for people with intellectual disabilities.

Will I be paid for taking part in this study?

Yes, you will be paid $80 for taking part in the workshop. If you do not complete a step, you will be paid for how much you complete. If you want to stop at any point during the workshop, you will still receive the full amount for participating.

Who will know what I said or did in the study?

You can tell anyone you like about the research, but I will not tell anyone you are participating. I will also treat anything you say or draw as confidential. No one else will be able to see or read it. I will not use your name in any presentations or reports unless you want me to. In the workshop, it is not always possible to keep everything you share in the large group private. I will ask all the participants to respect each other's privacy, but I cannot promise that everyone will do this. The arts facilitator as well as any other support people who will be joining us will sign an oath of confidentiality asking them not to share any details of the session.

The information I gather during the project will be kept private. The data will be stored on a secure computer, that only my supervisor and I can access. When the study is finished, your name and contact details, audio files, and transcripts will be destroyed.

What happens if I don't want to participate or if I change my mind later?

It is your choice to be part of the study of not, no one else can make you participate if you do not want it. If you decide to participate, you can decide to stop at any time - even if you already signed the consent form, and even if you are already part way through the study. You can also refuse to answer certain questions if they make you uncomfortable. If you decide to stop participating, the information you have shared up to that point will be destroyed unless you say otherwise. However, we will not be able to remove the information you have provided to me if I have already put the information in a final report or a presentation. For this reason, the last day to withdraw from the study is February 1, 2022.

What happens when I am finished participating in the study?

After you have finished participating in the project, I will write my report. You and the other participants will be asked to review the report to make sure I got it right. I will also prepare a summary of the project and the things I learned from you and the other participants. If you want, I will send a copy of the longer report and/or the summary to you once they are finished.

Can I contact you if I have more questions?

Yes! You can contact me by email at odonnels@mcmaster.ca or call me at (905) 317-8485

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster University Research Ethics Board
Telephone: (905) 525-9140 x23142
c/o Office of Research Services
Email: ethicsoffice@mcmaster.ca

Consent questions:

- Do you have any questions or would like any additional details?

- Do you agree to participate in this study knowing that you can withdraw at any point up to February 1, 2022, with no consequences to you?

  [if yes, continue]

  [if no, thank the participant for their time]

- Do you agree to have the interview audio recorded?

- Do you agree to be contacted about looking over research analysis, understanding that you can always decline the request?

- Do you agree to have your artwork included in research publications from this study?

- Would you like to remain anonymous in this study?

- Would you like to receive a summary of the study's results? By email or by mail?

Appendix D. Participant Artwork

Figure 1. Lily's artwork – Current Home (Family) photo collage.

Figure 2. Lily's artwork – Ideal Future Home (Supportive) photo collage.

Figure 3. Timothy's artwork – Current Home, people important to him. Pencil crayons on paper.

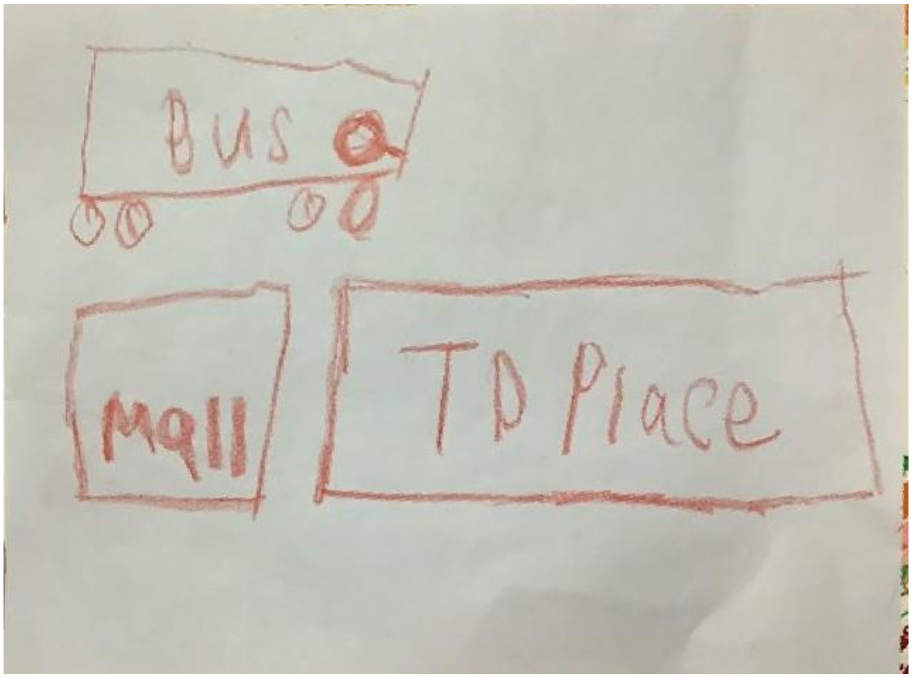


Figure 4. Timothy's artwork – Current Home, places important to him (Bus, Mall, TD Place). Pencil crayons on paper.

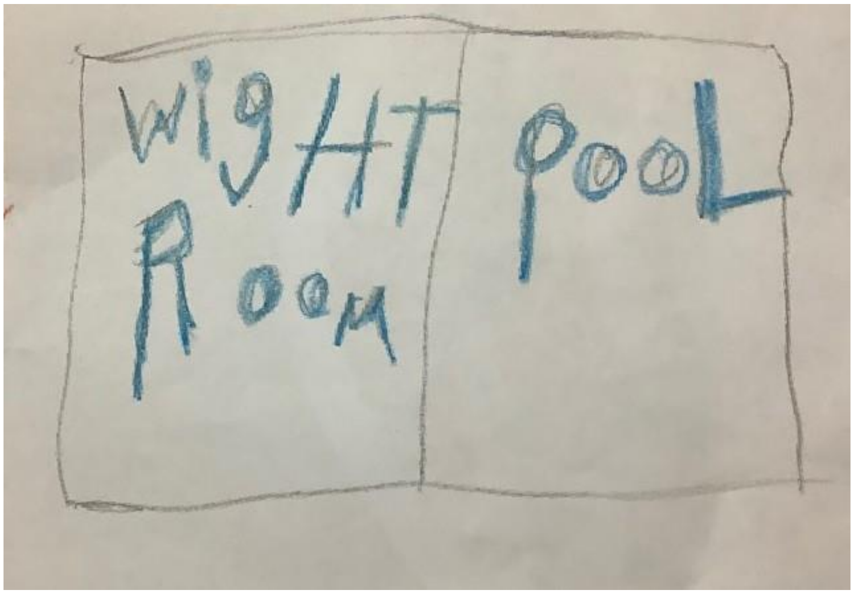


Figure 5. *Timothy's artwork – Future Home (weight room, pool). Pencil crayons on paper.*

