



A Feasibility Study for a Housing Trust for Adults with Intellectual Disabilities in Ottawa-Carleton

Prepared for:

Citizen Advocacy Ottawa

Housing Trust Research Project, Ontario Government Housing Task Force

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Executive Summary

Purpose

This exploratory report reflects the findings of a research team tasked with exploring the feasibility of a housing trust in the Ottawa-Carleton area for adults with intellectual disabilities. The research process was grounded in the needs of adults with intellectual disabilities and their families and included stakeholder focus groups, and a thorough review of the literature.

Key Findings

- An aging population of caregivers and an increasing number of adults with intellectual disabilities outliving their parents represents a pressing need to identify viable housing trust models for the Ottawa-Carleton area.
- Respondents in the Ottawa-Carleton area situate housing trusts within the broader context of supporting the housing needs of adults with intellectual disabilities. This is consistent with the research literature.
- Housing Trusts are part of a continuum of housing options for independent living, under the banner of affordability. A general environmental scan of housing options in the Ottawa-Carleton area for adults with intellectual disabilities is needed to better situate new housing models. There needs to be a strong continuum of housing choices to ensure individual choice and personal autonomy are promoted.
- Support for housing initiatives can be found at all three levels of government. Any models moving forward must separate housing costs from support costs to ensure conflicting interests are minimized, and requirements can be met using various sources of funding.
- While this research remained focused on housing trusts, various gaps within parallel areas of disability require policy makers to be proactive and apply a

holistic lens in supporting this population. There is a need to better understand financial dynamics of families supporting individuals with intellectual disabilities to help identify needed policy interventions.

- Serious gaps mean that existing policy frameworks fail to address the needs of our aging population of adults with intellectual disabilities and their caregivers.

Recommendations

1. A local **Community Housing Trust should be established specifically devoted to the housing needs of persons with intellectual disabilities**. An Advisory Committee to set up this Housing Trust should include a group of stakeholders from government (federal, provincial, municipal), legal community, developer community, parent groups, etc. to review the various forms, challenges, and opportunities of community housing trusts.
2. In order to accomplish the above, **Citizen Advocacy Ottawa, as a recognized champion of person-directed solutions for community participation, should submit a proposal to the second round of Housing Task Force studies**. This proposal would:
 - a. **Create an Ottawa-Carleton Housing Trust for Persons with Developmental Disabilities**, as a separate non-profit corporation, using input from family groups, individuals, similar community agencies such as Multifaith Housing Initiative, Options Bytown and Salus, Canada Mortgage and Housing, City of Ottawa Affordable Housing Division, estate planning specialists, and property managers in the affordable housing sector.
 - b. **Establish an Advisory Board** leading to the formation of this Community Housing/Land Trust to ensure address the housing needs/desires of persons with intellectual disabilities.
 - c. **Hire a community development officer or project manager** experienced in community development projects to guide the Advisory Board through the process of establishing the non-profit housing corporation (Ottawa-Carleton Housing Trust for Person with Developmental Disabilities), using Lights (Toronto), Guelph Services for the Autistic (Guelph), and Brockville (Community Involvement) as models. The project manager will also ensure that the recommendations of this research study are implemented.

- d. Engage a **communications/information specialist** to create a communications strategy and educational program geared to individuals and their families, to address the various forms of ownership, needs assessment, and lessons learned, and to develop a web site and teaching materials.
 - e. **Test the operation and tools of the proposed Housing Trust** agency by using two local family-based housing initiatives to do a case study in setting up a housing trust. These case studies will inform various housing trust issues and organizational issues, and will inform the community knowledge base.
 - f. **Conduct a series of focus groups:**
 - i. with agencies to share lessons learned and discover their challenges related to housing,
 - ii. with families to share lessons learned and discover challenges.
 - g. Provide **on-going documentation** of success, failures, plans and lessons learned via the community website.
3. **Findings of this study should be shared with families and agencies** in the region, to ensure cohesion and consistency across the service sector, and a better understanding of how we can use programs and services of other provincial, municipal and federal agencies to support housing initiatives.
4. Our community requires more information about housing needs for persons with intellectual disabilities in our region. **Creation of this information base** should use resources from the local MCSS to help gather demographics related to age, affordability, and access to current housing options.
5. A **comprehensive communications and education program** is needed to raise community awareness of options in independent living and housing for persons with intellectual disabilities in our region. This should be done within the context of overall person-directed planning and should use examples from other groups within our community, who have addressed housing and affordability.
6. There is a need for **plain language material related to housing options**. This should include opportunities and challenges of various home ownership options. Resources from across the housing community (Canada Mortgage and Housing, Ontario Ministry of Housing, municipal housing authorities, social housing registry, developers, legal and property management), should be available. A website dedicated to this should be established.

Recommendations for the Housing Task Force

The following recommendations are based on findings and conversations with focus group participants during the course of the study. These recommendations address issues that go beyond the capacity of local organizations and point to the need for a review of how government resources could be delivered to support person-directed lives and full participation in community.

1. **The Task Force should encourage the Ministry of Community and Social Services to focus on funding of supports and services rather than buildings.** We need to look to other Ministries and levels of governments and partnerships (including public/private partnerships, social and co-up housing, etc) to manage and explore how to create the physical infrastructure to address affordable housing for vulnerable individuals.
2. The Task Force should **recommend the revision of policy (legislation and regulations) to introduce direct funding to individuals for residential services.** This would allow families to consider community housing trust options knowing that they could afford the supports to independence.
3. The Task Force should encourage the **creation of an on-going inter-ministerial and intergovernmental Working Group** to identify now to ensure the human rights and affordable housing of adults with intellectual disabilities living in community, using a person-centred not program-centred approach.
4. The Task Force should **encourage partnerships and knowledge sharing outside the developmental services community when funding projects.** There is a lot of knowledge in the housing community and affordable housing movement that could help.
5. The Task Force should **encourage municipalities managing social housing registries to de-couple the rent subsidy** application process and assessment from the social housing registry which favours big landlords.

Background

Citizen Advocacy Ottawa (CAO) is a non-profit organization designed to support people with a wide range of disabilities, including physical limitations, intellectual disabilities, mental health needs, and disabilities related to aging. CAO's main strength lies in the relational work it does to create more inclusive opportunities for people with disabilities through matching them with volunteer advocates in Ottawa, creating circles of support, providing independently facilitated person-directed planning support and championing their right to be included as full participating community members. Over the years CAO has been approached numerous times by families who have expressed interest in bequeathing property for their family member with an intellectual disability. Property management does not fall within the range of CAO's mission statement; however, it is part of CAO's mandate to find ways to advocate for people with disabilities and assist them in problem resolution. In response to that mandate, this exploratory research project examined the feasibility of forming a housing trust program in Ottawa-Carleton.

Overview

This report presents a review of the research literature on housing for Canadian adults with intellectual disabilities¹ with a focus on housing trust issues. We supplemented this knowledge by conducting focus groups as well as individual interviews with a number of professionals in the Ottawa-Carleton district who represent various housing trust stakeholders. This stakeholder sample included experts in the field of housing, lawyers, representatives of intellectually disabled parent organizations and agency workers involved with housing trusts in other Ontario districts. Our sampling frame is very strategic and small; however, the study is exploratory and designed mainly to acquire a sense of the feasibility of developing a housing trust program for adults with intellectual disabilities in Ottawa-Carleton.

