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Attainable Dreams and Harsh Realities: Housing for Individuals With Intellectual and Developmental Disabilities

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Abstract

Individuals with intellectual and developmental disabilities (IDD) and their families are often faced with little to no choice regarding where and with whom the individual can live, and many remain living in the family home well into adulthood, despite this not being the desired arrangement for the individual or his or her ageing parents. To address this significant gap in access to housing, a research team interviewed individuals with IDD, family members, service providers, researchers, policy makers, students, and educators to determine what they saw as the most pressing and impactful concerns regarding the state of housing, and where to go in the future to ensure fair and accessible housing for this chronically undervalued population. Results indicate that significant positive change in the housing landscape could result from separating support from housing, including housing for individuals with IDD in the broader housing discussion, and increasing individualized funding opportunities to facilitate the development of personalized housing.

Despite concerted efforts toward community integration, individuals with intellectual and developmental disabilities (IDD) remain marginalized and disadvantaged (Ditchman, Kosyluk, Lee, & Jones, 2016). One of the key barriers to true integration is access to housing, ranging from the most basic concern of homelessness (Mercier & Picard, 2011), to the more nuanced influences that housing can have on one's quality of life, including access to community and relationships (Gjermestad, Luteberget, Midjo, & Witsø, 2017). Historically, individuals with IDD were often sequestered to segregated large-scale living institutions (Brown & Radford, 2015). Societies in the global north are now moving away from mass institutions and are focusing on small cluster group-home models that are meant to provide more integrated and community-based housing. Although group homes are an improvement over large institutions, they too face criticism due to a lack of choice regarding where and with whom an individual will live (Gjermestad et al., 2017).

While research indicates that Canadian adults with IDD often want to live independently (Canada Mortgage and Housing Corporation, 2006), 50 to 60% live with family members for various reasons (Weeks, Nilsson, Bryanton, & Kozma; 2009). Strain on residential services is increasing at a rate that is untenable; the Auditor General of Ontario found that from 2009 to 2014 there was a 50% increase in the number of individuals awaiting residential services, while the number of individuals served increased by only 1% (Ministry of

Community and Social Services, 2016). Despite efforts toward deinstitutionalization, some individuals with IDD end up "institutionalized by default" because of a lack of available housing and support options (Dube, 2016). Increasingly, individuals, families and service agencies are looking to support semi-independent living options. While semi-independent living is a phrase that is open to interpretation, it is generally framed as an individual residing in their own dwelling, alone or with roommates of their choosing, and receiving drop-in support from one or more community agencies throughout the week.

The purpose of this study was to gain a better understanding of the current state of housing for individuals with IDD and to provide direction for potential policy changes in the move toward true community integration. This study was part of a larger housing innovation study conducted by developmental services faculty and researchers from Centennial College and staff from Community Living Toronto, a large urban social service agency (Atack et al., 2019). Interviews took place between 2016 and 2017.

Materials and Methods

The study was approved by the participating organizations' research ethics review committees and all participants provided informed consent. A qualitative design using semi-structured interviews was conducted with stakeholders including people with IDD and those who had direct experience in researching, managing, supporting, or living in housing with people with IDD. The conceptual framework for the study was the Appreciative Inquiry approach (Whitney, Trosten-Bloom & Cooperrider, 2003). This approach explores community action and development from a capacity-building perspective. Key concepts from the Appreciative Inquiry approach were applied when developing the research design and interview questions and included: ownership, collaboration, access and control. Appreciative Inquiry is now regarded as best practice in conducting research with marginalized populations and communities.