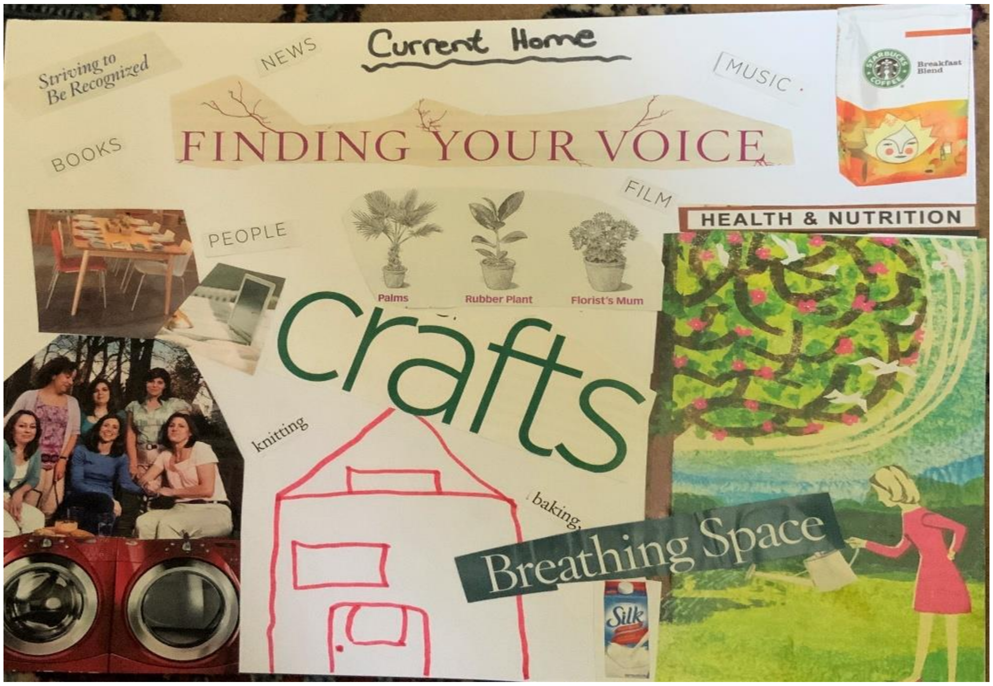


Figure 6. *Lear's artwork – Current Home (finding your voice). Collage.*

Figure 7. Lear's artwork – Future Home (Family). Collage.

Figure 8. Jack's artwork – Future Home. Rendering by arts facilitator.

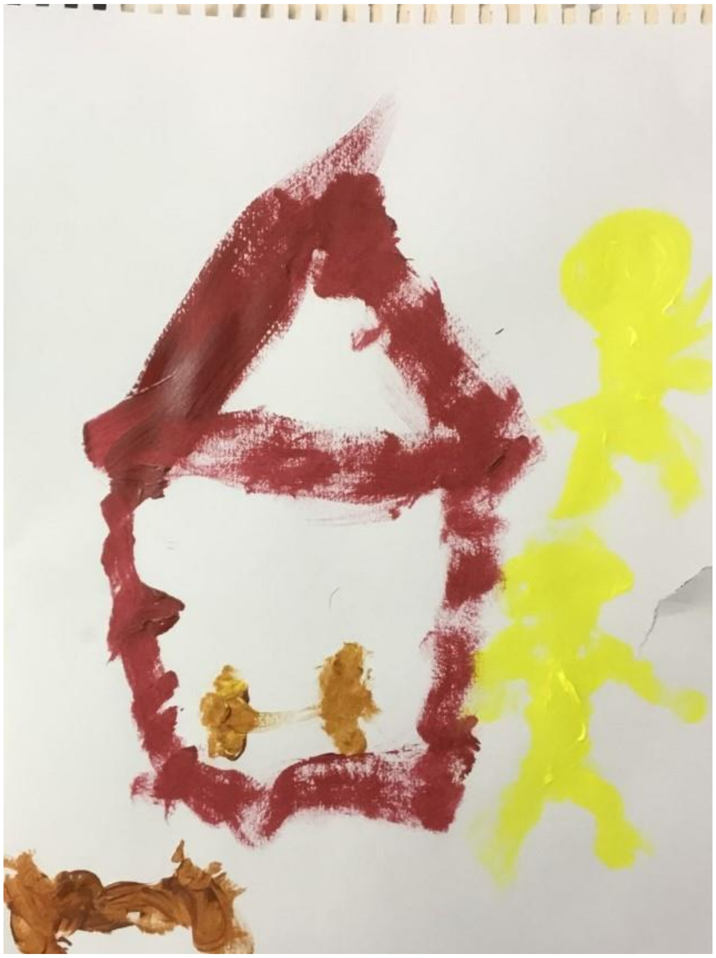


Figure 9. Jack's artwork – Future Home. Acrylic paint on paper.

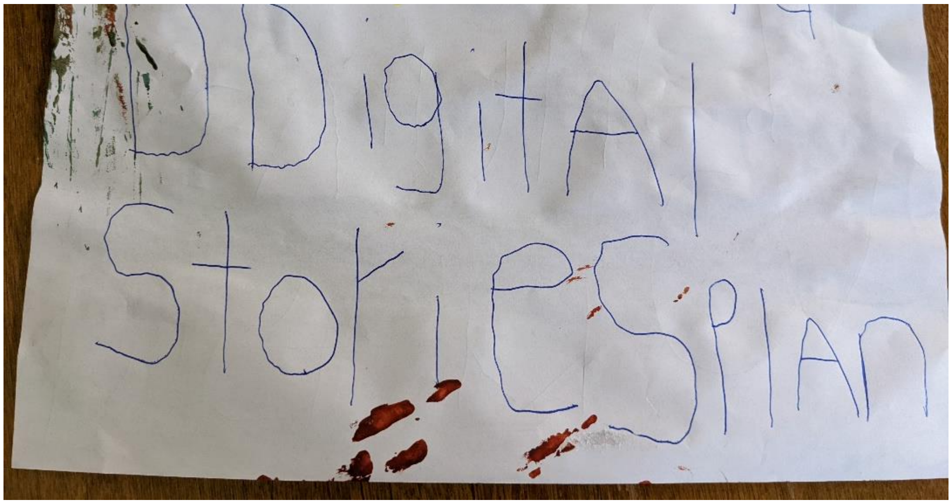


Figure 10. Jonathan's artwork – Future Home (Digital Stories Plan). Pen on paper.

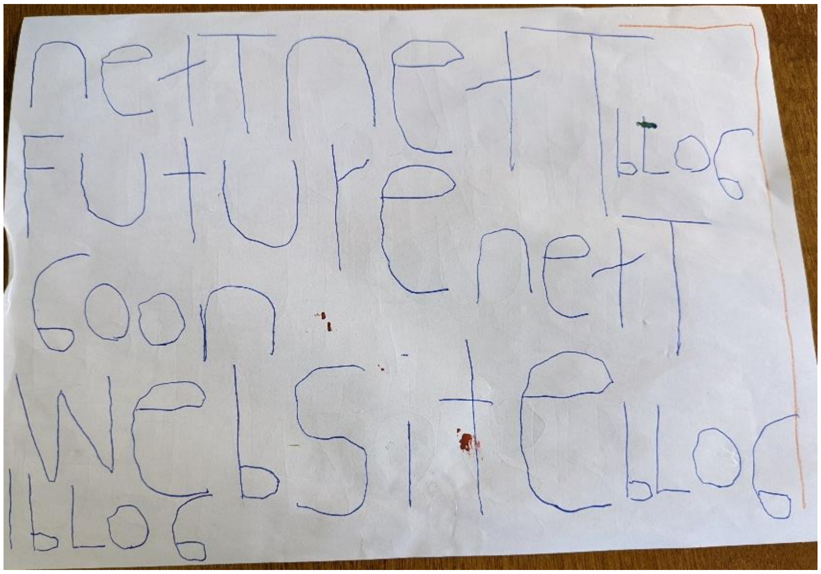


Figure 11. Jonathan's artwork – Future Home "website blog soon". Pen on paper.

