



# Course Correction or Crisis?

## Housing Needs of Adults with Developmental Disabilities and High Complex Needs

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# 1. EXECUTIVE SUMMARY

## The Problem

That there are various types of housing crises in Ontario is familiar to those involved, and the issues involved occasionally surface in the popular media. Affordable housing is in short supply. Housing that is accessible in ways that meet the needs of people with various sorts of disability is also scarce and generally expensive, and so homes that are accessible and affordable in ways that meet the needs of people with disabilities *and* low incomes are even harder to come by.<sup>1</sup>

For people with developmental disabilities in particular, the “deinstitutionalization” process that resulted in the closure of long-term care facilities in the 1990s – a process, to be clear, that is almost universally regarded as a positive development – led to reliance on families to care for many of those who moved out of the institutions. This situation is, for many, no longer sustainable (because of parents aging, for instance). In the face of 1400 complaints from families of adults with developmental disabilities, the Ontario Ombudsman’s 2016 report, *Nowhere to Turn*,<sup>2</sup> highlighted 18 cases where people were left homeless, abused, abandoned, or inappropriately housed in hospitals or jails.

All of these are large problems, which seem to call for large-scale, systemic solutions. The present study arises from a sense that discussions of such systemic solutions *overlook*

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<sup>1</sup> There are many variables in each person’s situation, of course, consider this likely scenario: an adult with developmental disabilities and high, complex needs and their caregiver are looking for housing for the adult in Waterloo Region. A change of accommodations for the adult are needed due to the caregiver aging, and they will soon be unable to continue providing care. Focusing on the cost of housing alone, the current average house price in Waterloo is roughly \$574 000 (<https://www.zolo.ca/waterloo-real-estate/trends>), which is prohibitive to many prospective home buyers. Turning to apartment rentals, the current average cost for a one-bedroom apartment is \$1356/monthly, just over \$16 000 annually (rentboard.ca). This adult and their caregiver may consider putting the adult’s name on the list for affordable housing, but this requires one resident to be able live independently “with or without support services” which is likely to be prohibitive in this case (*DSO Housing Toolkit* <https://www.dsontario.ca/resources/housing/welcome-to-the-dso-housing-toolkit>). And this is only the cost of housing and does not take into consideration other living expenses (food, internet/cable) let alone the cost of securing adequate supports required when someone has high, complex needs.

Affording living accommodations for the adult in addition the caregiver’s own housing is further complicated by the nature of government supports. For example, this adult is likely to receive “Passport” funding from Developmental Services Ontario, which offers individuals with a developmental disability diagnosis *up to* \$35 000 a year. The average allocation of funds is closer to \$10 000 a year (Easter Seals Ontario, [education.easterseals.org](http://education.easterseals.org)), and furthermore, one is not permitted to use their Passport funding for housing costs, among other restrictions (<https://www.dsontario.ca/passport-program>). If this adult receives \$10 000 a year to cover certain needs (but not housing), and perhaps the occasional one-time sums from the government, it is unclear how to secure financially feasible living accommodations, and somewhere the adult can receive the adequate support.

<sup>2</sup> Paul Dubé, Ontario Ombudsman, *Nowhere to Turn*, (August 2016):

<https://www.ombudsman.on.ca/Media/ombudsman/ombudsman/resources/Reports-on-Investigations/NTT-Final-EN-w-cover.pdf>

*the particular needs and desires of some of the most vulnerable people in the province.* A number of caregivers have found that many existing options (traditional group homes, for instance) or proposed innovative approaches to making homes for adults with developmental disabilities, would not suit the needs of the person they care for.

This project was initiated by Waterloo Wellington Autism Services (WWAS), who had heard this sentiment expressed by many of the people they support or are in touch with. The sense of the WWAS leadership was that there were distinctive challenges confronting any attempt to find or develop suitable homes for adults with developmental disabilities and what they called “high, complex needs.” Their hope was to generate useful evidence about the nature of these challenges by becoming clearer on the needs and desires of the people themselves, and of those who care for them. Good evidence about this will be useful both by making clearer what these distinctive needs are and by helping those considering projects or policies to address these needs with useful information.

WWAS partnered with researchers at the University of Waterloo, with Professor David DeVidi as the Principal Investigator. The project was jointly funded by WWAS, a Mitacs Accelerate Grant, and University of Waterloo funding available to DeVidi.

## The Project and Method

Two key factors framed the approach taken in the study.

First is the view that a fundamental aspect of any approach to providing adequate homes for any group of people is that they be treated *as people*. Among other things, this involves recognizing the rights of everyone to have an appropriate say in how and where they will live, and to make choices. An important aspect of treating people with appropriate respect, in general, is that when asking about what they want and need we should be asking *them*, rather than someone else. For the people of central concern to this study, this can be complicated, because many of them do not speak with their voices (but via some method of augmented communication, say), while others do not communicate verbally at all, but use gestures and body language that those close to them have come to understand. Moreover, in most cases there are others, often family members, whose interests in the well-being of the person and whose own interests in their housing arrangement are beyond legitimate question. In all stages of the evidence gathering, there were therefore two parts. One part

involved directly asking people able and willing to participate, with or without communication supports, for their own answers. The second part involved asking caregivers for their opinions, but also asking them directly how they came to know what the needs and desires of the focus person are.

The second key factor that framed the approach is that the notion of “high complex needs,” as used by WWAS, is not an established technical term with a well-understood definition. This meant that possible survey or interview participants might not be clear on whether they were the intended target of the research, and that there are no accessible lists of members of this group to be targeted for sampling. To address the definitional challenge, the researchers therefore worked with WWAS to develop a provisional definition of “high complex needs” (HCNs), and used it to allow participants to self-identify as a person with a developmental disability and HCNs or a primary caregiver for one. We provided an opportunity for participants to comment on the provisional definition to seek suggestions about how the definition could be more useful. To address the sampling challenge, the researchers employed a “snowball sampling” method, where they began by directly approaching people thought likely to be in the target populations, and asking them to pass the survey information to others they knew who they thought likely to be in it. This obviously limits the claims that can be made about how representative some results will be (e.g., with respect to demographics).

The research was carried out in Fall 2019.<sup>3</sup> There were two online surveys, one aimed at people with developmental disabilities and HCNs (i.e., Individuals), another at Caregivers. We received 19 responses to the Individual survey, 11 of which self-identified as having developmental disabilities and HCNs (nine of them complete) and 79 Caregiver responses (53 complete). Only responses from Individual surveys of participants who self-identified as someone with developmental disabilities and HCNs (11), and Caregivers who completed their survey (53) are used in this report. Caregiver respondents were asked about their willingness to participate in follow up interviews. From Caregivers who said “yes,” a selection was made to ensure, to the extent possible, diversity of the type of community, e.g., rural/urban, gender,

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<sup>3</sup> This research was carried out prior to the vast changes brought about by the COVID-19 pandemic. Had this research taken place after March 2020, participants of the surveys and interviews may have said things differently, as the pandemic has changed so much of daily life. The barriers people face to achieving housing solutions highlighted in this report (e.g., financial barriers, lack of available and qualified personal support workers) have likely been exacerbated. However, we can only analyze what was reported at the time, and the considerations drawn from this study remain true: people’s needs for adequate housing, and the lack of available options.

age, and so on. Interviews were carried out with nine Caregivers. The results were analyzed using standard qualitative methods.