Key informant groups were identified and included: individuals with IDD, families, educators, researchers, service providers, and policy makers who were recruited using purposive, snowball and convenience sampling from within the IDD sector. The number of participants was not fixed at the start of the study; our goal was to interview until the team felt that data saturation across the stakeholder groups had been achieved. Criteria for data saturation included: no new coding or themes emerged, the data was deemed 'rich' and sufficient information had been obtained so that the study could be replicated (Fusch & Ness, 2015). The study included 29 participants across a range of different roles including educators, service providers, policy makers, researchers, family members, and individuals with IDD (Table 1). Most interviews took place between the interviewee and the interviewer, although some individuals with IDD had a family member present to facilitate communication. Interviews lasted anywhere between 20 minutes to two hours. Most participants resided in Ontario, Canada.

Table 1. Stakeholder Role

Role	*n*
Educator	5
Service Provider	10
Policymaker/Analyst/Researcher	3
Family Member	7
Person With Intellectual Disability	4

The interviews were conducted by a researcher with extensive experience working with individuals with IDD. Participants were asked to describe their experience with different housing models and the benefits and limitations of those models. Questions were shortened and provided in a plain language format for individuals with IDD when necessary or desired.

All interviews were recorded and transcribed and an editing analysis approach was used for data analysis (Loiselle & Profetto-McGrath, 2011). Major interview questions were used to structure the initial analysis template. Five transcripts were read and coded. Some key messages that arose repeatedly became subthemes and the template was revised accordingly. All tran-

scripts were then reviewed using the template, and the template was revised as necessary. All transcripts were coded by one researcher with a sampling of interviews coded by a second researcher to validate coding and themes. Major findings were reviewed by the extended research team which included developmental service educators and community agency staff. Stakeholder meetings were held in the community where the results from the study were presented. Twenty stakeholders attended the meetings, including people with IDD, parents, representatives from community organizations and policy makers. Those attending were invited to discuss the results; there was strong agreement regarding the findings.

Results

There was considerable consensus across responses; however, where groups or individuals differed, that was noted. Results and subsequent themes identified were guided by interview questions (Table 2).

Table 2. Interviews: Major Themes

Optimal housing models
Family decision making and housing
Availability
Securing and peace of mind
Affordability
Benefits and challenges: Current group housing models
Future alternative models
New directions for policy
Normalize housing
Separate support from housing
Increase overall funding

Optimal Housing Models

Across participants, consensus was that the ideal housing model is one that is flexible, individualized, sustainable, and open to the changing needs and desires of the individual in question. As one participant noted, ideally a person with IDD would have a "whole smorgasbord and you just take what you want."

Individuals with IDD reported that it was important to live somewhere where they could "make new friends," and preferably to live with a friend they already knew. This was echoed among family members who indicated that it was very important to ensure that the individual with IDD was matched with a friend or someone who could become a friend in their housing arrangement. Family members felt the individual should not live with someone selected at random.

Individuals with IDD were keen to move out of their parents' homes and expressed their readiness for autonomy. This was balanced by a desire to feel safe and secure in their home and to have people around to help in case of emergencies. Individuals with IDD also reported that it was important to have good access to public transportation and to live near family, work and leisure activities.

Decision Making Regarding Housing

Three major factors affected decisions regarding housing: availability, security, and resources.

Availability. Availability was the primary issue voiced by educators and family members, and a major issue among other groups as well. Family members noted that a lack of available options forced them to "choose" whatever housing was available.

Educators reported that since quality housing (i.e., housing that is safe, secure, personalized and where living companions are chosen by the individual and family) is rarely available, housing decisions are based on desperation and taking what is available. They explained that housing scarcity is due to a lack of funding and limited funding flexibility. Educators further described how funding is typically directed to group-based residences and funnelled through community service agencies, meaning that there is little available for establishing alternative or semi-independent living arrangements. Families reported being placed on wait lists and ultimately feeling obliged to choose from options that are funded, like group homes, rather than establishing an alternative housing model. Moreover, some families reported that some community agencies are chronically underfunded; shared living spaces have little room for innovation or personalization.