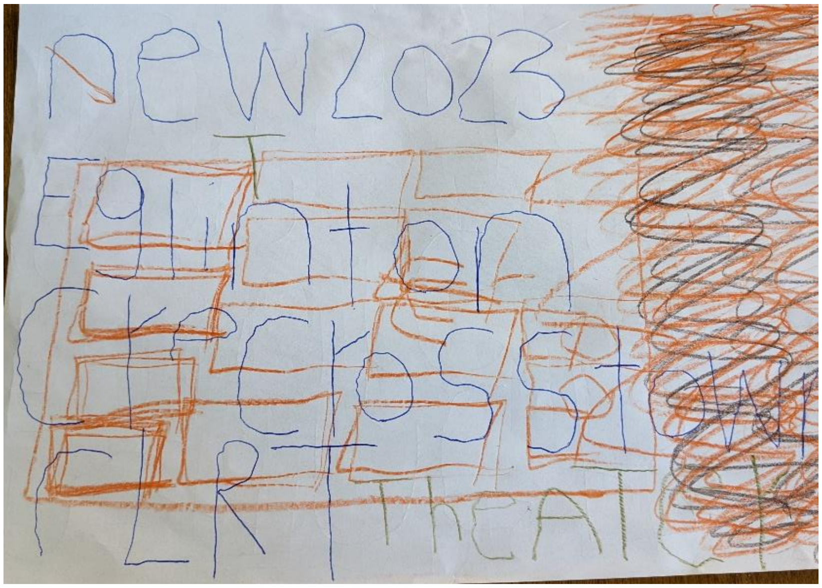


Figure 12. Jonathan's artwork – Future Home "New 2023 Eglington Crosstown LRT". Pen and pencil crayon on paper.

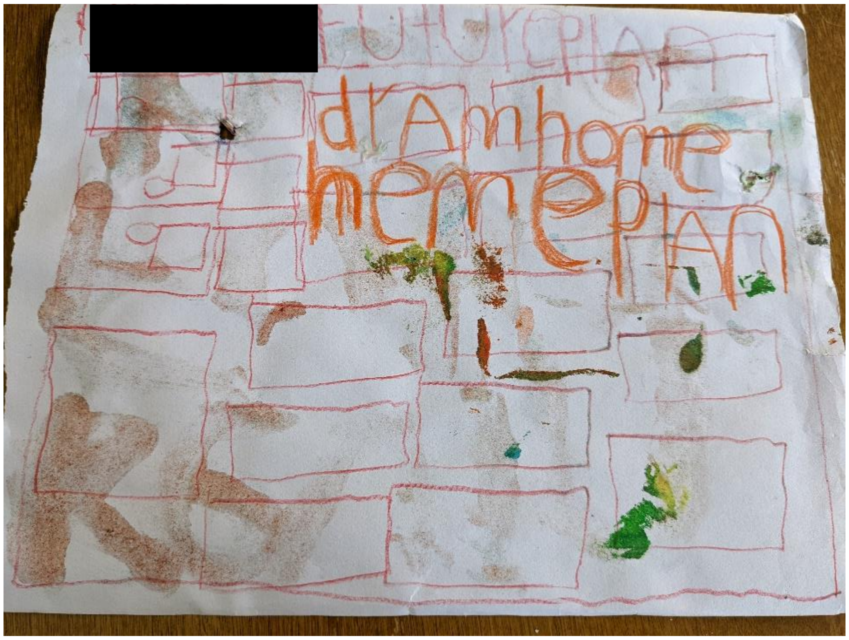

[redacted]

Figure 13. Jonathan's artwork – Future Home "Dream home plan". Pencil crayon and paint on paper.

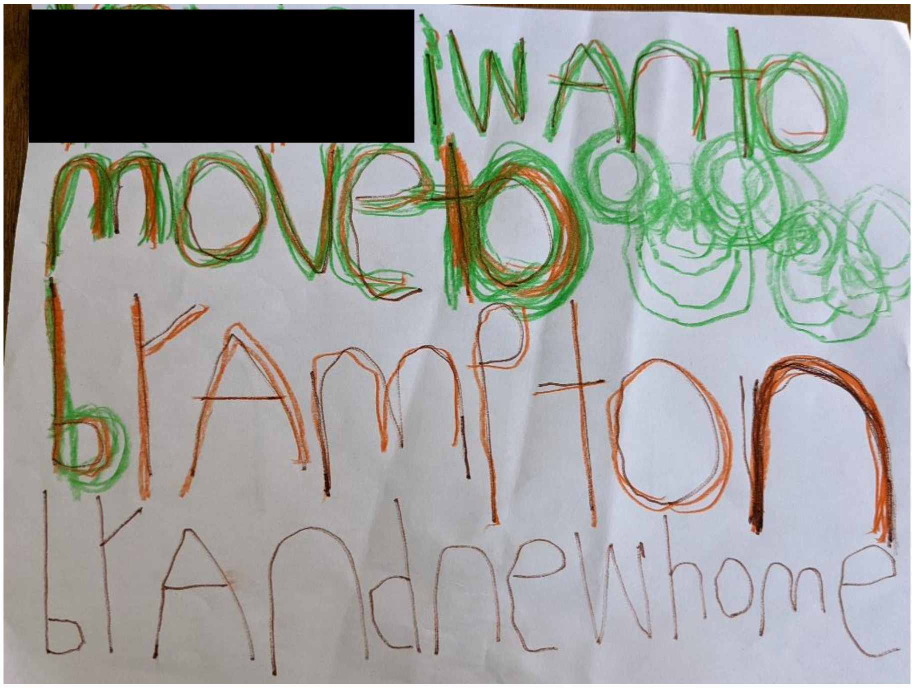

[redacted]

Figure 14. Jonathan's artwork – Future Home "I want to move to Brampton brand new home." Pencil crayon on paper.

Figure 15. Jonathan's artwork – Future Home. Collage.

Figure 16. Jonathan's artwork – Future Home. Collage.

Figure 17. Jonathan’s artwork – Future Home. Collage.