## Key Findings

The concept of “high complex needs” (HCNs) is one survey participants recognized as important to their situations and is analytically useful for understanding the needs of adults with developmental disabilities who don’t see themselves represented in the larger conversations about housing options. The survey offered participants a “working definition” of HCNs so they could determine whether they fell within the (Individual or Caregiver) target group for the study. They were also offered an opportunity to suggest amendments to the definition. The working definition is focused on the degree of support a person requires, in particular that the person requires 24/7 care that means, for instance, that a person cannot be left home alone even for short periods of time. So defined, the concept does not refer to a need for a specific kind of support, since the reasons someone cannot be left alone may be medical, or involve a person’s proneness to wandering, or any number of other things.

Nevertheless, survey participants recognized the definition as applicable to their situations. In response to the opportunity to suggest modifications, participants tended instead to offer details about the reasons that, in their situation, the definition applied. Such responses provide useful information in this context because the nature of the HCNs for an adult were seen by many as the reason behind the housing challenges the adult faces. Obviously, the definition of HCNs implies that supports will be resource intensive, but the nature of the HCNs are quite specific, which means that the supports need to be highly individualized. Furthermore, through analysis of participant’s particular situations, a modification of the definition was made to explicitly include proactive - and not just reactive - support (for more on this see §4). The complexity and need for proactive support create a challenge for any housing arrangements where the supports are not tailored to the adults’ needs.

**The need for suitable homes for adults with developmental disabilities and HCNs is acute, but will grow substantially in coming years.**

That the situation with respect to homes for many in the group we are investigating is already dire, with many individuals and families going into crisis, is amply displayed by the Ombudsman's report. The results of the present study suggest things will soon be considerably worse.

1. For Caregivers, the percentage was >90% that the adult lived in the family home, with the majority of others indicating some sort of temporary crisis arrangement (e.g., being at CAMH waiting for a treatment bed). Only 13% of Caregivers saw no need for a change in living arrangements in the "foreseeable future," and this is true for every age group of Caregivers or adults.
2. Presented with a range of options for why a change is necessary (including finances, inadequacies of current supports, interpersonal issues, or others), regardless of the age of the Caregivers, the vast majority (87%) of respondents selected "Current Caregivers are Aging/Exhausted" and will not be able to continue providing supports.
3. When asked if there are housing options they can access, 80% of Caregivers said "no", 18% said "maybe," and one participant responded "yes."
4. The survey and follow up interviews showed that being a primary Caregiver for someone with developmental disabilities and HCNs has career, financial, social and mental health implications for the Caregiver.

Taken together, these results suggest that continuing reliance on Caregivers by family members in the family home is not sustainable. Caregivers are wearing out, but they see no viable alternatives. More individuals and families going into crisis is a predictable outcome if steps are not taken to open up new options for suitable homes.

## There are lessons to learn from experience with alternative arrangements.

About one third of Caregivers reported that the adult they care for has experience with living arrangements besides the family home. Of these, about half were in group homes or other shared living arrangements, and half were in a range of institutional settings (e.g., hospitals, residential schools, institutions). The survey did not differentiate between arrangements intended to be long term and shorter-term respite arrangements.

The benefits of alternatives were of two sorts. For many Individuals, these arrangements provided them with an opportunity to develop social connections, experience new activities, and to grow in independence. For Caregivers, the alternative living arrangement was often viewed positively as relieving the stresses of their role.

The problems with these arrangements are also instructive. Several Caregivers responded that the care provided was not sufficient because of the type and level of support needs involved. Care was described as insufficient to meet health or safety needs, or as insufficiently individualized. It is notable that the alternatives were not universally regarded as positive on the social side, with some Caregivers and Individuals describing the situations as creating loneliness, or that they “felt like jails.”

## **With rare exceptions, people would be willing to consider homes that include more than one person with a disability, but traditional group homes are not generally viewed as the answer.**

Survey and interview responses revealed that while it might seem clear enough what a *group home* is, that term suggests different things to different people, and these differences of understanding drive quite different responses to the question of whether group homes are an acceptable home for adults with developmental disabilities and HCNs. There were some responses which made clear that for some adults the nature of their challenges makes any sort of shared living arrangement difficult. This might be the case for those with extreme sensitivity to noise, difficulty with changes of routine, and so on.

More generally, though, for some the phrase “group home” suggested arrangements in which all residents run on the same schedule and take part in the same activities. While some responses suggested that Caregivers would accept this sort of arrangement if it were offered (e.g., “that’s all I ever really thought I had as an option ... I don’t know how many years we

have”), this was not because it was a *preferred* option. That sort of group home is viewed by almost everyone as insufficient to meet the needs of those with developmental disabilities and HCNs.

In the responses, an unfortunate divide can be discerned at this point. Some respondents feel “judged” because they are willing to consider arrangements where more than one person with a disability lives in a home, and that others have adopted a blanket rejection of group living, regarding group homes as too institutional and insufficiently person-centred. Those willing to consider group home options want to approach the inadequacy of standard group homes to meet the needs of the person they care for by improving them. In particular, they want group homes with more individualized and higher levels of support, more individualized activity, support so that the people who live in the house can make choices about their own lives, and so on.

On the other hand, some of those who reject the notion of a group home are not averse to *shared living arrangements*. Some, presumably, are skeptical about the prospects of modifying traditional group homes to make them suitably individualized. Key aspects of shared living arrangements, as distinct from group homes, involve the residents having considerable control over with whom they live, and control of practical details like arranging maintenance and hiring support workers, responsibilities that would rest upon the residents or their families/friends/supporters. It seems that, conceptually, the dividing line between a group home and a shared living arrangement is the question of control over these practical details around maintenance, employment, and the like. In a group home these are roles played by a third party (an “agency”). Some respondents suggested that it is precisely this handing off of responsibility that is a valuable aspect of group homes.

### **People are interested in “creative options,” but there are barriers.**

As noted, some Caregivers reported that options besides group homes have not previously been on their radar. This is not surprising – given the level of stress involved in being a caregiver, time to research housing options is obviously in short supply. Many, though, perceive a push for families to create their own housing options. Respondents identified a number of challenges to doing so.

- Finances. Being creative, especially given the need for individualization and significant supports identified above, will require money, which is not available. Moreover, as one participant noted, “often government funding comes with strings attached that don’t work for what you’re trying to achieve.”
- Personal support workers are needed to make many options viable. But good ones are in short supply because they are generally underpaid, overworked, and their training can be inconsistent.
- There is a lack of information about options that have been tried by others.
- The options and models touted as possibilities are aimed at a different population than those with developmental disabilities and HCNs, presuming that people are “higher functioning,” more physically able, more social, or in other ways easier to fit into an arrangement involving others who need support than are the adults that are the focus of this study.

## Summing Up

The evidence gathered in this small study in the Central West region of Ontario offers some stark lessons. While some would say that housing is already a crisis for adults with developmental disabilities and HCNs, things are clearly going to get worse, and soon. As a society, we should remember that being unprepared for unpleasant surprises often shows a blameworthy lack of prudence. To fail to address a problem that is obviously coming is a more serious failure.