¹ We use the definition provided by the Canadian Association for Community Living (CACL) which defines intellectual disability "as a term used to refer to the challenges that some people face in learning and often communication. These challenges are usually present from the time they are born or from an early age."# While historically there have been many other terms used to describe this group, this term is preferable to us because it is inclusive of a broad range of individuals who access supports through CAO. Additionally, as intellectual disability is currently a preferred term among self-advocates and community-based organizations, we use this terminology as a way to connect our research more strongly to stakeholder realities and needs. <http://cacl.ca/about-us/definitions-terminology>

Key Research Findings

There were a number of key findings identified through the research process. While we have outlined these below, it is important to briefly note that respondents reflect a need that is also identified in the research literature, that is, the need to view housing trusts within the broader context of how we support adults with intellectual disabilities and their families, especially as these populations age. Indeed, with disabled adults living within the community and having better overall access to health supports, we are seeing the first significant wave of adults with disabilities aging. We recognize serious gaps appear in existing policy frameworks that fail to account for the aging process of these adults or their aging caregivers. Thus, while our research project is focused on questions specific to housing trusts in the Ottawa area, we caution that there are other parallel areas of support and services which impact intellectually disabled adults and their families where housing is concerned, and that policy makers need to plan using a proactive and holistic lens through which these related items and their overall effects are considered.

Pre-empting a Community Housing Crisis

Home is an important component and support to stability, security and inclusiveness. One of the challenges for adults with intellectual disabilities and their families is the identification, acquisition and maintenance of a stable, secure home while respecting the person's aspirations for independence and community living. These challenges are great while parents and families are available to support a impaired family member. They can become overwhelming when considering the future without their supportive presence. In the case of estate planning, parents struggle with how to set up the legal, governance and operational foundations required to ensure their intellectually disabled family member can continue to live in a home of his/her own.

A study published by the Canadian Association for Community Living in 2008 highlights the hidden amount of personal and financial support provided by parents to their intellectually disabled child.² Only a small number (i.e. 15,000 across Canada) live in group home settings (i.e. a facility with four beds or more).³ The majority reside either

² Canadian Association for Community Living. (2008). *A Report on the Housing Needs of People with Intellectual Disabilities*.

³ Canadian Association for Community Living. (2008). *A Report on the Housing Needs of People with Intellectual Disabilities*, pg. 7.

in a family home with parents (38% compared with 18% of the general population) or with other family members (6% compared with 4% of the general population).⁴ Notably, living with family tends to be associated more with issues of low employment and high cost of living than to issues stemming from intellectual disability. In other words, **close to half (42%) of the population of Canadians with intellectual disabilities are 'hidden in the household' where their basic living needs are either subsidized or covered totally by their families.** This finding reflects the research literature at large which indicates few adults with intellectual disabilities live independently, have paying jobs, or have power over who provides support for them.⁵ Given the right financial and social resources, most would be able to create and reside in a home of their own.

These important issues around housing occur against a backdrop that includes greater shifts towards community living frameworks and a drastically changing landscape of care and service delivery for adults with intellectual disabilities.⁶ The Canadian population is aging and predictions of a support service crisis for the elderly are growing. According to Statistics Canada, 16% of women and 13.4% of men are 65 years of age or older, and these numbers are expected to almost double within the next 25 years.⁷ Similar to the aging population worldwide, this Canadian cohort is preparing for retirement, establishing informal and formal contingency plans for when their health begins to deteriorate, and making estate plans for their children. Those who have a child with an intellectual disability must also help prepare their child for a successful transition to these life change events without their continued presence. Part of that preparation is finding a place for their child to create a home that accommodates his/her disability needs. **Taken together, these situations illustrate a hidden, and pressing layer of housing needs that individuals, families, community-organizations and policy makers must urgently address.**

The need to address a potential housing crisis is paramount. As of the year 2006, in Ottawa alone, 149,425 people had a disability—this was 17.7% of the Ottawa population and 2.2% higher than the provincial average.⁸ Significantly, 5705 families and 3,530 unattached individuals with disabilities lived in houses requiring major

⁴ Canadian Association for Community Living. (2008). *A Report on the Housing Needs of People with Intellectual Disabilities*, pg. 9.

⁵ Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*. 54(1): 48-57.

⁶ Bollard, M. (2009). A Review and Critique. In Bollard, M., & Mitchell, D. (Eds.) *Intellectual Disability and Social Inclusion: A Critical Review*. (5-18). Elsevier.

⁷ Statistics Canada, (2012). *Women in Canada: A Gender Based Statistical Report*. 6th edition.

⁸ *Disability Profile of the City of Ottawa A Profile of Persons with Disabilities in Ottawa Based on the 2006 Census*, Social Planning Council of Ottawa, 2010

repairs” while “8,840 unattached tenant households and 2,145 owner households were in unaffordable housing.”⁹ Moreover, 6,855 family renter households and 6,490 owner households who reported a person with a disability spent 30% or more of their income on major payments (rent/mortgage, electricity, heat, municipal services).¹⁰ Clearly, a need exists for affordable housing for people with disabilities in our community. Although these numbers do not focus specifically on adults with intellectual disabilities, the question remains over how this current situation will be affected by the age demographics of the Ottawa-Carleton community.

Given current changes in the way adults with intellectual disabilities are being supported in the community, their individual desires, and an aging population of caregivers, there is a pressing need to identify innovative solutions to this pending housing crisis.¹¹ As mentioned above, a noticeable number of Ottawa-Carleton parents with children with intellectual disabilities consider a housing trust to be the most effective response to their situation. As an initial step in addressing this concern, we designed an exploratory research study formulated around the following research question: **“Would a housing trust program be an effective way to assist the home ownership needs of adults with intellectual disabilities in Ottawa-Carleton? If yes, what would be the most effective housing trust model? If no, what barriers may hinder this creation?”**

The Housing Trust Model

Canada Mortgage and Housing (CMHC) conducts comprehensive research into various options for supporting and sustaining affordable housing for vulnerable populations.¹² In a study entitled *“Critical Success Factors for Community Land Trusts in Canada*, CMHC identified the concept of a community land trust (CLT) as a “private non-profit corporation created to acquire and hold land for the benefit of a community and provide secure affordable access to land and housing for community residents.”¹³ **CLTs focus on meeting the housing needs of low to moderate income residents through a**

⁹ *The State of Homelessness in Canada 2014*. Canadian Homelessness Research Network, 2014, pg. 25.

¹⁰ *The State of Homelessness in Canada 2014*. Canadian Homelessness Research Network, 2014, pg. 25.

¹¹ Gaetz, Stephen, Tanya Gulliver, and Tim Richter. *The State of Homelessness in Canada 2014*. Canadian Homelessness Research Network, 2014.

¹² A member of our research team, Minda Bojin attended an all day conference offered by CMHC on December 2, 2015 entitled “Building Resilient Partnerships in Housing, a forum in honour of National Housing Day” which provided powerpoint outlines, summaries and discussions of much of this literature. Most of the reports are contained in our bibliography.

¹³ Canada Mortgage and Housing. (2005) *Critical Success Factors for Community Land Trusts in Canada*. Pg. 3

process of “acquiring land in the community either by purchasing land directly or by receiving as a donation land, land and buildings, or money to purchase land.”¹⁴

CLTs exist worldwide and they have been promoted in a variety of forms in countries such as Australia, Canada, Great Britain and the United States since the early 1960s.¹⁵ Depending on the structure, CLTs are managed via partnerships – among individuals, private owners/funders, and publicly managed organizations. Each CLT represents a distinct configuration by which resources are pooled and individual responsibilities are allocated. The main focus is upon the client, his/her needs and how those needs may be met most effectively.