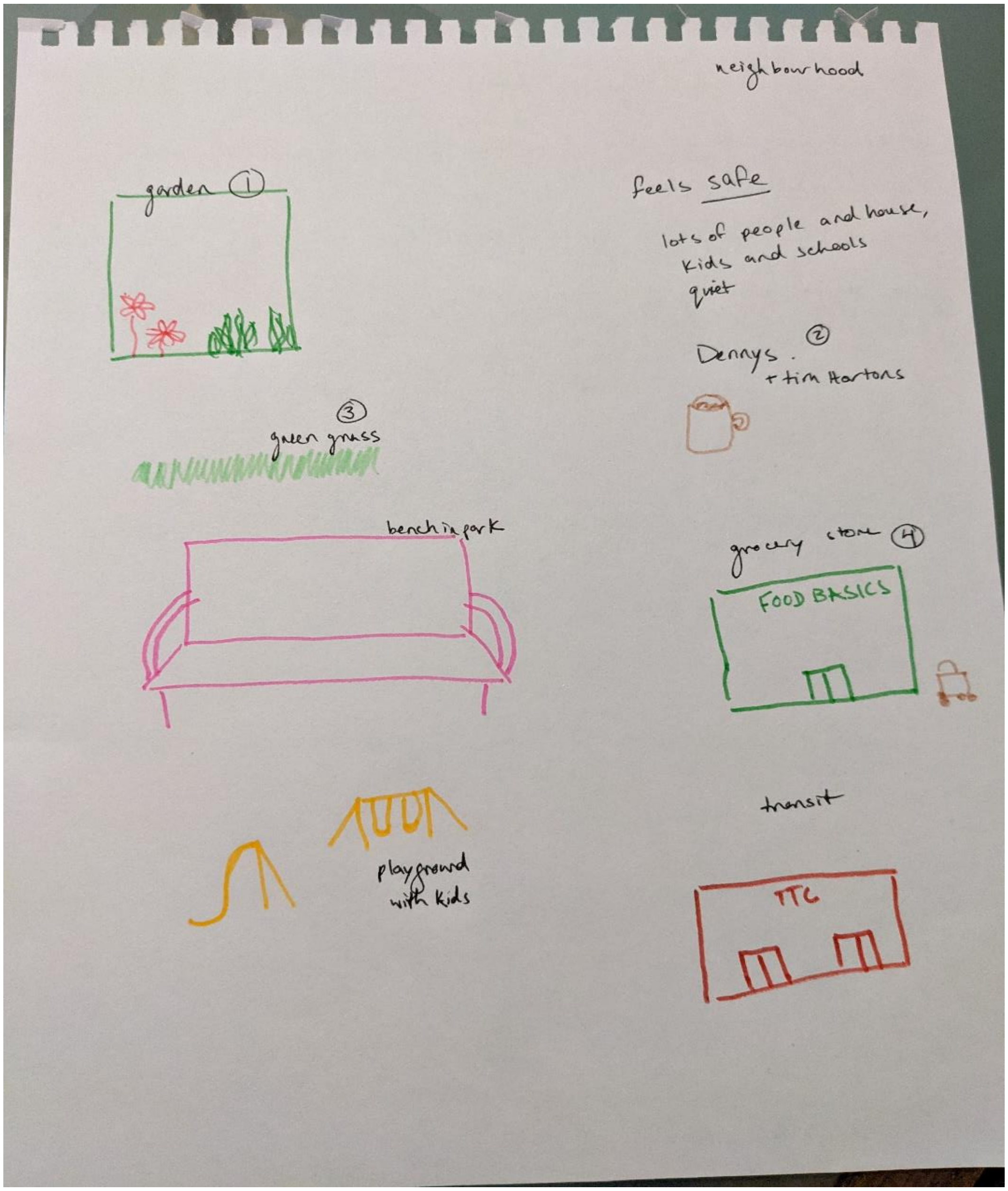
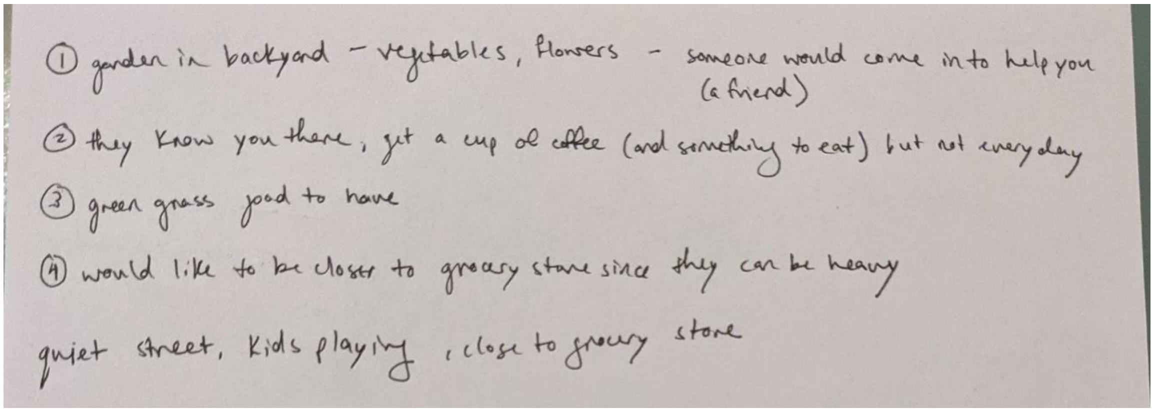


Figure 18. Ruth's artwork – Future Home (neighbourhood). Marker and pen on paper, done collaboratively with researcher.



① garden in backyard – vegetables, flowers – someone would come in to help you (a friend)

② they know you there, get a cup of coffee (and something to eat) but not everyday

③ green grass good to have

④ would like to be closer to grocery store since they can be heavy

quiet street, kids playing, close to grocery store

Figure 19. Ruth's artwork – Future Home (neighbourhood) guide, "closer to grocery store, quiet street, someone would help with gardening." Pen and paper.

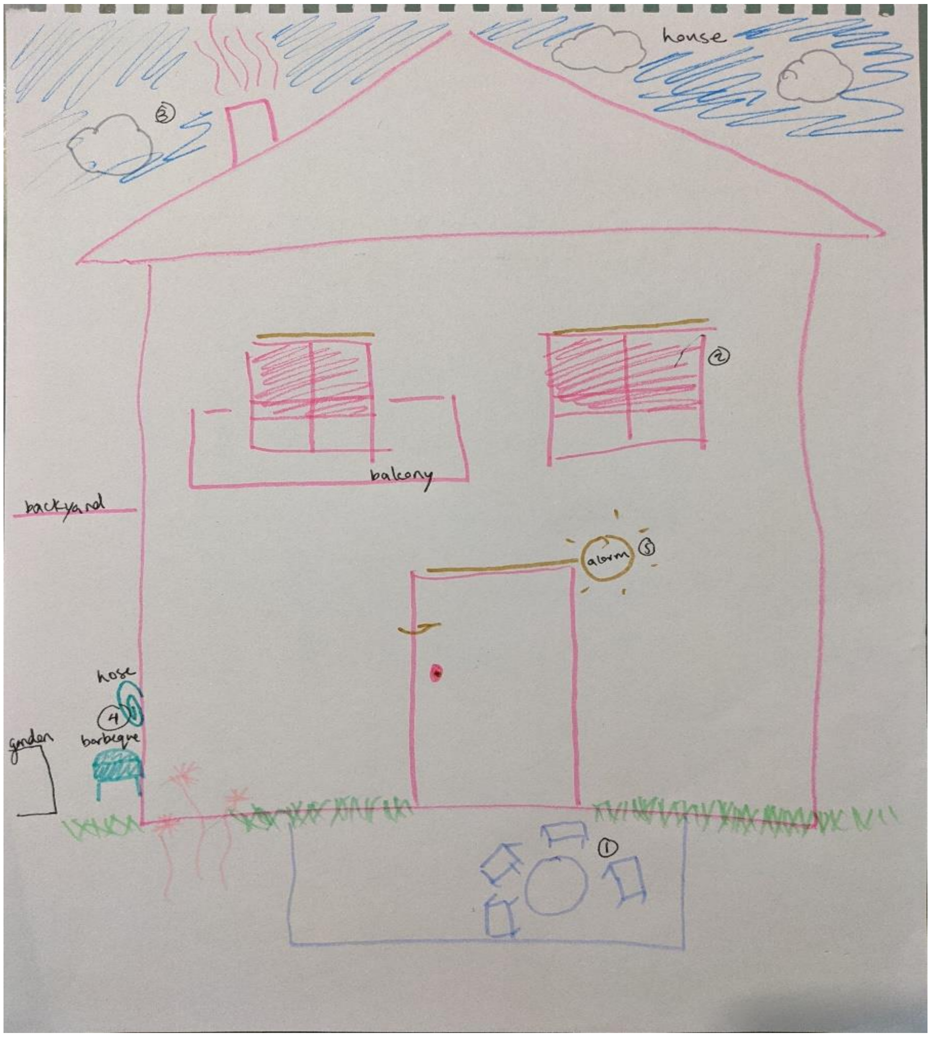
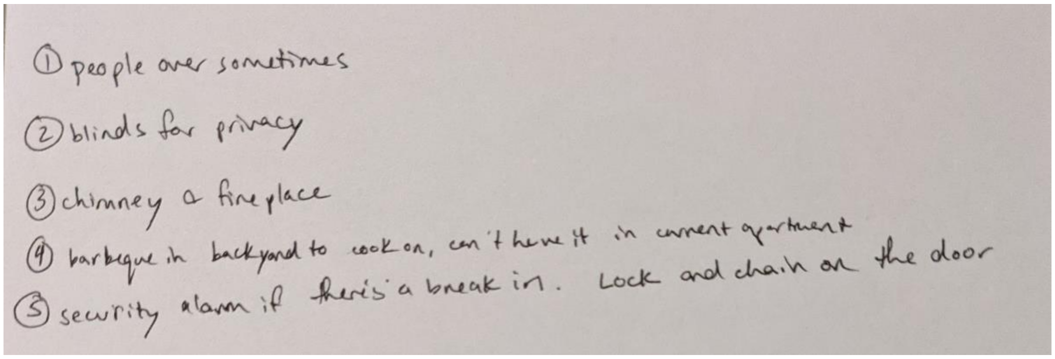