Security and peace of mind. All participants agreed that security, both in terms of personal safety and housing stability, is an essential element of housing. However, the majority noted that there was tension between families wanting the most secure, stable environment possible and the person with IDD's desire for independence. One parent noted, "Safety and security are the top priorities for the families but for the individuals it's being able to live with friends. Being able to do things without your mom and dad over your shoulder." This was reflected in the interviews with individuals with IDD, who mentioned the importance of feeling safe, but also said that they wanted to move out of the family home to meet new people and become more independent. Family members, educators, policy makers, and service providers suggested that the need for present and future security pushed families to favour group living arrangements.

Affordability. Across stakeholder groups, many participants stated that finances played a major role in determining housing. In Ontario, individuals with IDD generally receive their primary source of funding via the Ontario Disability Support Program (ODSP), where the maximum shelter allowance for a single person receiving ODSP is $479 per month (MCSS, 2016).

Family members with sufficient personal finances reported being able to provide their own alternative housing arrangements. One educator stated, "Placement is simply based on availability, perceived need; the models are almost irrelevant in terms of considering what might work for someone. The exception is when the family has the skill or resources to negotiate something better." These points were exemplified by three family members who had set up their own housing arrangements for their family members with IDD. They were able to invest in housing, which allowed them to create more flexible and suitable arrangements. One of the parents remarked, "We're fortunate enough to be able to afford to see our son have good living accommodation. Many, many people aren't."

Benefits and Challenges of Current Group Housing Models

Several participants reported that current group housing models were useful in terms of the stability they provided. Two family members said that group housing provided support to the family as well as a degree of independence to the person who might otherwise be living at home with their parents. Group homes were also viewed as beneficial in that they provided long-term security and were sustainable over time, which was necessary since health, family support and disability are not constants.

By contrast, several educators and family members mentioned that group housing made having "normal" relationships very difficult; they noted that there is a dehumanizing aspect of forming relationships exclusively with paid staff or having to live with individuals one would not normally choose. Moreover, they believed that living in such a housing situation emphasized a person's segregation from the rest of the community, making it more difficult to become socially integrated.

Movement Toward Future Housing Options: Alternative Housing Models

Families and service providers reflected upon the growing movement away from traditional group homes and the growth of new models. Driven by families, these "pockets of innovation" were born out of need, creativity, or sometimes, desperation. Families and service providers shared several examples of housing innovation to which they were connected. For example, two individuals with IDD renting a home together and sharing caregiver costs; individuals with IDD who live with students who provide informal support; a duplex, in which individuals with IDD resided in one unit with supportive neighbours; a single-family home where two individuals with IDD resided with two "family facilitators" who provided care and lived rent-free thanks to a private family foundation; and a neighbourly co-op apartment building housing a typical mix of residents including people with IDD.

Overall, most service providers reported an excitement around future housing options, with one participant stating, "The government is just starting to think about the fact that people with intellectual disabilities have the same housing needs as everybody else, which bodes well for having access to subsidized and affordable housing outside traditional models." That said, some service providers also

expressed concern that while innovation was developing, there remained financial pressures to return to congregated living arrangements. A number of family members, educators, and service agency members also articulated ideas regarding policy changes that they thought would lead to better and more varied housing opportunities for individuals with IDD.

Normalize housing. Some participants suggested that government and agencies needed to view housing for individuals with IDD as part of broader housing issues rather than as a developmental services-specific concern. This philosophical shift would result in viewing individuals with IDD as full and equal citizens not only in the eyes of the government, but, by extension, in greater society. Further, this position would open doors to greater linkages between service systems, including housing corporations, Habitat for Humanity and mortgage financing companies.

Separate support from housing. Further separation of funding for support from housing would allow families and individuals with IDD to find their own housing solutions and to obtain the level of support they require, rather than forcing them to accept any available premade housing solution with built-in support simply because it is funded. A researcher stated, "If you separate out housing and social care, I can live somewhere and if I don't like where I live I can move somewhere else, but I can take my social care staff with me and vice versa." One policy-maker recommended increasing funding for people who are trying to pursue alternate housing options, and providing more support for organizations who want to unbundle housing and support. Families noted that current policy focuses too much on oversight and not enough on individual empowerment.