CLT structures offer proven models for providing safe and secure housing for individuals who cannot afford to manage the ongoing costs of home ownership. Of particular interest, the CMHC review of CLTs found that, while some community living arrangements aspire to include “natural supports” to the human side, **best practice indicates that the entities responsible for personal supports should be separate from those that own and maintain the homes.**¹⁶ For this reason, CMHC recommends a separation of housing from living supports. This separation ensures that the contractual agreements are clear – agreements which can vary depending on the type of legal and financial structures used to support the CLT trust.¹⁷

Similar to CLTs, housing trusts exist in a variety of forms in England, Australia, New Zealand and the United States; however few exist in Canada. Additionally, cultural distinctions, different funding guidelines, dissimilar social service support regulations, and contrasting legal requirements existing among Canadian provinces and their municipalities made it impossible to identify a universal Canadian housing trust model. Thus, we narrowed our focus to housing trusts in Ontario where the most well-known housing trust program for adults with intellectual disabilities is the one created and offered by Guelph Services for the Autistic (GSA). This agency has integrated the CMHC definition of CLTs as part of its housing trust model. It has also adopted the CMHC recommendation to separate personal support and housing support.¹⁸

¹⁴ Canada Mortgage and Housing. (2005) *Critical Success Factors for Community Land Trusts in Canada*. Pg. 3

¹⁵ Canada Mortgage and Housing. (2005) *Critical Success Factors for Community Land Trusts in Canada identifies “over 115 CLTs in the U.S. spanning 31 States ...with only a handful of CLTs operating across Canada”* Pg. i

¹⁶ Guelph Services for the Autistic. (2012). *Creating a Home and Good Life of my Own: The Roles of a Housing Trust*. Guelph Ontario: Bloomfield, E., Bloomfield, G. Pg. 10

¹⁷ Canada Mortgage and Housing. (2005) *Critical Success Factors for Community Land Trusts in Canada*, Pg. 4.

¹⁸ Guelph Services for the Autistic. (2012). *Creating a Home and Good Life of my Own: The Roles of a Housing Trust*. Guelph Ontario: Bloomfield, E., Bloomfield, G. Pg. 53

The GSA offers a Housing Trust program consisting mainly of two separate types of contractual agreements formed with the intellectually disabled adult: (1) an agreement of personal support and (2) an agreement of home ownership and maintenance. The first involves consideration of “the sum of the formal and informal relationships of trust around each person when an agreement is made to support the lifelong occupancy by a vulnerable person in his/her home.”¹⁹ In this case, a legally defined contract outlines the conditions under which the housing trust will be effected and the roles played by each member of the housing trust in supporting the person’s everyday needs. The second involves corporate responsibility, that is, “the mission and focus of the charitable not for profit corporation that has the function of making these agreements.”²⁰ In this case, the Housing Trust may be a profit or non-profit organization; it may or may not have charitable status; it may have a board of directors or a list of donors; it may have a mission statement and it may consider many people with intellectual disabilities as a client base. GSA views both agreements as necessary for an effective housing trust program.

One of the major reasons for GSA’s success is its identification and use of “circles of support.” Specifically, “core members of the circle of friends incorporate as an Aroha entity of personal support in order to complement and eventually succeed the roles of parents. An Aroha is equivalent to entities known as microboards or self-directed support corporations elsewhere”²¹ and has powers to support the person with all necessary funds and in contracts and agreements with any people or organization that provide service. An Aroha’s directors help the intellectually disabled adult with supported decision-making in the three areas of financial/business matters, health, daily living and personal care. In this way, a balance is created between the Housing Trust corporation, which finances housing and housing maintenance, the Aroha which plans, facilitates and brokers service provision, and the individual who is able to choose what happens in his/her home.²² Significantly, each of these contractual agreements can be made when the parents are still alive to help ensure a positive housing transition for their child before a crisis intervention is necessitated by their own illness or death.²³

¹⁹ Guelph Services for the Autistic. (2012). *Creating a Home and Good Life of my Own: The Roles of a Housing Trust*. Guelph Ontario: Bloomfield, E., Bloomfield, G. Pg. 53

²⁰ Guelph Services for the Autistic. (2012). *Creating a Home and Good Life of my Own: The Roles of a Housing Trust*. Guelph Ontario: Bloomfield, E., Bloomfield, G. Pg. 53

²¹ Guelph Services for the Autistic. (2012). *Creating a Home and Good Life of my Own: The Roles of a Housing Trust*. Guelph Ontario: Bloomfield, E., Bloomfield, G. Pg. 19.

²² Guelph Services for the Autistic. (2012). *Creating a Home and Good Life of my Own: The Roles of a Housing Trust*. Guelph Ontario: Bloomfield, E., Bloomfield, G. Pg. 21.

²³ Having two distinct contractual agreements identified by the term ‘housing trust’ creates confusion in discussing the research literature. For example, each requires legal contracts, a board of directors, and formalized designation of individual roles and responsibilities held toward the adult with an intellectual disability.

The GSA model is important for our study because it highlights and separates out the two main components of a housing trust, that is, ‘relations of trust’ and ‘housing ownership and maintenance’. Given its relative success in Ontario, we also used the GSA model as a template for assessing the type of housing trust model that might be effective for Ottawa-Carleton. Thus, we followed GSA’s lead and modified the CMHC definition of CLT to formulate our own definition of a Housing Trust “as a private non-profit corporation created to acquire and hold property for the benefit of a community and to provide secure affordable access to land and housing for community residents.”²⁴ We also identified the issue of personal support as a separate issue distinct from, but highly pertinent to, the development of an effective housing trust program.

The Housing Literature and Housing Trust Concerns

The goal of our research project was to explore the possibility of creating a housing trust program for families in the Ottawa-Carleton area that enables secure, long term housing for a loved one with intellectual disabilities. As a first step, we examined the research literature on the issue of housing provision for adults with intellectual disabilities in Canada with a particular focus on Ontario. That examination revealed the following themes:

a) financial feasibility

Significant concern exists over the issue of financial feasibility. Home ownership is expensive and home maintenance is on-going. The funding regulations within the Ontario Disability Support Program (ODSP) make it difficult for adults with intellectual disabilities to charge for shared accommodation, possess financial assets or hold a mortgage. Moreover, due to strict ODSP funding regulations, adults with intellectual disabilities may have this funding eliminated if they own a home if they need to find extra income to operate the home. Others may find their ODSP funding inadequate to make rent payments, cover hydro or heat costs and/or pay for housing maintenance

Additionally, the same individual who serves as a medical or financial guardian for the adult with an intellectual disability may serve as a representative of that person’s interests on the corporate housing trust board. Because both types of GSA agreements are discussed together frequently in the housing literature, and are often used interchangeably, we differentiate between the two by using the form “housing trust” when referring to issues involving “relations of trust” and the form “Housing Trust” when referring to a formal corporate entity.