This is not to understate the logistical and financial challenges of addressing the problem. The term ‘HCNs’ usefully categorizes a kind of need, one that explains why many approaches to creating homes of any generic sort are not going to work. Given the many ways that an adult can fall in the HCNs category, providing what people with developmental disabilities and HCNs with satisfactory homes will involve creating capacity for living spaces and supports to be thoroughly individualized. Investing now in an array of different approaches, including much more individualized group homes, other suitably supported shared living arrangements, and individual living arrangements for those who need and want them, involves a significant investment. This investment is well justified when one considers the human and financial costs of allowing people to go into crisis.

## 2. INTRODUCTION

In the wake of the closure of so-called long-term care facilities for people with developmental disabilities in Ontario - a process often referred to as “deinstitutionalization” - the Province of Ontario has relied extensively on families to provide homes (and other supports) for people with cognitive and developmental disabilities. With the exception of a small amount of funding for “innovating housing projects,” Ministry funding for housing options has been directed almost exclusively to traditional group homes, with these homes being run by service agencies, often agencies that also provide a range of other services. Traditional group homes, which tend to be inflexible and resemble one another in essential respects, are not satisfactory for many people. Moreover, very few new group homes have opened in recent years, so even this option has been available to very few, typically only after their lives go into crisis.

Evidence that this is no longer a viable approach, if ever it was, is not hard to find. For instance, in the face of 1,400 complaints from families of adults with developmental disability, the Ontario Ombudsman launched an investigation in November 2012. The resulting report, entitled *Nowhere to Turn*, was released in August 2016.<sup>4</sup> The report highlights 18 cases of adults with developmental disabilities who were left homeless, abused, abandoned, or inappropriately housed in hospitals, long-term care facilities, and jails. The study documented below indicates that similar situations are not hard to find today, four years later.

Recent steps taken by various arms of the Government of Ontario, and some of the social service agencies it funds, suggest some awareness of these problems and an intention to begin addressing them. Often these projects will pronounce themselves to have large goals to address systemic barriers to affordable housing.<sup>5</sup> This is obviously important and worthwhile work. Unfortunately, the large goals mean a focus on the barriers that confront everyone, or almost everyone, in the disadvantaged group. This entails that the work focuses on those whose support needs are “typical” for the group. This kind of approach, therefore, tends to leave out of the picture some of those most in need of support. A significant portion of adults with Autism Spectrum Disorder, for instance, have high and complex support needs

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<sup>4</sup> Paul Dubé, *Nowhere to Turn*, 2016.

<sup>5</sup> For example, see the “National Housing Co-Investment Fund,” <https://www.cmhc-schl.gc.ca/en/media-newsroom/news-releases/2019/government-canada-invests-affordable-housing-people-disabilities-hamilton>.

because of multiple health and neuro-developmental disorders, and live with social and communication challenges and hypersensitivities to most stimuli - making the task of finding suitable living arrangements uniquely difficult. The purpose of this research is to focus on the needs and desires of the people in this neglected group, and to consider what impact such needs have on the possibility of their finding satisfactory living arrangements. For the purposes of this study, we used the following working definition: a person has high, complex needs if, as a result of health and neuro-developmental disorders and social and communication challenges, they need 24/7 support where support is “never more than arms-length” away, that is, the person needs supports to be constantly at the ready, e.g., the person cannot be left alone in a house, even for a short time.

Existing housing options are inadequate for adults with developmental disabilities and high, complex needs in several ways. Most obvious, of course, is that for most adults with cognitive or developmental disabilities, there are simply no options outside of the homes maintained by their parents or family members (see §6). Even if there were more of them, many group homes are not equipped to meet the highly variable and intensive medical and other support needs of those with high, complex needs. Moreover, some prevalent models of “socially inclusive housing,” such as traditional agency-run group homes which tend to involve all members of a household having “group activities,” fails to account for the individual (and changing) goals, needs, and aspirations of the people who need supports to be able to live lives connected to their community.

The issue is increasingly urgent. Since Ontario’s deinstitutionalization process in the 1990s, the bulk of the support to those with developmental disabilities and high, complex needs has been provided by family members, usually parents. As everyone involved ages, exhaustion, depression, and despair, or simply age-related death, are increasingly a risk for caregivers. Increasing numbers of families can be expected to go into crisis in coming years.

In light of this urgency, this study seeks to offer a better understanding of the housing needs of adults with developmental disabilities and high, complex needs. This study was initiated by Waterloo Wellington Autistic Services (WWAS), in partnership with researchers at the University of Waterloo. The study focuses on a particular geographical region of Ontario (the Central West Region). This focus is motivated by the practical constraints of the study, namely the time and funding available, and the location of the funding organization and the

researchers. While we suspect that the results described below would be similar for other regions, some caution is of course warranted in making such generalizations.

The research was carried out by Elizabeth Guthrie, a PhD candidate at Waterloo, and Dr. Catherine Klausen, under the direction of Dr. David DeVidi, the principal investigator. It was funded by a Mitacs Accelerate Grant (which involved a matching contribution from WWAS) and with University of Waterloo research funds available to DeVidi.



## Methodology

The following report summarizes results of a study that gathered information from three sources: responses to two surveys, and a series of semi-structured qualitative interviews. One set of surveys was filled out by caregivers of adults with developmental disabilities and high complex needs, while also asking them directly how they came to know the needs and desires of the focus person. The other set of surveys was filled out, with or without communication supports, by individuals who self-identified as having developmental disabilities, and high, complex needs. Survey participants were selected using a “snowball sampling” technique, beginning with WWAS’s contact list of people they identified as likely falling in the target populations and encouraging recipients to share the survey with others in their personal networks who also might fall in those populations. Participants were chosen for interviews from among those who had initially completed the survey and indicated their willingness to be interviewed (yes to Q77). From those who selected “yes” to participate in an

interview, a subset was chosen in order to have representation along the various demographic dimensions, including the type of community in which they live (rural/small urban/large urban), gender, age, type of living arrangement, and level of experience with alternative living arrangements.

To reflect the source of information, this report will use the following terminology. We will say results are from “Caregivers” when it comes from those who self-identified as being the primary caregiver of an adult with developmental disabilities and high, complex needs. Caregivers completed the version of the survey designed for primary caregivers, and the interviews conducted were with members of this group. 79 participants responded to the Caregiver survey, with 53 of these surveys completed. Only the 53 completed surveys are used in the analysis below. Furthermore, 9 Caregivers participated in 8 interviews (one interview included two participants). These interviews were thematically analyzed using a grounded theory approach.

When results are indicated as being from “Individuals” this refers to surveys completed by people who self-identified as having developmental disabilities and high, complex needs. 19 people responded to the “Individual” version of the survey, and 11 of these surveys met the qualification of self-identifying to be someone with developmental disabilities and high complex needs (yes to Q2). These 11 responses are used below as a source of helpful insights and examples, but not to draw general conclusions due to the small sample size.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#41289). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or [ore-ceo@uwaterloo.ca](mailto:ore-ceo@uwaterloo.ca). Survey and interview questions are included in the appendix.