Increase overall funding. Every family member reported that lack of funding and difficulty acquiring available funding was a major issue. One policy-maker and several family members argued that currently, many individuals with IDD are living below the poverty line, and are therefore unable to access a variety of housing options, particularly in large urban centres. Providing individuals with IDD with sufficient income to pay for their own housing through employment opportunities or increased financial supports could help ensure individuals would be able to live in a housing situation of their own choice.

Discussion

Not surprisingly, the bulk of discussion around concerns and directions for improvement in housing for individuals with IDD centred on finances. With rental, real estate and staff costs increasing every year, traditional funding platforms like ODSP and Passport do not offer enough to support creative options for housing for individuals with IDD. ODSP's shelter allowance of $479 per month makes it extremely difficult for individuals to afford clean, safe, suitable housing. Further, for individuals who need daily staff support, the financial strains can be amplified, with funding offered through Passport – which provides a maximum of $35,000 individualized funding a year for individuals with IDD (MCSS, 2014) – often falling short. Notably, Passport functions as a reimbursement system – families need to pay for services out of pocket and submit receipts to the Passport office for approval, making its successful use difficult, if not impossible, for families with limited financial reserves.

Current housing supports through the Ontario government remain in line with the initial movement from large-scale institutionalization, focusing on access to traditional housing models such as group homes, where housing and support are tied together. This conservative model of housing and support delivery continues despite evidence that suggests that semi-independent living options not only result in better social and quality of life outcomes but are also less expensive on an individual basis (Stancliffe & Keane, 2009). Separating housing from care would require not only major policy shifts, but changes in oversight and new accountability structures. Historically, there has been reluctance to make these changes, not only due to the large-scale organizational changes required, but also the need for a significant philosophical change, placing more power in individuals' hands. Yet, by providing a more robust funding platform and separating care and housing through policy reforms, the Ontario government could facilitate the development of housing options as unique

and varied as the people with IDD who need them. All stakeholders agreed or implied that housing for individuals with IDD is currently insufficient and requires reform. However, it should not be misinterpreted that the goal of this project was simply to criticize group homes and group-based living options, or that all respondents viewed group homes in a negative light. To the contrary, the goal was to expand ideas of what different housing options might look like and how they can be accessed, providing more robust and varied options for housing that best fit the needs and desires of individuals with IDD. Rather than moving *away* from certain housing options, we should instead be moving *toward* a more varied housing palette and expanding individuals' opportunities to choose the type of housing that works for them. The goal should be empowerment and agency that allows individuals with IDD to choose where they want to live and with whom. This shift in housing options will require support services to adjust and change (Isaacson, Cocks, & Netto, 2014).

The need for greater social connection, community and friendship was another key message delivered by study participants. The majority of respondents viewed housing as a gateway to community integration, both in terms of where an individual lives, and with whom. This was particularly important from the perspective of individuals with IDD themselves, who frequently discussed the desire to live with friends, and near important personal landmarks. Strengthening personal networks was viewed as important not only for the individuals with IDD, but also for their family members, who often take on significant advocacy roles for their loved ones.

While the key messages conveyed by participants were remarkably consistent across groups, this study was limited in that it focused on a relatively small number of respondents who primarily lived in one particular geographic region; findings are applicable to some individuals, not intended to be generalized to every person in every region. Further research regarding a comparative analysis of funding and housing structures across several regions to determine best practices is needed.

Conclusion

Housing is an essential component of achieving self-realization and true social inclusion. Participants in this study indicated that progress has been made; however, significant policy change is needed to ensure the housing needs and goals of individuals with IDD are met.

Key Messages From This Article

People with disabilities. You deserve to be able to choose where you live, and with whom.

Professionals. Housing opportunities that promote greater social connection, community and friendship are needed.

Policymakers. Policy changes, including more funding and funding that does not tie support with housing, would help individuals with disabilities to have more choice in housing.

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