Figure 20. Ruth's artwork – Future Home (house). Marker and pen on paper, done collaboratively with researcher.



① people over sometimes
② blinds for privacy
③ chimney a fireplace
④ barbeque in backyard to cook on, can't have it in current apartment
⑤ security alarm if there's a break in. Lock and chain on the door

Figure 21. Ruth's artwork – Future Home (house) guide, "people over sometimes, security alarm if there's a break in. Lock and chain on the door." Pen and paper.

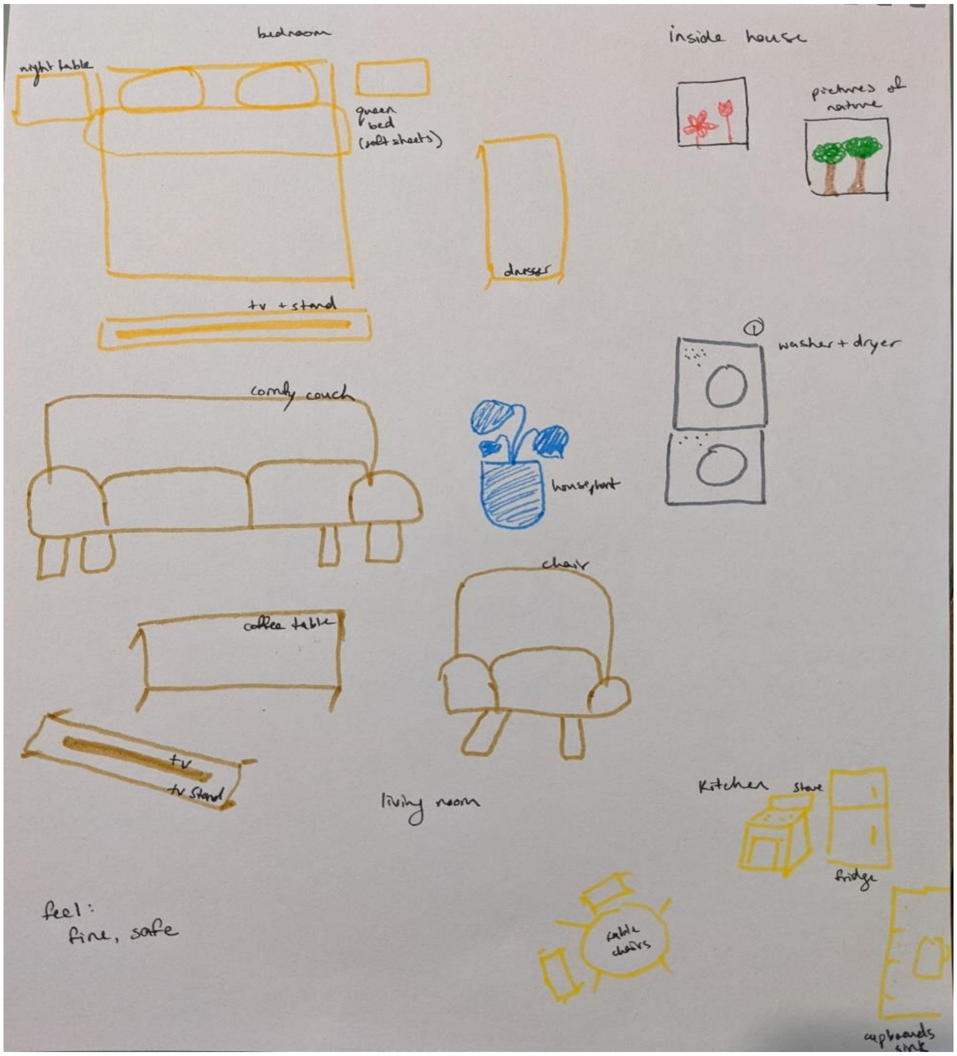


Figure 22. Ruth's artwork – Future Home (décor). Marker and pen on paper, done collaboratively with researcher.