### 3. BASIC DEMOGRAPHIC INFORMATION

Out of 53 Caregiver participants who completed the survey, all considered themselves the primary caregiver of an adult with developmental disabilities and high, complex needs (i.e., 100% said yes to Q1). Of these participants, 64.8% were 55 years old and over at the time of participation, and the majority (82%) of Caregivers are the primary caregiver for an adult with high, complex needs between 18-34 years of age at the time of participation (see Figures 3.1

and 3.2 in appendices). Of those surveyed, the most common caregiving combination was a female who is a parent or close relative in the role of primary caregiver for an adult male (see Figures 3.3-3.5 in appendices).

The majority of Caregivers (71%) reported that they live in an urban environment, which for the purposes of this survey was defined as over 10,000 people (see Figure 3.6 in appendices). Furthermore, when asked about their current living situation, a strong majority (91%) of Caregivers indicated that the adult with high complex needs for whom they provide care lives at home with them (see Figure 3.7 in appendices). Although there is a wide range of ages (falling within 18-64) of adults with developmental disabilities and high, complex needs who live with family (see Figure 3.8 in appendices), of those surveyed the most common age of adults with developmental disabilities and high, complex needs living at home is 18-34. Furthermore, 13% of Caregivers indicated that they are caring for more than one adult with developmental disabilities and high, complex needs at the time of the survey (see Figure 3.9 in appendices).

Of the remaining 9% of Caregiver participants who selected “other” when asked to indicate the current living arrangement for the adult for whom they are a primary caregiver, some described the current living situation of the adult with developmental disabilities and high, complex needs as temporary, e.g., “indefinite temporary respite” and “...at the Center [sic] for addiction and mental health...waiting for a treatment bed or high need group home.” Others indicated a permanent alternative, such as the adult they provide care for had their “[o]wn home...with combination of some paid support about 15 percent of [the] time and parents direct support and coordination for the rest of the time.” Finally, some caregivers indicated a combination of housing, e.g., that the adult with developmental disabilities and high, complex needs lives in a “supported living home during weekdays, in the [family] home on the weekends and holidays.”

Out of 15 Individual survey participants who answered this question, 11 identified themselves with the phrase “I consider myself an adult with developmental disabilities and high, complex needs” (Q2). Of those who identified as an adult with developmental disabilities and high, complex needs, most of those who responded (50%) were between the ages of 18-34 and live with family in a small urban area, or urban city (see Figures 3.10-3.12 in appendices).

Of the Individuals who selected “other” when asked about their current living situation, one participant explained their living arrangement as having “lived in my own home with individualized support from my parents, some friends and some paid workers” for over two decades.

## Identifying Preferences

In response to being asked what language is spoken in the home, 94% of Caregiver survey respondents indicated they speak English in the home (Q24), and several (6) participants noted that the adult with high complex needs they provide care for does not speak with their voice (Q8). The information regarding the ability of the adult with high complex needs to communicate verbally was not asked for directly, so it is possible that the actual frequency is higher. However, that this information was volunteered is important to note. Every participant of the Individual survey who answered this question identified English as their first language (Q6).

The Caregiver survey includes questions asking about the preferences and desires of someone other than the person completing the survey, some of whom as just noted do not speak with their voices. We therefore asked Caregivers to describe how they formed their judgements about these preferences. Drawing from analysis of answers provided by Caregivers in surveys and interviews, Caregivers speak of communicating with the adult with developmental disabilities and high, complex needs via verbal communication, sign language, and forms of augmented and alternative communication such as software, supported typing, and using communication boards/symbols. Caregivers also noted their reliance on interpreting the adult’s body language, gestures and sounds, and familiarity with preferences due to observation of an adult’s reactions to different situations over time (e.g., consistently displaying enjoyment of particular activities) as the basis by which they discern the preferences of the adult for whom they provide care. The aspect of communication as it relates to awareness of the adult’s housing preferences was asked for directly in Q32 of the Caregiver survey (see Figure 3.13 below).

Q32 - In some of the questions below, we ask for your perceptions about, for instance, the desires of the person you provide care for. Please briefly explain how you know what they might desire with regards to their living arrangement:

Figure 3.13: Text of caregiver survey Q32

The themes that emerged within the answers to this question offered a range of confidence Caregivers had regarding their knowledge of the adult's preferences. Some Caregivers recorded that have had conversations about housing options with the adult in question, and so they were confident they understood the adult's preferences. Other participants referred to their extensive experience with interpreting the adult's preferences, and doing so with varying levels of confidence.

### Addressing Housing Preferences Directly

Several Caregivers responded to this question by referring to the ways they have directly learned the housing preferences of the adult for whom they support, to varying degrees of specificity. For instance, Caregivers stated that “[m]y [son/daughter] is able to communicate verbally” and has shared their living preferences, or that “[he/she] tells us” their housing preferences. Another Caregiver reported that, “[he/she] has consistently expressed [their] firm desire” for a particular living arrangement over many years by using augmentative and alternative communication. For other Caregivers, their awareness of the adult's housing preferences was described in more general terms. For example, one Caregiver answered this question by saying that “we’ve spoken about it what the future might look like for [them] if [they] didn’t live with us, mom and dad,” and thus they are familiar with the adult's preferences regarding living situations.

An Individual participant reported how they expressed their housing preferences directly when they stated that “[o]nce I had a way to communicate reliably, I was able to tell my family and friends what was wrong [with my current living arrangements] and to say I needed a home of my own.”

### History

For many Caregivers, their confidence that they know the housing preferences of the adult was the result of their experience with, and extensive knowledge of, the person. Many

Caregivers referred to their experience of being the adult's primary caregiver over the course of the person's entire life as the basis of this knowledge, rather than citing knowledge of housing preferences in particular. This kind of response included: "21 years of experience with my [son/daughter]. I am acutely aware of [their] needs"; "[a]fter a lifetime of looking after [them] (since birth) I'm pretty good at guessing or encouraging [them] to answer if [they] can verbally"; "[a]s [their] primary caregiver all [their] life I have a pretty good feel of [their] needs and wants."

One Caregiver noted that in addition to their experience covering an extensive length of time, the diverse nature of that experience was also relevant. One said, for instance, that "[t]hirty years experience care for, guiding [them] through hospitalization and school system, and involving our [son/daughter] in the community," is the basis of the Caregiver's confidence to know the adult's preferences. In particular, the quote implies that the varied situations the Caregiver has had with the adult gave the Caregiver a wide breadth of knowledge to draw from when determining the adult's housing preferences.

Some Caregiver participants described a broad vision guiding how they determine the adult's preferences. For instance, one Caregiver noted that "[w]e have a vision for [their] future that incorporates the ways [he/she] has preferred [their] home to be throughout [their] life." Another Caregiver mentioned that their knowledge of the adult's desires comes from "our 20-yr history of caring for [them], as well as our best understanding of what constitutes the 'good life'."

## System

The most frequent kind of response that Caregivers gave to Q32 (see Figure 3.13 above) was to describe practices that they relied upon to learn of the adult's preferences for other areas of life, or daily life more generally. Describing these established, general ways of learning the adult's preferences is presumably intended to suggest that the same methods were used to learn the adult's housing preferences and that the Caregiver is confident interpreting the preferences of the adult for whom they provide care.