²⁴ Guelph Services for the Autistic. (2012). *Creating a Home and Good Life of my Own: The Roles of a Housing Trust. Guelph Ontario: Bloomfield, E., Bloomfield, G.* Pg. 53.

and repairs. Considerable financial forethought and legal preparation is required to create a viable housing trust plan for adults with intellectual disabilities in Ottawa-Carleton.

b) personal autonomy and the need for flexibility

A review of the housing research literature highlights a flexible ‘choice’ approach that focuses on working with individuals to find housing appropriate to their individual situation. An adult with an intellectual disability may wish to live with family, live in a group setting, share an apartment or live alone in a house of his/her own. Most want the freedom to choose their housing without the burden of being labelled as an intellectually disabled person. For example, the Woodstock and District Development Service (WDDS) notes the need for “an approach more reflective of living life without the label of having a disability, determining where and with whom you will live (if anyone), and doing so in a home that suits your lifestyle and needs.”²⁵ Like all of us, adults with intellectual disabilities want, and should have, freedom of choice and personal autonomy when it comes to housing. **Rather than taking a unilateral approach, any housing trust program needs to prioritize and maintain a continuum of housing options based on individual need, desire and choice.**

c) quality of life

Quality of life and the potential for housing contract breakdown must be addressed. Adults with intellectual disabilities often require additional supports that extend far beyond the point of finding suitable housing accommodations. Housing needs may also change rapidly. One’s physical health may deteriorate and a more accessible physical environment may be required, housing mates may move to other destinations, and family situations may alter daily routines. The quality and range of housing options and support service networks should reflect this reality. Rather than viewing the need for flexibility and personal choice as a selfish whim or desire, it must be considered as a primary component of any housing trust program offered.

The concept of quality of life emphasizes the fact that any housing “[d]ecision-making needs to happen with all stakeholders...serving as active partners”.²⁶ Similar to other citizens, adults with intellectual disabilities require guidance in understanding the often convoluted and professionalized legal and financial matters involved in finding and maintaining appropriate housing. They may, however, require more specific and direct

²⁵ Woodstock and District Developmental Service Alternative Support and Housing, Shannon Lang (2013), pg. 7

²⁶ Woodstock and District Developmental Service Alternative Support and Housing, Shannon Lang (2013), pg. 10.

assistance from family members or guardians who possess knowledge of their intellectual disability; someone they can trust, and who is able to interpret and advocate on their behalf. As can be seen in the GSA model of forming an Aroha, this decision-making process is strengthened when clear communication exists between all parties involved in the housing trust plan.

d) separation of social service support and home ownership

The need for additional support speaks to a major observation echoed throughout the housing research literature, that is, the idea that social service support systems should be kept separate from housing and the processes involved in making housing decisions. The separation of social service support and home ownership allows adults with intellectual disabilities to have continued and consistent access to support services once their housing trust is established and/or if any future residential changes may be required.

The *My Home* report is of considerable interest here because it considers the best possible living arrangements for adults with intellectual disabilities in the Leeds and Grenville district of Ontario, a geographical area close to Ottawa-Carleton.²⁷ The data analysis offered in the *My Home* study is based on interviews with 85 adults with intellectual disabilities and 43 family members/support persons. Significantly, the researchers employed the same interview questions used in a 2006 CMHC study on adults with intellectual disabilities. **Given the similarity between the findings of these two studies,²⁸ we believe the *My Home* study findings reflect the needs of adults with intellectual disabilities in Ottawa-Carleton.**

The *My Home* report identified 8 best housing practices for determining satisfactory living arrangements for adults with intellectual disabilities. Those best practices fall under the housing categories of “home ownership, microboards, housing trusts, rent subsidies, social housing, housing co-ops, supported independent living (SIL) and volunteer-based housing.”²⁹ Each practice offers an innovative method of housing provision; however, all of the practices emphasize the need to: (1) take a flexible approach, (2) maintain a continuum of housing choice and (3) respect personal

²⁷Community Living, North Grenville. (2015). *My Home: An Innovation Report Submitted to the Ministry of Community and Social Services*.

²⁸The findings in the two studies are almost identical except for the fact that the *My Home* study found a larger number of disabled respondents who desired a group living setting than were found in the CMHC study.

²⁹Community Living, North Grenville. (2015). *My Home: An Innovation Report Submitted to the Ministry of Community and Social Services*, pg. 31.

autonomy in the development of any housing plan. Notably, the *My Home* report underscores the issue of considering the intellectually disabled adult's financial reality in its statement that, "...current circumstances compels us to assess the implications of de-linking housing from service, allowing agencies to cease to be landlords and focus on service and advocacy and investigate the opportunity for creating a local Housing Trust, collaborating with all three levels of government and the local community. These challenges also encourage agencies in Leeds and Grenville to work together to create Knowledge Centres of excellence in technology applications, data management, mentoring and innovative practice."³⁰

An important finding in the *My Home* report, and one of particular relevance to the question of developing a housing trust program in Ottawa-Carleton, is the constant worry and anxiety expressed by the majority of interviewed parents who wanted to have stable living arrangements put into place for their child before they became seriously ill or died. In response to this parental concern, the housing trust model outlined in *My Home* is one that takes a "whole life approach," that is, an approach whereby the changeability of life circumstances for adults with intellectual disabilities is recognized and respected. Priority is given to the social value of any program that considers its impact on "individual well-being, quality of life, community development and other social goods that make them worthwhile."³¹ Furthermore, the report notes the difficulty of forming an effective housing trust program in a provincial environment in which ODSP funding and/or home support can be denied to clients who own property, possess financial assets, or gain income from renting rooms to housemates.

To counterbalance this situation, **the authors of *My Home* propose that a Housing Trust may be made financially viable through inheritance, rental income or donations; but, it should be managed by a non-profit board that takes responsibility for the housing trust fund and is able to re-sell the existing property if the life circumstances of the person with an intellectual disability change.** Notably, a Housing Trust of this type, "Legacy Homes," exists in Leeds and Grenville. Under the auspices of Legacy Homes, parents can either will or purchase a home for their child in trust and the Housing Trust (i.e. Legacy Homes) can seek various sources of financial support for the child as well as develop and store funds that can be

³⁰ Community Living, North Grenville. (2015). *My Home: An Innovation Report Submitted to the Ministry of Community and Social Services*, pg. 5.

³¹ Community Living, North Grenville. (2015). *My Home: An Innovation Report Submitted to the Ministry of Community and Social Services*, pg. 31.

used for ongoing home repairs and maintenance.³² In this way, the need for flexibility and personal autonomy required of a whole-life approach are ensured, legal protections are put into place, and ODSP funding/support guidelines are maintained.

e) the need for a continuum of housing options

Published by the Canada Mortgage and Housing Corporation in 2006, the document *Housing for Adults with Intellectual Disabilities* offers a comprehensive review of the housing research literature in North America. The document also contains data taken from 39 interviews with professionals in the field and 9 focus groups that included adults with intellectual disabilities, family members and service providers in Halifax, Ottawa and Victoria. As a whole, these research participants favoured a continuum of housing choices ranging from (1) an Independent Living Model whereby the person did not have to share living quarters; (2) Co-ops and Co-op like arrangements whereby a group might get together to build their own unit and share the common spaces; (3) individual home ownership/adaption of family home (N.B: this option is often seen as being out of reach for people with intellectual disabilities due to the costs involved); (4) the L'Arche model (a group home setting run by employees who function more like family than staff) and (5) being part of a seniors complex.³³ The senior's complex is an interesting choice because other studies do not consider it; however, many of these respondents liked the combination of independent living and personal support offered by this housing option.

This CMHC report is significant in its description of the unrelenting financial, physical and social support provided by parents and the constant anxiety experienced over their intellectually disabled child's future. For example, **most parents in the Ottawa focus group reported that their greatest fear was to have their intellectually disabled child be placed in inappropriate housing as a response to the parent's death rather than being pre-prepared for a housing transition by the parent while he/she was still alive. This finding indicates a housing trust program will be of considerable interest to a core group of parents in Ottawa-Carleton.**

f) housing trusts represent one option among many

³² Community Living, North Grenville. (2015). *My Home: An Innovation Report Submitted to the Ministry of Community and Social Services*, pg. 36.