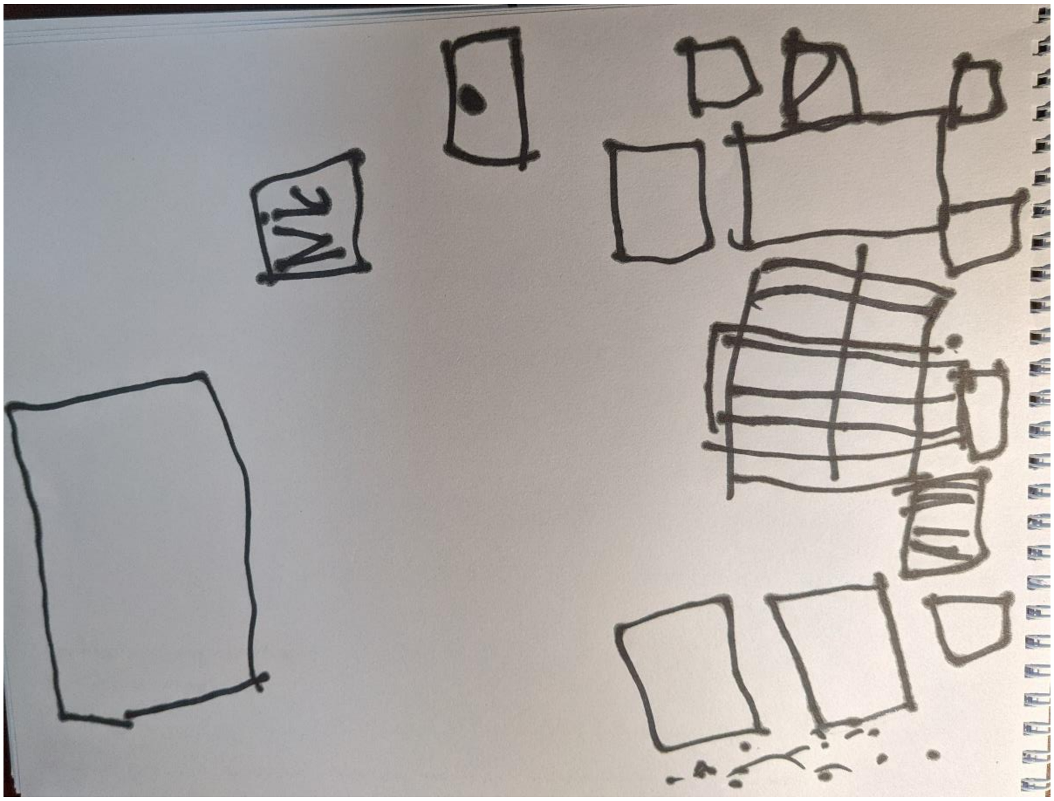
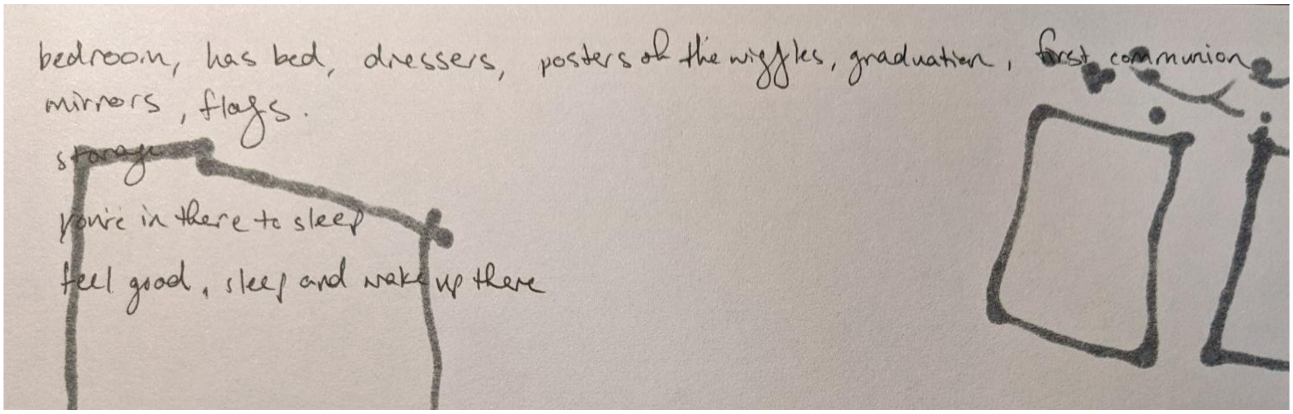


Figure 23. James' artwork – Current Home (bedroom). Marker on paper.



bedroom, has bed, dresses, posters of the wiggles, graduation, first communion
mirrors, flags.
storage
you're in there to sleep
feel good, sleep and wake up there

Figure 24. James' artwork – Current home (bedroom) guide, "You're in there to sleep, feel good." Pen on paper.

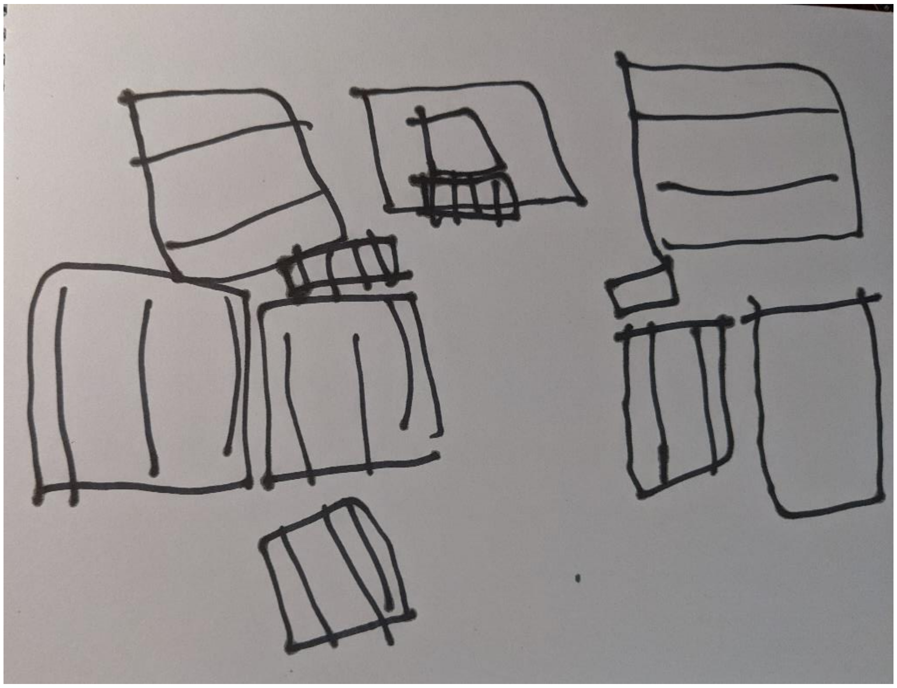
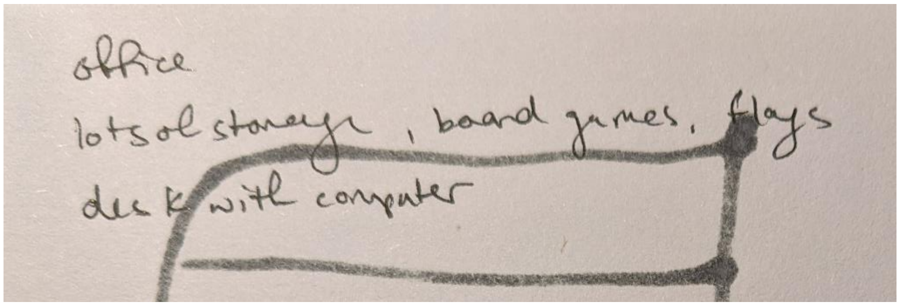


Figure 25. James' artwork – Current Home (office). Marker on paper.



office
lots of storage, board games, flags
desk with computer

Figure 26. James' artwork – Current Home (office) guide, "lots of storage, board games, flags, desk with computer." Pen on paper.