Some Caregivers described this process of identifying the adult's preferences as being intentionally systematic. For instance, one participant described a process that included observation of the adult's reactions while they presented scenarios or aspects of scenarios to the adult in short and ongoing comparisons, and then ask them to indicate their preference

between options. This process included revisiting the topic multiple times. Another Caregiver described a similar process, but that “when topics are such that [he/she] is unable to fully understand and comprehend, as [their] parent we make the decision for [them].”

Other Caregivers described practical ways they gather information about the adult’s preferences. This included the adult using sign language, answering “yes/no” questions, using communication software, gestures, noises, and other body language. Some Caregivers indicated that they rely on a mix of several methods, as they need ways for “figuring out what [they] might like or want if [he/she] doesn’t have the words for what [he/she] wishes.” For example, Caregivers reported that “[he/she] uses gestures and noises to let us know what [he/she] wants”, and that “[he/she] indicates with crying and gestures when [he/she] is unhappy.” For some Caregivers, the interpretation of the adult’s gestures, noises, and other body language was the sole source of information to identify the adult’s preferences.

### Hesitant Optimism

Some Caregivers responded to this question by indicating that they don’t know the adult’s housing preferences. For instance, one participant answered that they “[d]on’t know [the individual’s housing preferences] since [the individual] cannot express [their] needs.” Another shared that they are “[n]ot sure, my [son/daughter] is non verbal. I feel [they] would like to be with people [their] own age but this is just a guess.” This idea of guessing was also mentioned when a Caregiver reported that “[m]y [son/daughter] is none verbal [sic]. I can only guess base on observation [sic].”

## Discussion

The majority of the caregivers surveyed were: female; caring for an adult male living in the same home; the adult male’s parent. It is important to note that there are situations where an adult with high complex needs had alternative housing arrangements (temporary or permanent), but this is the situation of a small minority of those surveyed. This combination of female family caregiver aligns with previous reports of caregiving for older adults with disabilities in Canada, with women being “overrepresented relative to the general population.”<sup>6</sup>

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<sup>6</sup> Janet Fast, “Caregiving for Older Adults with Disabilities: Present Costs, Future Challenges,” *IRRP Study* 58, (December 2015): 4, <http://irpp.org/wp-content/uploads/2015/12/study-no58.pdf>.

Caregivers reported that they base their knowledge of the adult’s desires and needs on many years of experience caring for them. Clearly, there is a substantial range in the methods available to those adults to articulate their desires and needs. Some Caregivers cited direct discussion with the adult about their living preferences, while others reported interpreting the adult’s non-verbal communication as an indication of preferences and expressed varying degrees of confidence in these interpretations. It is possible that the respondents claiming less awareness of an adult’s preferences are interpreting the question more narrowly than the other participants. Many participants answered the question as a general question about how they learn any of the adult’s preferences, whereas others answered it in a way that addressed their awareness about the adult’s housing preferences in particular. Furthermore, since (according to Caregiver responses) 68% of adults do not have experience with living accommodations other than their current situation (Q50), it is possible that this lack of experience translates into a lack of opportunity to learn about an adult’s preferences from observing their responses to other living accommodations.

## 4. HIGH COMPLEX NEEDS – RESPONSE TO WORKING DEFINITION

Caregivers were asked whether they agreed with the working definition of “high complex needs” as provided in the survey (see Figure 4.1 below):

Q33 - We define high, complex needs as: A person has high, complex needs if, as a result of health and neuro-developmental disorders and social and communication challenges, they need 24/7 support where support is “never more than arms-length” away, that is, the person needs supports to be constantly at the ready, e.g. the person cannot be left alone in a house, even for a short time. If your definition is different, please briefly describe how you define “high complex needs”?

Figure 4.1: Text of Caregiver survey Q33

In response to Q33, some Caregiver participants noted their direct agreement with this definition: for instance, “This is a good description, and it fits my [son/daughter].” No participant directly disagreed with the definition. An analysis of the comments made by the participants in response to “please briefly describe how you define ‘high, complex needs’,”

found that most comments fall within three main categories. The first are descriptions that offer greater insight into the *complexity* of the needs, that is, what makes the needs complex. The second are comments that further elaborate on the reasons for *why* an adult has high and complex needs, offering a picture of the different circumstances that lead to an adult being considered part of this subgroup. The third category of comments further elaborate on the *kind of care* needed.

## Complexity

Some answers provided by Caregivers gave further insight into what “complex” represents in the working definition. The majority of comments that fell within this category gave examples of the complexity of the adult’s need, describing multiple overlapping conditions that have mental and physical health needs associated with them. As one participant said, high, complex needs includes “physical, mental and [...] medical disabilities as well.” The unique combinations and interplay result in complex needs.

Other participants offered more general comments about complexity. For instance, one participant noted that an adult’s needs are “highly individualized,” and so methods to meet those needs are likewise highly individualized and require “trained support which could be [a] team of people bringing with them their different strengths and community connection.” This quote calls attention to how the complex needs are unique to the adult, and so one-size-fits-all approaches to meeting those needs are unlikely to succeed. Furthermore, this participant seems to be highlighting the role of others - beyond a primary caregiver - must contribute to meeting an adult’s needs.

Another participant noted that their understanding of high, complex needs includes the element that “the behavioural, cognitive and/or medical needs are a barrier to others in the community offering their help.” Here, the participant seems to be highlighting some restrictive, or limiting, consequences of the complexity of an adult’s needs as it relates to possible sources of support. This quote implies that the complexity of the needs themselves can sometimes preclude community members from offering help; complex needs can limit what sources of support are possible.

## Reasons for 24/7 Support

In their answers to Q33, many Caregiver participants offered descriptions of circumstances that illustrate *why* the adult for whom they provide care has high, complex needs. Several elaborated on the component of “health” in the initial definition. The additions to health circumstances include dual-diagnosis, specialized diet, medical fragility, and mental illness. For instance, one participant noted that “extreme extreme high anxiety [sic] disorder” is a large part of why they consider the adult they care for as having high, complex needs. Of course, such answers do not tell us anything directly about the suitability of the *definition* of high, complex needs, since none of these particular conditions are a necessary part of high, complex needs. Nevertheless, these responses offer important context, indicating the range of scenarios that participants experience within this category.

## Nature of 24/7 Support Needed

The majority of responses to Q33 from Caregiver participants included a description of the support that the adult in their care requires, offering examples of the kind of care needed 24/7. Themes that emerged from analysis of these descriptions are discussed below.

### Social Support

Many responses gave insight into a Caregiver’s experience supporting an adult with “social challenges.” Participants noted that the adults with developmental disabilities they provide care for need support to make social connections. For instance, one participant said that the adult in their life “[r]equires consistent programming and activity to ensure growth and to have a sense of ‘purpose’.” But the notion of “social challenges” also includes the need for support to avoid interpersonal harms, not only providing opportunities for positive social experiences. For instance, this might include preventing someone from taking advantage of the adult with developmental disabilities.

### Communication Support

A small number of participants mentioned that the adult’s inability to identify and adequately respond to emergencies (e.g., call 911) demonstrates an important need for support. Although this is related to the mention of “communication challenges” in the initial working definition, its connection to safety is worth noting.