³³ Canada Mortgage and Housing Corporation. (2006) *Housing for Adults with Intellectual Disabilities*, pg. 3.

The research literature reveals a strong desire exists within the intellectually disabled population and their families to be able to select from a continuum of housing options ranging from living at home with family to owning a house of one's own. **Housing Trusts offer one option among many and require special personal, financial and legal arrangements to ensure adequate housing be available for an adult with an intellectual disability throughout his/her lifespan.** Ultimate housing choice depends, however, upon housing availability, the specific needs of individuals and their families, and the legal/financial requirements of support service structures.

The Stakeholder Focus Group Findings

The most common themes to appear in the housing research literature are: (1) a desire for a person-centred approach to housing, (2) control over services, (3) a separation between housing and personal/social support, (4) variation in housing choice options and (5) finances. Models of group living do not necessarily work and family members, especially parents, carry the load in providing housing, personal, and financial assistance. Housing Trusts offer one option among many; however, without strong community support, they are a choice made available only to families with the resources needed to buy property and pay the legal fees required to meet the provisions of a housing trust contract. Similar themes were highlighted in the professional stakeholder focus group discussions in more complex and multi-layered ways. This next section of the report describes those findings.

a) challenges exist in terms of legal ownership and contract design

Housing contract structures differ and a variety of potential models exist such as, for example, a personal trust versus a community trust versus a number of trusts under the umbrella of one organization. This variation is complicated by the fact that different adults with intellectual disabilities and their families may want a housing trust that addresses their distinct needs. Having a range of housing trust models in the housing trust program addresses these types of concerns.

In addition to these issues, the land title system in Ontario doesn't recognize trusts and has eliminated the holding of a property in trust. As a result, a trust agreement may be put into place but the property must be registered in the name(s) of one or more individuals or a corporation. Such agreements may, however, diffuse the problem of liability and any concerns over housing security that goes with owning a property

because an entity/corporation does not give personal guarantees. Similar to the GSA model and the Leeds-Grenville model, there should be a trust agreement separate from property ownership agreements. This finding indicates the most effective model would be to set up a Housing Trust corporation.

b) complex rules and constant regulatory changes add confusion

Government agency rules and legal regulations are multi-layered, complex and variable. **Many of the professional stakeholders who participated in our focus groups were highly educated and strongly schooled in their field but confessed they find it challenging to interpret the variety of municipal, provincial and federal housing laws and/or guidelines. They are also required to upgrade their knowledge base continually because they operate within an environment of constant regulatory change as new government bodies emerge and new legislation is enacted.** In consequence, they noted parents and family members of adults with intellectual disabilities might experience increased confusion in the face of new regulations and added stress in trying to adapt to altered agency requirements. Perceiving that family members, especially parents, tended to take on the major load of housing support for adults with intellectual disabilities, they perceived a housing trust program as a positive way to ease the impact of such bureaucratic requirements.

c) current programs are set up and focused around the needs of formal agencies

The current framework of housing support for adults with intellectual disabilities doesn't appear to be working. Along with constant policy change, many existing policies are often contradictory. Agency needs such as meeting the requirements of union contracts may also supercede the needs of clients. Target groups such as adults with intellectual disabilities tend not to be given priority in these transactions and client service is often lost in the process. Specifically, once effective housing is found, if the need for adequate support services that include well-trained staff is not addressed, housing trust contracts are likely to either break or require major readjustment.

d) group housing is not the same as group living

Similar to the housing research literature, the stakeholders in our focus groups emphasized the idea that, **“the operative term of ownership...should be defined as feeling and knowing that you have control within your environment, your day to day choices and decisions are respected.”**³⁴ Rather than single domiciles, many envisioned creating a multi-unit house or a housing complex consisting of

³⁴ Woodstock and District Developmental Service *Alternative Support and Housing*, Shannon Lang (2013), pg. 7

separate living units where adults with intellectual disabilities could reside independently but still be able to access the support services they required. Access to these support services would remain independent from housing and at the discretion of the adult with an intellectual disability rather than be imposed by the property manager, ODSP regulations or social service agency directives. To ensure this division of responsibility required a separation of personal and housing support.

e) the need for strong financial support

Both the research literature and anecdotal evidence indicates families are heavily subsidizing housing costs - either by having the individual live with them or in housing they have set up independent of agencies. Many families have become financially strapped and are unable to provide the funds required to buy independent housing for their intellectually disabled family member, to support continued home maintenance, or pay the property taxes required by a housing trust. The majority of adults with intellectual disabilities are unable to arrange mortgages due to bank funding requirements. ODSP funding, MCSS money and DSO support also fail to cover such contingencies and many elderly parents are experiencing financial restraint due to claw-backs in pension programs, estate planning regulations and capital gain taxation rules. Tax exemptions and changes in charitable status allocation would alleviate these types of pressures and enable more individual housing trust participation.

Along with home purchases and home maintenance, there is maintenance and upkeep to a housing trust. The most effective scenario for administering and sustaining that cash flow, liability and housing maintenance would be a Board of Directors. More strategic governmental involvement and support is also required to ensure an effective financial base, however. For example, many of the stakeholders discussed the increased financial cutbacks occurring in established programs and the scarcity of funding for new initiatives due to the current economy. Some noted the city of Ottawa had less and less funding for new initiatives due to the current economy. Rent subsidies/supplements are governed by the province and the city of Ottawa follows their policy. Housing trust program viability requires a consistent and reliable cash flow.

f) exploring innovative partnerships

The stakeholders in our focus groups were knowledgeable of housing and other programs existing in our region. In light of this knowledge, they raised the idea of

drawing upon pre-existing resources and basing our own success on past successes. Given its position as the capital city, Ottawa has a high demand for land and property and it is very difficult to obtain affordable housing. In consequence, **several stakeholders discussed the usefulness of becoming affiliated with another agency such as Habitat for Humanities which has a forgivable loan program or the CMHC Residential Rehabilitation Assistance Program which is exploring the creation of a greater mix of subsidized housing initiatives.** Suggestions of this type indicate the need to think more seriously about developing more innovative partnerships in our housing trust plan.

g) balancing public versus private interests

As noted in the above points, there are considerations outside of the dwelling that influence what models families or adults with intellectual disabilities may prefer. Person-directed planning is important. This understanding draws into question the idea of who needs to be at the table, that is, what parties need to be represented when it comes to creating a housing trust. The roles that parents/family members play and the roles they would like to play are key elements. But, as noted above, the majority of family members are mentally, physically and financially depleted from the everyday tasks of supporting their intellectually disabled family member. Moreover, **the expertise required to design and maintain housing trust contracts extends beyond the knowledge-base of most of us. We need people with a lot of commitment and the proficiency required to perform the task of balancing these private family matters with the public interests of the community-at-large.**

Conclusion

A large gap exists between the housing needed for adults with intellectual disabilities in Canada and the types of housing available to them. Notably, a CMHC study conducted in 2006 on this segment of the Canadian population provides a list of best housing practices for adults with intellectual disabilities that emphasizes (1) flexibility and choice, (2) a focus on de-linking funding so that housing is separate from service provision, and (3) a person-directed approach.³⁵ Housing trust programs fit that agenda in their emphasis on moderating the existence of “formal and informal relationships of trust by

³⁵Canada Mortgage and Housing Corporation. (2006). *Housing for Adults with Intellectual Disabilities*.

which the lifelong occupancy by a vulnerable person in their own home”³⁶ can be sustained.