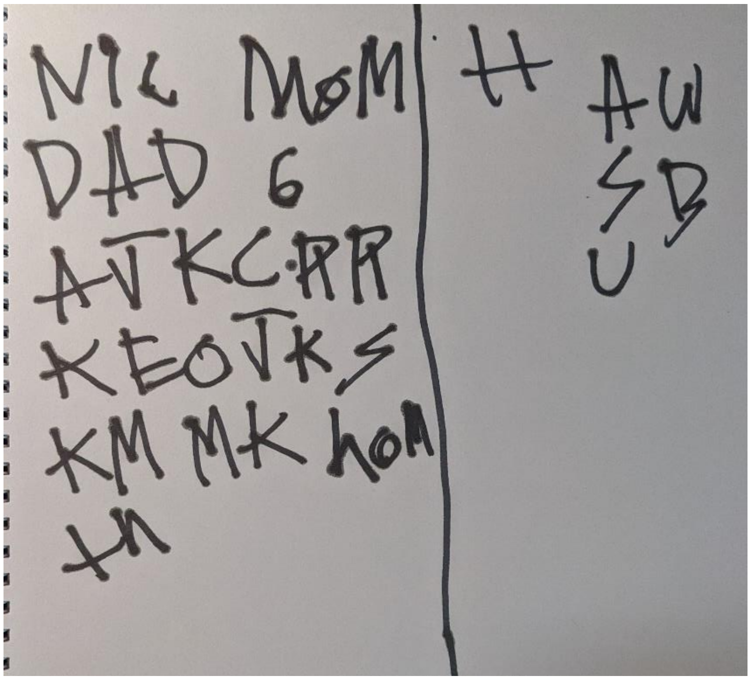


Figure 27. Current Home – initials of people and places important to him. Marker on paper.

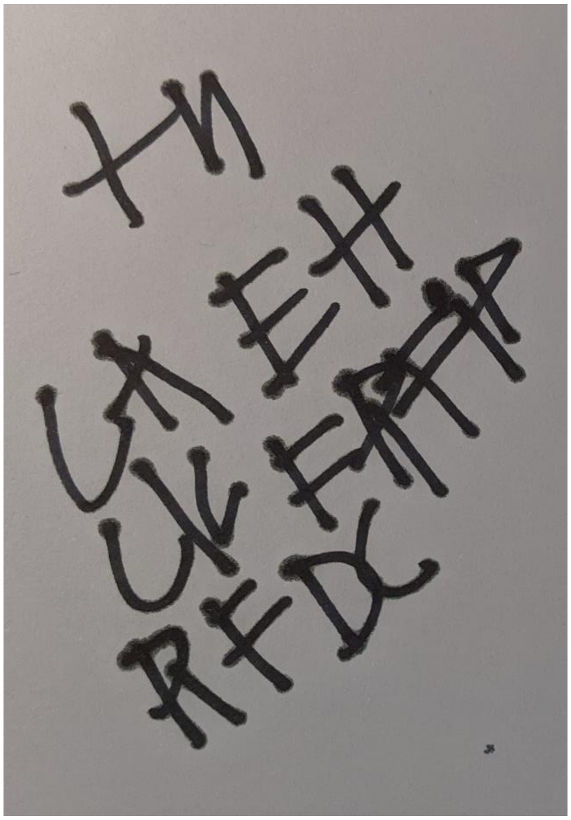


Figure 28. James' artwork – Future Home – "Youtube, decorations, furniture, being by myself." Marker on paper.

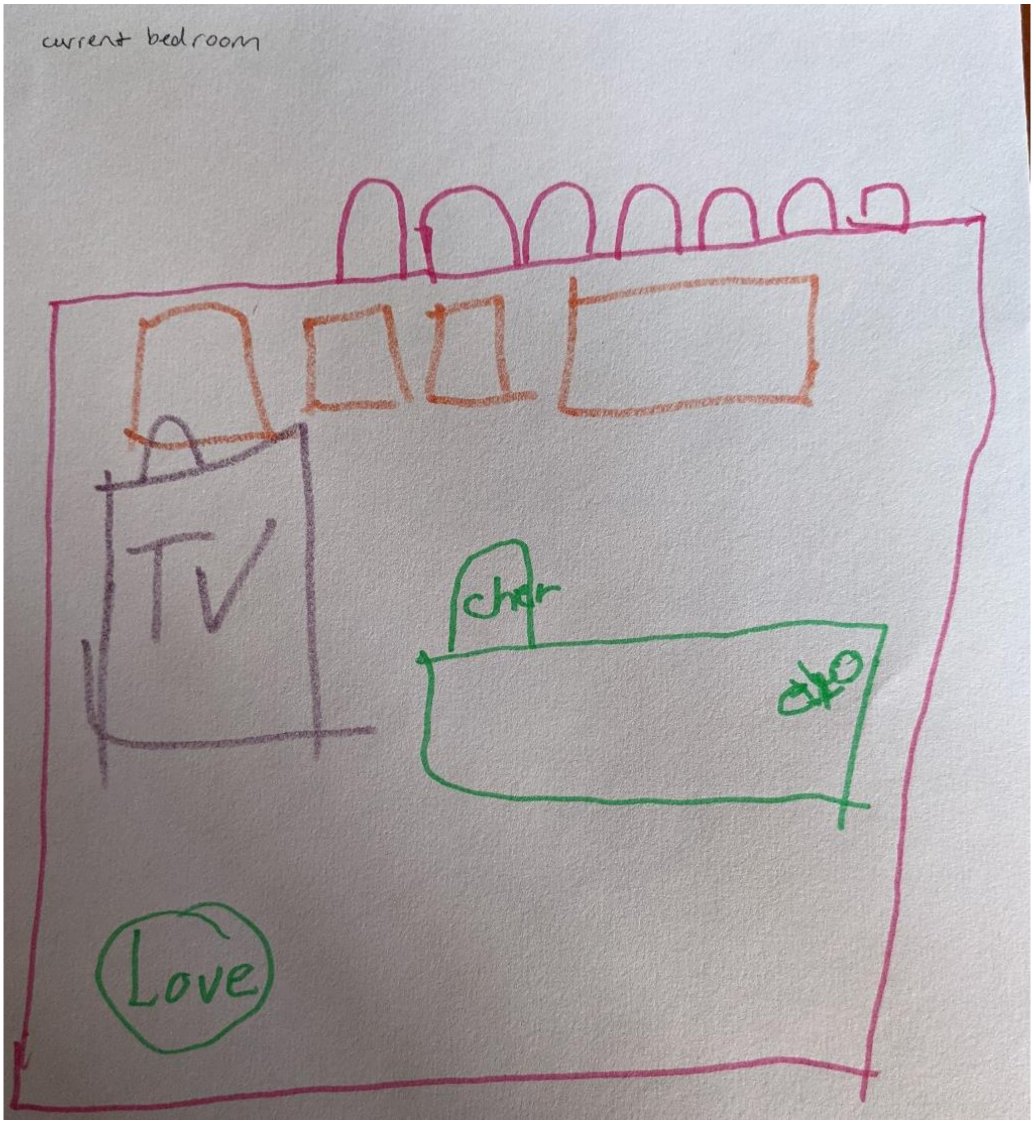


Figure 29. Alan's artwork – Current Home (bedroom) – TV, bed, Cher poster, 'love.' Marker on paper.