## Personal Care

Many Caregiver responses clustered around the support needed for personal care activities, and what in healthcare are called “activities of daily living” (or ADLs).<sup>7</sup> Many participants spoke of care needs that conveyed familiarity with this term.

Some participants elaborated on the needs of care by describing their role in supporting the adult they care for in support to achieve their ‘ADLs’, or “activities of daily living,” using this term explicitly. According to several responses, the role of the Caregiver in relation to ADLs included “assistance with,” and “supervision for,” *all* activities of daily living. In the health care context, which was implied or directly mentioned by many participants, ADLs include bathing, dressing, grooming, mouth care, toileting, transferring bed/chair, walking, climbing stairs, and eating. One participant summed it up as “1:1 care.” The Caregivers’ role in meeting adults’ need for personal care was the most common ADL mentioned. This includes toileting (including disposable briefs), “washing, shaving, [and] proper personal hygiene.”

Another noteworthy category of Caregiver response was the adult’s need for support to ensure physical safety as part of the caregiving role. One participant stated that the needs of the adult they care for include support to avoid “flight risk, risk of self-injury or harm from others who would take unfair advantage.” Further, a small number of participants mentioned the adult’s need for support to manage their finances.<sup>8</sup> This could be interpreted as falling within the category of support to avoid circumstances in which other would take unfair advantage, but it is more likely in reference to all financial matters, not only guarding against misuse.

Caregiver participants used the words “assistance,” “supervision,” “monitoring,” and “coaching” to describe their role in daily tasks with the adult they provide care for. Although each description implies slightly different degrees of Caregiver involvement for a given task,

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<sup>7</sup> Activities of Daily Living, often referred to as ADLs is a term used in healthcare to describe the daily personal tasks that an person must do every day, with one’s ability to perform these activities forming a scale representing the person’s level of need for support. ADLs include bathing, dressing, grooming, mouth care, toileting, transferring bed/chair, walking, climbing stairs, and eating. IADLs, or *instrumental* activities of daily living include shopping, cooking, managing medications, using phones and looking up numbers, doing housework, doing laundry, driving or using public transportation, and managing finances. ADLs and IADLs are often evaluated on a scale of “independent”, “needs help”, “dependent”, and “cannot do”. For more, see A.K. Troyer, “Activities of Daily Living (ADL),” in *Encyclopedia of Clinical Neuropsychology*, eds. J.S. Kreutzer, J. DeLuca, and B. Caplan (New York: Springer, 2011).

<sup>8</sup> As previously noted, managing finances is considered an IADL.

each require the attention and involvement of a Caregiver over the course of the many activities.

## Important Modification: Need for Continual Support

The responses to Q33 surveyed so far suggests a way to better understand the definition of “high, complex needs.” As we will see below, this clarification aids in understanding the aspects of the lives of adults with developmental disabilities and high, complex needs that specifically relate to their housing options. The responses summarized above do not challenge the working definition of high, complex needs, but they do offer a glimpse into the diversity of situations the category includes. An important aspect of these situations that is arguably not adequately captured by the initial working definition is that some adults always, and many adults at some times, need attentive and proactive care, which is to say they require something that goes beyond having supports *available 24/7*.

The suggestion of the working definition was that supports must be “constantly at the ready,” which implies that they are available *when needed*. Since the needs may arise at any time, the support must be available at any time, *24/7*. However, for adults who need *consistent, ongoing, and proactive* support, support “constantly at the ready” seems to leave out a crucial part of the situation. It fails to recognize the variety of ways Caregivers provide support continually throughout the day in ways that are not in response to one particular need, and that Caregivers are doing so in addition to the support offered when particular needs do arise (e.g., toileting, medical event etc.).

This additional level of constant attention is reflected in participants’ comments that the adult they care for “cannot care for themselves without *monitoring* or coaching on a daily basis” (emphasis added), or that they “must keep an eye out for any change in health as now [their son or daughter has] many medical issues that need watching for even small hints that there is a problem.” Caregiver participants also described the need to control and avoid particular sensory stimuli in the home, such as controlling noise and busyness, to meet the adult’s highly sensitive environmental needs.

This ongoing attentive nature of such support is not always easily distinguished from simply meeting a person’s needs as they arise, and there is probably a continuum of cases

here. But in the clearest examples, such as supporting someone to bathe vs. ongoing monitoring of the temperature of the environment, we can see a different kind of attentiveness and constant involvement that is required to keep a home environment finely tuned so that things go smoothly. Such support is more proactive than reactive to an adult's needs. We therefore suggest that to accurately reflect the lived experience of Caregivers and adults, the definition of high, complex needs should include mention of the varying degrees to which individuals need *consistent and proactive* support, and not only that supports must be “constantly at the ready.”

Incorporating this into the initial working definition:

We define high, complex needs as: A person has high, complex needs if, as a result of health (including mental health) and neuro-developmental disorders and social and communication challenges, they need 24/7 support where support is “never more than arms-length” away. For some people at all times and for some people at some times, this is a need for continual and proactive support – that is, the person needs support to be constantly at the ready, e.g., the person cannot be left alone in a house, even for a short time, and they require a range of proactive and ongoing attentive support for themselves and managing their environment.

With this updated definition, the responses to Q33 (see Figure 4.1 above) that directly relate to the statement that the adult “cannot be left alone,” can be better interpreted.

## “Cannot Be Left Alone”

Caregiver participants elaborated on the notion of the adult not being left alone, and what it means to have support “within arm’s reach.” This included statements that short times alone may be possible, for instance that an adult needs “total care but if I run to the corner store for 5-10 minutes [they] should be OK only because [they are] happy [with an activity] and shouldn’t require immediate attention.” As one participant put it, “very short periods of time alone may be possible,” but like other Caregiver participants who indicated this, the adult would need certain things in place (food, activity, certain time of day, etc.), and that even a short period alone comes with the potential for harm (e.g., “flight risk”), so “support is needed 24/7.” One participant stretched the time to include the adult being left alone for half an hour

“if occupied,” but noted that even then there is a risk to the adult’s well-being, and implied that they are unlikely to leave the person alone for that long.

Overall, even those answers that indicated that some time “alone” was possible, qualified the suggestion by noting that it is possible only after a significant degree of planning. However, due to the risks involved it was not often considered a feasible option. Coupled with the clarified definition of high, complex needs that includes varying degrees of ongoing and proactive need for care, we can see that these short periods of possible “alone” time are consistent with the definition: someone may not need to eat, use the washroom, or have any kind of emergency in a short amount of time, but the ongoing needs for attentive monitoring and proactive support remains, and the removal of *that* support is likely to have negative consequences for the adult.

## Discussion

The working definition used in the survey was developed to articulate the key aspect of what differentiates members of this particular group who, while considered part of the larger demographic of adults with developmental disabilities in Ontario, historically have felt left out of conversations that inform housing recommendations (see §2). It is not a distinct category we’ve drawn from the literature. Rather, it is a category that is helpful to conceptualize a distinctive range of needs and desires people within the category may share with respect to suitable homes, in hope that such knowledge can help with the crafting of appropriate mechanisms and policies that would allow them to find those homes. The responses from the participants shed light on whether the category, as provisionally defined, is suitable for this conceptual role.