The goal of our research project was to explore the possibility of creating a housing trust program in the Ottawa-Carleton area that enables secure, long term housing for an adult with intellectual disabilities. To perform this task, we tried to be sensitive to the needs and desires of all parties involved. We explored the values of individuals and tried to understand the stories they told. We examined other models and embraced positive components of models that have been proven to work in other districts. In this way, we sought to advise on the feasibility and potential effectiveness of a housing trust program for our community.

The research literature on housing for adults with intellectual disabilities shows a narrative of both struggle and success. There is strong economic incentive as well where the establishment of housing trusts are concerned. We have a growing number of adults with intellectual disabilities who remain invisible within developmental services and social housing because of the tremendous efforts of their parents. Yet, any sudden physical or material change in a family member’s, especially the parents’ living situation could result in an immediate crisis where housing is concerned. **As homelessness costs Canadians almost seven billion dollars annually, including social services and emergency shelters,³⁷ there is strong incentive to proactively work with individuals, families, and community organizations to create innovative solutions that leverage existing arrangements and support networks established by individuals and their families.**

As noted in this report, an effective approach to exploring the topic of housing trusts requires understanding of the general housing situation of people with intellectual disabilities. This population exhibits a variety of living styles that needs to be matched through the existence of a wide range of housing options accompanied by the ability to accommodate individual choice. The challenge of finding appropriate housing for individuals with intellectual disabilities requires a compassionate, person-centred approach that takes into account the individual, the family and the community. For example, in the *My Home* report, respondents tended to speak about the need for independence. “Those who rated their housing highly were those who felt it was their

³⁶ Guelph Services for the Autistic. (2012). *Creating a Home and Good Life of my Own: The Roles of a Housing Trust. Guelph Ontario: Bloomfield, E., Bloomfield, G.* Pg. 53.

³⁷ Gaetz, Stephen, Tanya Gulliver, and Tim Richter. *The State of Homelessness in Canada 2014.* Canadian Homelessness Research Network, 2014.

home”.³⁸ The creation of housing trusts is not the only housing option; however, by taking into consideration the uniqueness of each individual applicant, housing trust models offer a dynamic approach that responds to individual needs while involving the whole community, that is, all stakeholders, in this decision-making process.

³⁸ Community Living, North Grenville. (2015). *My Home: An Innovation Report Submitted to the Ministry of Community and Social Services*, pg. 76.

Recommendations

- 1. A local Community Housing Trust should be established specifically devoted to the housing needs of persons with intellectual disabilities. An Advisory Committee to set up this Housing Trust should include a group of stakeholders from government (federal, provincial, municipal), legal community, developer community, parent groups, etc. to review the various forms, challenges, and opportunities of community housing trusts.**

Rationale: The establishment of a housing trust model has been extremely challenging in the Ottawa area for a number of reasons contained in the report such as, for example, lack of affordable housing, ODSP funding rules, taxation legislation, and the lack of a “community living” focus in service provision. In particular, our conversations with key stakeholders indicate a need to create an advisory and stakeholder committee to help steer efforts in establishing a housing trust model in Ottawa-Carleton. It is our recommendation that the advisory committee have strong representation from experts in social housing, property management, land management, etc rather than only from the developmental services side.

As a way to increase the availability of housing options for individuals with intellectual disabilities, consideration should be made as to how we could preserve access to individuals in this client group without creating an overly segregated setting, and to give the community flexibility in the future. There is a need to explore further the experiences of individuals and families who might be able to take advantage of a housing trust as some confusion exists over its definition, how it should work and about its potential effectiveness to address the needs of adults with intellectual disabilities.

Throughout the research process and within the literature, it is clear that partnerships are an important potential aspect where success in establishing a housing trust is concerned. Therefore, the establishment of formal partnerships in any venture moving forward is an important and necessary step.

While the literature and research highlighted the active and important role of developers in the successful establishment of housing trusts elsewhere, it is clear that this has not been the case in Ottawa. There is the need to engage these stakeholders and think about innovative ways they can leverage their expertise in

support of the development of housing trusts. For example, are there opportunities for in-kind professional consultation that would otherwise be unaffordable?

2. **In order to accomplish the above, Citizen Advocacy Ottawa, as a recognized champion of person-directed solutions for community participation, should submit a proposal to the second round of Housing Task Force studies.** This proposal would:
 - a. **Create an Ottawa-Carleton Housing Trust for Persons with Intellectual/Developmental Disabilities**, as a separate non-profit corporation, using input from family groups, individuals, similar community agencies such as Multifaith Housing Initiative, Options Bytowne and Salus, Canada Mortgage and Housing, City of Ottawa Affordable Housing Division, estate planning specialists, and property managers in the affordable housing sector.
 - b. **Establish an Advisory Board** leading to the formation of this Community Housing/Land Trust to ensure address the housing needs/desires of persons with intellectual disabilities.
 - c. **Hire a community development officer or project manager** experienced in community development projects to guide the Advisory Board through the process of establishing the non-profit housing corporation (Ottawa-Carleton Housing Trust for Person with Developmental Disabilities), using Lights (Toronto), Guelph Services for the Autistic (Guelph), and Brockville (Community Involvement) as models. The project manager will also ensure that the recommendations of this research study are implemented.
 - d. Engage a **communications/information specialist** to create a communications strategy and educational program geared to individuals and their families, to address the various forms of ownership, needs assessment, and lessons learned, and to develop a web site and teaching materials.
 - e. **Test the operation and tools of the proposed Housing Trust** agency by using two local family-based housing initiatives to do a case study in setting up a housing trust. These case studies will inform various housing trust issues and organizational issues, and will inform the community knowledge base.

- f. **Conduct a series of focus groups:**
 - i. with agencies to share lessons learned and discover their challenges related to housing,
 - ii. with families to share lessons learned and discover challenges.
 - g. Provide **on-going documentation** of success, failures, plans and lessons learned via the community website.
3. **A comprehensive communications and education program is needed to raise community awareness of options in independent living and housing for persons with intellectual disabilities in our region. This should be done within the context of overall person-directed planning and should use examples from other groups within our community, who have addressed housing and affordability.**

Rationale: There is significant confusion around policy, funding, legislation, and taxation issues around housing trusts. Individual stakeholders and families, including stakeholders who were well versed in these areas, find the system confusing, contradictory, and difficult to navigate. This overall sense of confusion speaks to the need for clear and concise guidelines around the establishment of a housing trust in Ottawa-Carleton. There is a need for policy makers and funders to clarify roles and responsibilities. As a parallel process, there may also be a need for CAO to develop plain-language resources that provide information in one place for families.

Families, especially parents, provide a major source of financial, personal and community support for an intellectually disabled child. They represent a key stakeholder group and must be represented strongly in any housing initiative or housing trust plan developed. There is also a need to better understand the current financial commitment of this group to better understand how their needs can be supported through policy interventions.

4. **There is a need for plain language material related to housing options. This should include opportunities and challenges of various home ownership options. Resources from across the housing community (Canada Mortgage and Housing, Ontario Ministry of Housing, municipal housing authorities, social housing registry, developers, legal and property management), should be available in a comprehensive source. A website dedicated to this should be established.**

Rationale: Research time constraints made it difficult to engage caregivers, impaired adults and their families in the research study. Individuals with intellectual disabilities and their families are, by policy, being told to find their own solutions. Agency waitlists are long, and there is no direct funding available for residential supports and services outside the agency system. Community outreach in the form of a Housing 101 Introduction to land/housing trusts and social housing, estate planning and legacy giving options should be developed.