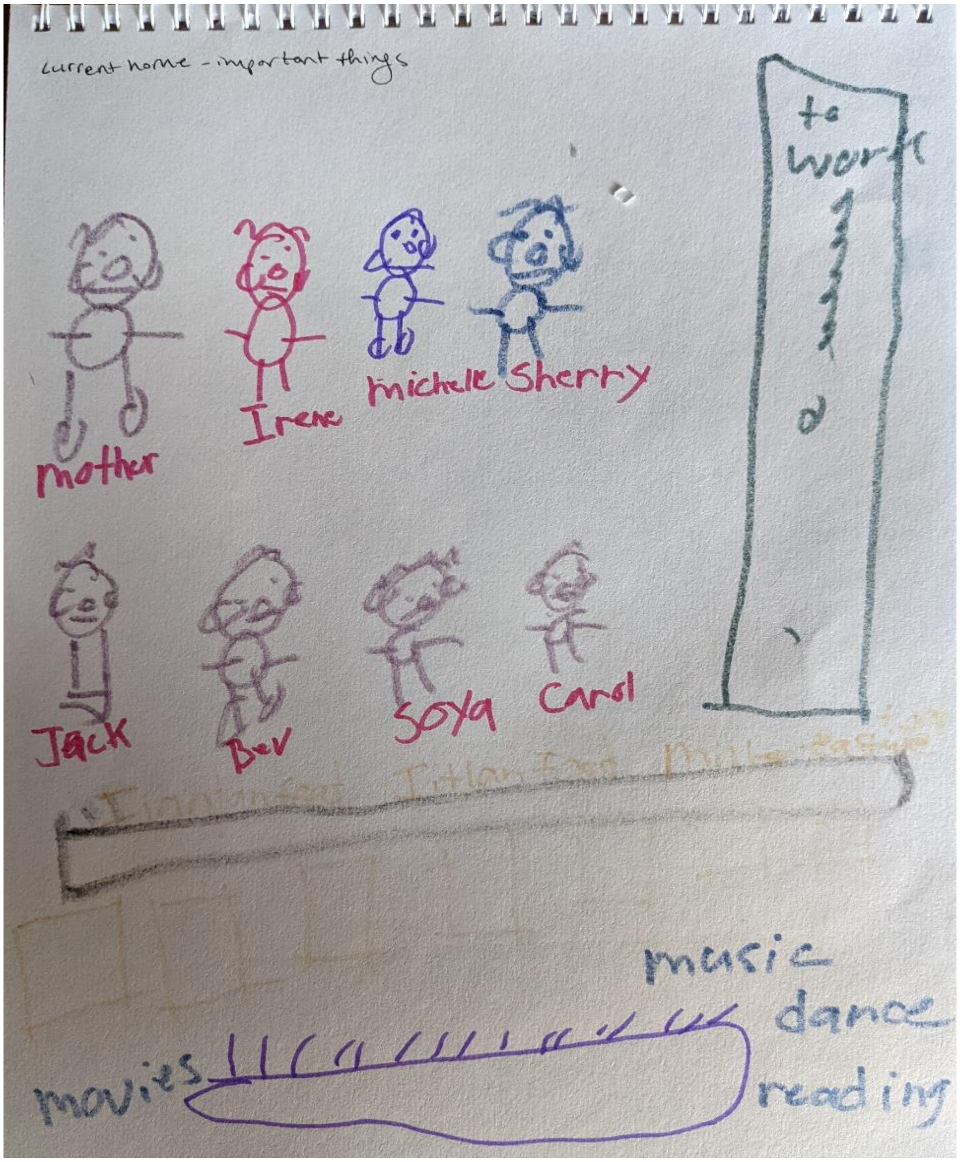


Figure 30. Alan's artwork – Current Home (people, places that are important). Marker on paper.

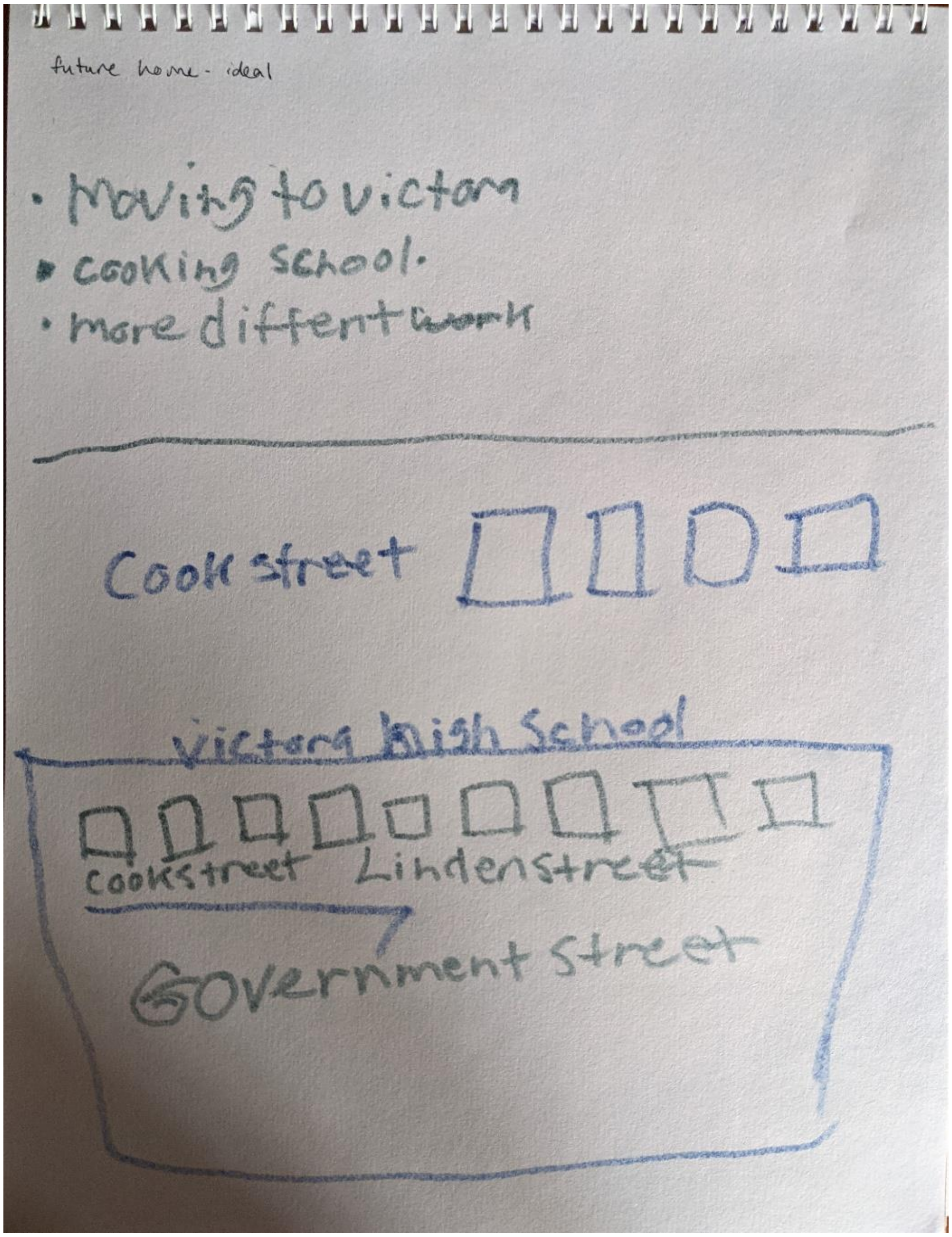


Figure 31. Alan's artwork – Future Home (moving to Victoria, cooking school, more different work). Marker on paper.