The specific reasons for *why* adults need care and support 24/7 vary widely, as does the nature of support and care that adults require to have those needs met. The responses offered by the Caregivers to further describe their understanding of “high, complex needs” include a great deal of insight into what the needs and kinds of support required look like on a daily basis. Although these do not expand the definition, they provide the necessary information to infer what is needed in adequate living arrangements.

Of course, these needs are difficult to quantify, since a particular need can be experienced a number of ways depending on the context. For example, where we live has a large bearing on how particular needs are experienced. Consider the degree of concern associated with an adult prone to wandering. If someone lives in a densely populated urban area with high levels of traffic for instance, wandering would be much more of a concern than someone who lives on a farm with more space and a number of employees present to contribute to an adult's safety. Likewise, then, whether particular personal characteristics constitute high, complex needs may in some cases depend on factors such as where someone lives. Having high, complex needs, is not an intrinsic feature a person either has or doesn't have. But this is compatible with the notion being useful for analytic purposes; since the analytic purposes are ones that involve highly personal aspects of some people's lives, it is important and heartening that people saw the provisional definition as one they could identify with.

By incorporating the *ongoing and proactive* aspect of support that some respondents identified as an important requirement beyond the active and responsive support caregivers provide, we are in a better position to infer what different adults are likely to need in a living environment. That is, we are poised to identify why some options will be inadequate for some with high, complex needs but not for others. If a living arrangement provides the active and responsive forms of support for an adult (e.g., having someone nearby and aware, who checks in at particular times), but fails to provide the ongoing and proactive support that some people need at all times, and others need some of the time, it will not be a suitable arrangement, and may leave the person at grave risk of harm.

## 5. PRACTICAL IMPLICATIONS: SUPPORT NEEDED IN THE HOME

This section focuses on the practical implications of providing support for someone with high, complex needs, which is now understood as entailing 24/7 support both in a proactive way to varying degrees, as well as in a responsive manner to the adult's needs as they arise.

## Caregiver Results

Question 45 of the Caregiver survey asked participants about the kinds of supports a home needs to offer to be suitable for the adult they care for. The responses draw a picture of the kinds of support that needs to be available at all times. The question offered participants the broad support categories of “safety and security,” “healthcare supports,” “dietary supports,” and “other,” with the instruction to “select all that apply.” The need for safety and security supports rated the highest by a small margin, followed by healthcare supports, dietary supports, and then “other” (see Figure 5.1 below).

Many descriptions of the “other” kinds of support fell within the parameters of personal care, and included “[he/she] wears diapers and need to take [them] to washroom every hour”; “24 hour care - dressing, diapering, bathing etc... G-Tube feeding - 4 x day Repositioning from bed to wheelchair and getting ready for outings etc....”; “...how to dress for weather, to shower, to properly bathe (shampoo, wash body, brush teeth, put on deodorant).” Hence, Caregiver participants mentioned the adult’s need for support to perform activities of daily living, something addressed in the previous section.

Needs related to maintaining an adult’s environment also emerged as a theme of the kind of support required for a home to work well, and fall within the scope of ongoing and proactive care articulated above. Caregiver participants included the need to control stimuli in the home of the adult with high, complex needs as a form of support required for the home to function well. As one Caregiver explained, it is the need for a “controlled environment that limits or prevents sensory issues to become a significant issue: ie. noise, smell, light, temperature, high levels of activity - these must be controlled and minimized,” and another participant shared that the adult they provide care for has “many environmental needs, [...], temperature, [...and] temperature regulated transportation.” The support to meet these needs may be offered at particular times, such as providing support in response to an intrusive event or planning to have supports in place for particular times, but it also includes proactive monitoring of the adult’s environment to avoid these kinds of events from occurring as much as possible.

Another category that emerged as a theme within the “other” kind of support in a home was an adult’s need for support throughout the activities of their day, and in a way that goes beyond activities of personal care. Caregivers described examples of both responsive and

proactive support: the planning or arranging of activities, providing support with “[d]aily structure” and routine, and “constant reminder of days activities,” as well as the content of those activities. Relatedly, one Caregiver participant noted the need for a “community connector,” indicating an adult’s need for support to have ongoing opportunities to connect with others. The need to be sensitive to the nature and time-appropriateness of the activities was also mentioned, as one participant noted that the adult for whom they provide care needs “to be constantly stimulated to be happy...” and that part of supporting someone in their daily activities requires them to monitor the adult’s energy. The seamless combination of responsive and proactive support Caregivers provide is demonstrated here, in the case of arranging and reminding about daily activities while also monitoring an adult’s energy levels and anticipating their needs with respect to facilitating those activities.

Finally, support for communication was highlighted as an “other” need for support in the home. One Caregiver participant stated that communication supports for the adult with high, complex needs were “vital.” Another Caregiver implied the importance of support to communicate when they shared that the adult “[w]ill become extremely violent (physically) when [they] can not [sic] communicate what desired or needs [sic],” pointing to the possible consequences of not having adequate communication support.

## Individual Results

Results of the survey completed by Individuals who self-identify as having high, complex needs showed a very similar rating of the kinds of support needed in their homes as found in Caregiver responses. Similarly to the Caregiver survey results, “safety and security supports” rated slightly higher than other kinds of support, with the difference from Caregiver results that “dietary supports,” “other supports,” and “healthcare supports” tied close behind (see Figure 5.1 below).

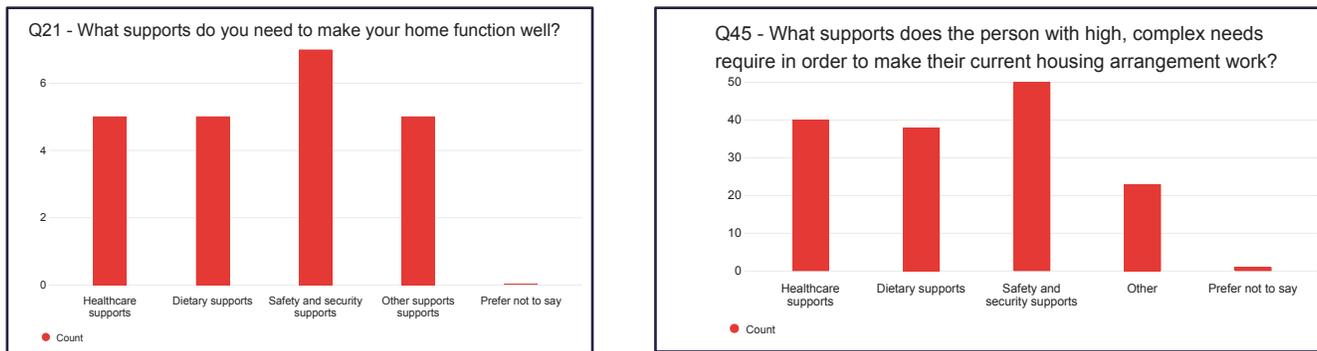


Figure 5.1: Individual responses to Q21 (L) beside Caregiver responses to Q45 (R)

In response to the survey prompt to explain the “other supports,” Individuals included the need for communication support (technology, strategies, etc.), support “within arm’s reach,” and support for larger life goals. The last mentioned, “support for larger life goals,” is important to highlight, as it demonstrates a shift in perspective from focusing on the daily needs to a larger picture of one’s life. According to Individual responses to Q11, the majority (but not all) of Individuals surveyed live with family (see Figure 3.11 in appendices), and so most of these supports are being provided in the Individual’s family home.