5. **Our community requires more information about housing needs for persons with intellectual disabilities in our region. Creation of this information base should use resources from the local MCSS to help gather demographics related to age, affordability, and access to current housing options.**

Rationale: A housing trust plan represents one option among many. There is a need for a continuum of housing choices necessary to ensure individual choice and personal autonomy based on a whole-life approach for adults with intellectual disabilities.

A general environmental scan of housing options in the Ottawa-Carleton area for adults with intellectual disabilities is needed to better situate any new housing model. This is of particular importance given the unique issues facing adults with intellectual disabilities and their families. An environmental scan would help identify gaps and situate any future activities here within the existing housing continuum.

6. **Findings of this study should be shared with families and agencies in the region, to ensure cohesion and consistency across the service sector, and a better understanding of how we can use programs and services of other provincial, municipal and federal agencies to support housing initiatives.**

Rationale: There are different models of housing trusts and these must be tailored to meet the unique needs of adults with intellectual disabilities in the Ottawa-Carleton area. For example, there are various different scenarios including questions about who purchases the property, how are homes transferred, and how are they held in trust. As the needs of adults with intellectual disabilities and their families in the Ottawa-Carleton area are unique, these are questions that require further exploration with local stakeholders.

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Appendix A

Project Methodology

A Team Research Approach:

This study was conducted by a four member research team selected by Citizen Advocacy of Ottawa (CAO) on the basis of each team member's expertise in disability issues, social policy and research methodology.³⁹ Team research builds on the individual strengths of the team members by integrating their theoretical perspectives, methodological conceptualizations and specialized knowledge to advance the basic understanding of an issue or to solve specific problems. Due to her background as a former project leader for Industry Canada, Minda Bojin served as the project leader who scheduled team meetings, contacted focus group participants and arranged interview sessions. Decisions regarding methodological approach, coding and data analysis emerged collectively, however, through a continuous process of consultation and shared discussion. The team met at least once every two weeks from September 30, 2015 to February 5, 2016. Draft documents were placed on the Google docs program with members writing report sections, editing and adding reference material as needed. Each team member participated fully in the research process and recommendations developed naturally through a mutual understanding of the data findings.

An Exploratory Project Design:

Given CAO's request to examine the feasibility of forming a housing trust program in Ottawa-Carleton, the team took an exploratory research approach. Exploratory research projects are designed to gain insight into a topic and have the ultimate goal of identifying significant issues and factors of interest. The approach permits flexibility and breadth of coverage because researchers are able to keep their research question

³⁹ Minda Bojin retired recently from her position as Project Leader and Technical Advisor in the Department of Industry Canada, is Acting Chair of the Steering Committee for United Families Matter, and a parent of an adult daughter with an intellectual disability. Jihan Abba has a Ph.D. in Sociology, teaches and conducts research on disability, human rights and the labour market, and has an adult brother with an intellectual disability. Ian Ford has an MSW degree with a specialty in direct intervention and issues pertaining to people with disabilities and disability identity. He co-founded a group called Men for Equality and Non-Violence and holds a position as a group social worker at the Salvation Army Transitional House in Ottawa. Karen March has a Ph.D. in Sociology and has taught social research methods and Family Studies at Carleton University for over 20 years. She was involved in creating the Disability Studies minor at Carleton and is the Interim Chair of the Disability Studies Program Committee.

open-ended and follow the direction of their findings rather than keep to a rigid, pre-determined research design. The team believed exploratory research enabled a more effective investigation of the variety of perceptions held toward housing for intellectually disabled adults and how a housing trust program might be created in Ottawa-Carleton. An analysis of that data could then be used to formulate recommendations concerning the supportive role CAO might take in that process.

Conducting the Literature Review:

The study began with a review of the research literature on housing for adults with intellectual disabilities in Canada with a focus on housing trusts. A literature review ensured all members of the team became familiar with the research topic and provided an awareness of the positive and negative issues involved in creating an effective housing trust program. Conducting the literature review meant searching through library data bases, newspaper and magazine articles and government and social service agency reports. The Central Mortgage and Housing Corporation (CMHC) publication listings were most helpful. As the major government agency designed to support social and public housing programs for low-income families in Canada, CMHC has conducted a number of research studies that contain good definitions, strong data sets and comprehensive information relevant to the project.

The literature review process provided an overall sense of 'best practices' and existing housing trust models that contributed to the team's understanding of the complexity of the research topic. In particular, the team noted a number of common themes about housing for the intellectually disabled that confirmed and supported the descriptions offered by the stakeholders who participated in the focus groups. As such, the literature review offered a comparative base-line for assessing the validity and reliability of our own research findings and recommendations.

Taking a Focus Group Interview Approach:

The team employed a focus group interview method to obtain a sense of how a housing trust program might be developed successfully within Ottawa-Carleton. The focus group approach is similar to open-ended interviews but, rather than interviewing individuals separately, the interview is conducted in a group of about five to seven individuals. Each group is given a topic to discuss and data are derived from the group discussion. A moderator presents the topic and guides the conversation but intervenes as little as possible so discussion may emerge naturally among group members. The focus group interview approach is advantageous because data can be collected from numerous individuals at the same time. Participants also have a sense of empowerment because they are encouraged to express their ideas freely and may ask each other questions to get more detailed information or clarification.

Focus groups are used frequently in exploratory research. Researchers are able to identify and explore a more complete range of issues about their research topic while simultaneously gaining a sympathetic understanding of how these issues are viewed and debated by people involved directly with the issue at hand.⁴⁰ Subtle nuances and unidentified differences are also more likely to emerge through focus group conversations than during individual interviews. When research participants respond openly in a group discussion, researchers are able to identify where agreements/disagreements may lie, how defences and justifications may develop, where potential difficulties are likely to arise, where further clarification may be required, and what challenges may need to be addressed.⁴¹

“Polarization effects” can occur in focus group research if more dominant focus group members express extreme opinions and/or silence others.⁴² No indication of polarization effects appeared in this study, however. All focus group participants contributed actively to the discussion and seemed to be secure in expressing their opinions openly and without hesitation. Many asked either the moderator or other group members for clarification and some disagreed or offered alternative perspectives. None appeared to withdraw or be silenced. This result may be due to the fact that the majority of the sample are professionals in their field and are accustomed to engaging in group discussions on complex topics so may be more confident and relaxed in the focus group setting. It may also stem from each participant’s overall commitment to enriching the lives of others and the general interest each held toward the possibility of creating a housing trust program in their community.

Selecting a Sample:

The main study objective was to acquire a sense of the feasibility of developing a housing trust for adults with intellectual disabilities in Ottawa-Carleton. The research team believed the complexity of the social, legal, taxation and government policy requirements of creating a housing trust necessitated a stronger understanding of the perspectives of individuals who might be involved with these issues. For this reason, we decided to interview a sample of key stakeholders that included experts in the field of housing, lawyers, representatives of intellectually disabled parent organizations and agency workers.

The sample is purposive, that is, “a type of non-random sample in which the researcher uses a wide range of methods to locate all possible cases of a highly specific and

⁴⁰ Hennink, M., Hutter, I. and Bailey, A. (2011). *Qualitative Research Methods*. Sage, pg. 136.

⁴¹ Krueger, R.A. and Casey, M. (2000). *Focus Groups: A Practical Guide for Applied Research*. Sage

⁴² Neuman, W.L. and Robson, K. (2009). *Basics of Social Research: Qualitative and Quantitative Approaches*. Pearson Press, pg. 360.

difficult-to-reach population.”⁴³ Representation is neither a goal nor a requirement of exploratory research. Moreover, “the intent of focus groups is not to infer but to understand, not to generalize but to determine the range, and not to make statements about the population but to provide insights about how people in the groups perceive a situation.”⁴⁴ For these reasons, randomness was neither a primary factor in the study’s sample selection nor a major consideration in the analysis of the focus group data collected.

The sampling frame was strategic and biased and the ultimate response rate was small (i.e. 12 people). CAO provided a list of potential interviewee names. To fill in the gaps, additional names were taken from agency or professional websites as well as personal references provided by colleagues and friends. People on the list were contacted by email with a letter of explanation about the study and its goals.⁴⁵ Many did not respond or expressed interest but were unable to participate due to other commitments. Such refusals are not unusual given the employment requirements of professionals. The social research literature also indicates respondent acceptance is increasingly smaller for all types of studies because people experience ‘research burnout’ from repetitive requests initiated by survey companies and telemarketers.⁴⁶ Despite these respondent issues, we believe there is enough range and variation in the characteristics of the focus group participants for the data to provide a generalizable sense of stakeholder housing trust concerns.⁴⁷

The Focus Group Process:

Once a potential participant responded to the email study request, they were sent an additional email to set up a time and date for their focus group participation. That email also included information containing the working definition of housing trust based on the CMHC definition of community land trust and a number of questions for their consideration.⁴⁸ Often focus group respondents are not given such material but we wanted to gain a full sense of the social policy, legal and financial complexities involved in the creation of a housing trust and believed the sample’s ability to prepare for the focus group interview would enable a more effective picture of those complexities.

⁴³ Neuman, W.L. and Robson, K. (2009). *Basics of Social Research: Qualitative and Quantitative Approaches*. Pearson Press, pg. 136.

⁴⁴ Krueger, R.A. and Casey, M. (2000). *Focus Groups: A Practical Guide for Applied Research*. Sage, pg. 83.

⁴⁵ See Appendix B for a copy of the email letter and a list of questions that we sent in advance.

⁴⁶ Del Balso, M. and Lewis, A.D. (2008). *First Steps: A Guide to Social Research*. Thompson Press, pg. 116-117.

⁴⁷ We guaranteed the focus group participants confidentiality in the presentation and analysis of specific data results. Most agreed to having their name identified on a list at the end of the Report. As can be seen from that list, focus group participants include a lawyer, a CMHC representative, the president of a parent group, a City of Ottawa representative, a social service worker and so forth.

⁴⁸ See Item 2 for a copy of the information sheet.

We conducted three focus groups with an attendance of 9 people in total. All four team members attended each group but, to avoid confusion, only one served as the moderator while the remainder observed and took notes. Apart from the questions sent to the participants, there was no specific interview script followed other than a brief introduction outlining our research purpose and our research goals. The focus group participants were very expressive and formulated additional questions and potential solutions of their own. Thus, for example, several offered the idea of approaching other agencies who are involved with housing and either asking their advice or trying to form a partnership with them. Others raised their own agency's sense of frustration over ODSP funding rules and the need to separate social support from housing support. Many noted the need to draw in developers, legal representatives and government officials. These types of stakeholder responses revealed a pattern of overlap and repetition that enabled a more effective analysis of the focus group data.

Data Analysis and Development of Recommendations:

Qualitative data analysis is done concurrently with the data collection. As noted above, the team acted collectively throughout the research process. We met at least once every two weeks, discussed our findings and made decisions regarding how to proceed to the next step. For example, in conducting the literature review, each team member added articles and documents to Dropbox for the others to read. When we met, we would discuss that material and what other material should be explored and evaluated. Additionally, one team member (Ian Ford) placed his summary of the material on Google Docs and the other team members added to and edited those summaries. In this way, the team began to identify themes in the literature and to discuss together the relevance of those themes for making our Report recommendations.

In a similar fashion, each member of the team took notes during the focus group sessions. However, one team member (Jihan Abbas) placed her notes on Google Docs and the others added and edited that material based on what they had recorded. We also met after each focus group and discussed our views of the focus group discussions. In this way, we began to identify emerging themes as well as themes matching the research literature that could be used to inform our own work and the development of our Report recommendations.

Finally, given her expertise in qualitative research methods and qualitative data analysis, Karen March summarized the themes to compose a rough report draft. The remainder of the team edited and revised that draft repeatedly until a final report ensued.

Appendix B

List of Interviewees

Group 1

Bonnie Dinning, Parent, and formerly Housing Expert with City of Ottawa

Vivian Chih, Canada Mortgage and Housing Corporation, Affordable Housing Unit

Serge Lavoie, Project Leader, Housing Task Group, Coalition des familles francophone d'Ottawa

Eileen Rankin, Parent, Currently investigation establishment of Housing Trust for her son.

Group 2

Ron Tomosk, Lawyer specializing in estate planning and disability law

Julie Livingston, LiveWorkPlay

Saide Sayad, Affordable Housing Unit, City of Ottawa

Group 3

George Brown, Mills Community Supports, Almonte

Mike Coxon, Mills Community Supports, Almonte

Appendix C

Text of Email and List of Questions Sent to Focus Group Participants

I am writing to you as a member of a research team hired by Citizen Advocacy and Families Matter Coop to study the mechanisms for starting a Housing Trust initiative in Ottawa. This study is being funded by the Ontario Government's Developmental Services Housing Task Force.

Below is a summary of the purpose and brief scope for the project:

Families have expressed an interest in bequeathing purchased property or bequeathing their family home for their family member with a disability that can be shared with others. In doing so, families have indicated a preference for ensuring housing and the provision of support for daily living remain separate. There is no legal entity that exists to support families in a transfer of property in this way. This project proposes to examine the possibility of creating a housing trust in Ottawa, the legal and governance implications, and if the research concludes this is a viable option, a plan to move forward.

Our research methodology includes a review of existing literature and housing trust models as well as interviews with experts in the field of trusts, housing issues and developmental services. Interviews with families and individuals with developmental disabilities will follow, to ensure that the solutions that emerge from the research meet the needs of the community.

The other members of the study team are:

Dr. Jihan Abbas, PhD. Instructor of a course on disability, Carleton University and sibling of a person with a disability

Ian Ford, Masters of SocialWork

Dr. Karen March, PhD. Qualitative Methodologist and Associate Professor, Women's & Gender Studies, Carleton University

We are writing to ask for your participation as a representative of a community agency that has explored partnership and social housing opportunities in our community. A list of the research questions are attached to this email.

Housing Trust Research Project:

Questions for Key Informants

December 15th 2015

Working Definition of Housing Trust based on CMHC definition of community land trust:

A "private non-profit corporation created to acquire and hold land for the benefit of a community

And ...to provide secure affordable access to land and housing for community residents."

Community land trusts focus on meeting housing needs of low to moderate income residents,

By "acquiring land in the community either by purchasing land directly or by receiving as a donation land, land and buildings, or money to purchase land.

Questions for Key Informants

1. Do you think this definition of housing trust is adequate? If so, why? If not, why not?
2. What do you think might be as some of the barriers to implementing a housing trust in our community?
3. What are the key things you feel those exploring housing trusts should know/do?
4. Do you know of any housing trusts currently operating in the Ottawa/Carleton area?
5. What, if any are the regulatory considerations that should be considered (policy, legislation etc.)?
6. What types of inputs, expertise or partnerships do you think need to be in place to make such a housing trust initiative successful in the Ottawa/Carleton region?.
7. What types or organizations might, in your opinion, be the most capable to lead a housing trust initiative in the Ottawa/Carleton region?