## Discussion

Caregiver and Individual responses to questions about what support is needed in a living arrangement (Caregiver survey Q45, Individual survey Q11) offer the practical implications of the definition of high, complex needs as it relates to what is required in one’s home for it to function well. Adequate supports in a home include support for safety and security, healthcare, and dietary needs, as well as support for personal care, constant environment management, social support and support to communicate. In addition to these daily forms of support, Individuals noted that they also need support for the larger aspects of their lives, such as defining and pursuing larger life goals. Further, according to the updated definition, the support is needed at home both in responsive forms - as when an adult has a need the Caregiver is present to provide support - and in a proactive monitoring sense of providing care. These answers represent the kinds of support the Caregivers surveyed are providing to make a living situation function well, at present usually in the family home, but they also tell us what would need to be provided in other living arrangements.

## 6. NEED FOR ADEQUATE HOUSING

The surveys also sought information about the impact the caregiver role has on Caregivers and about perceptions about what changes will be needed in the foreseeable future.

Of the participants who completed the Caregiver survey, 63% indicated that there are reasons that the current living arrangement will need to change in the foreseeable future, and only 13% said there is no reason for a foreseeable change (see Figure 6.1 in appendices). When Individuals who identified as having developmental disabilities and high, complex needs answered this question (Q27), all those that live with family (Q11) answered “yes” or “maybe” to there being reasons for a change of living arrangements in the foreseeable future (see Figure 6.2 in appendices).

When looking at the Caregiver responses for whether there are reasons that their current living arrangements will need to change in conjunction with *where* the adult they care for currently lives, responses showed that the majority of participants who said that the adult they care for lives at *home* also said that there will be a need for change in the foreseeable future (see Figure 6.3 below). However, it is worth noting that participants within both the “with family” and the “other” categories of current living situations reported a foreseeable need for change, indicating not just Caregivers who provide care in the family home recognize a need for change in living accommodations in the foreseeable future.

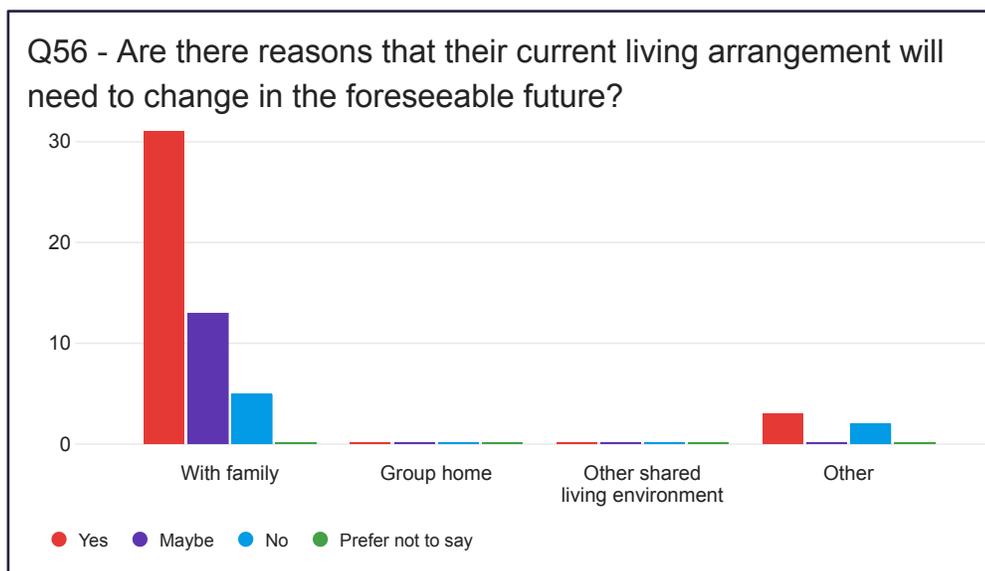


Figure 6.3: Caregiver responses to Q56 with a breakout of *where* the adult with high complex needs lives (Q36)

By analyzing the relationship between the age of the adult with developmental disabilities and high, complex needs and the number of Caregivers selecting “yes” to a foreseeable need for change in the living arrangement, we see a significant foreseeable need for change throughout each age category (see Figure 6.4 below). This goes against assumptions that change is needed only as adults with high complex needs grow older. It is also pertinent to mention that it is not only as Caregivers advance in years that a foreseeable change is needed, as Caregivers of most age categories indicated a foreseeable need for change (see Figure 6.5 below). Hence, rather than assuming age as the sole or predominant determining factor, the need for change is better understood in light of the documented nature and extent of responsive and proactive support provided by Caregivers.

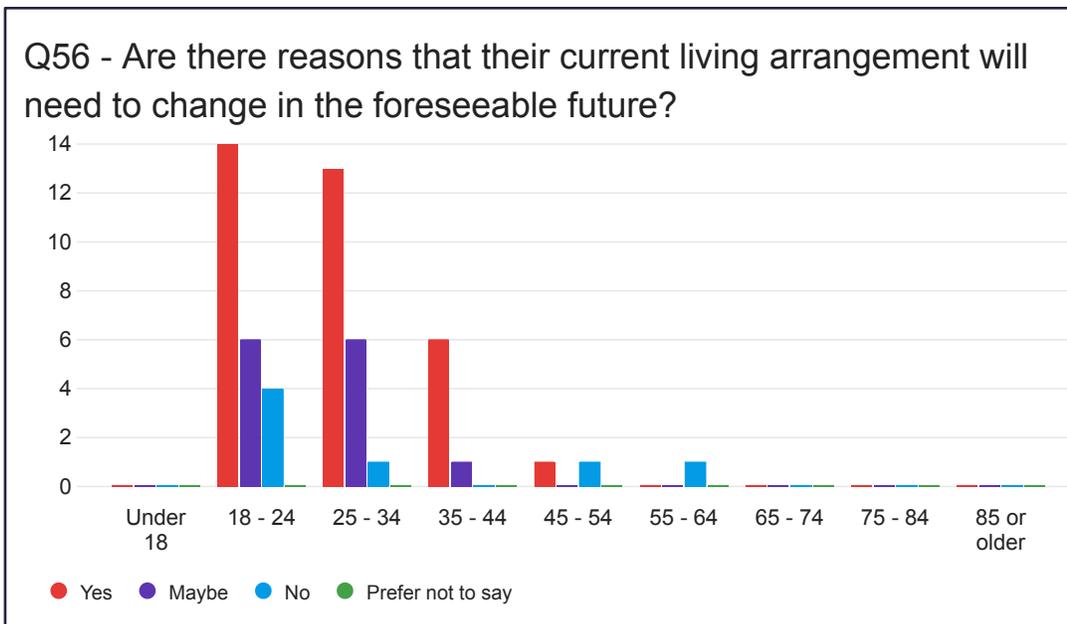


Figure 6.4: Caregiver responses to Q56 with a breakout of age of individual with high, complex needs (Q4)

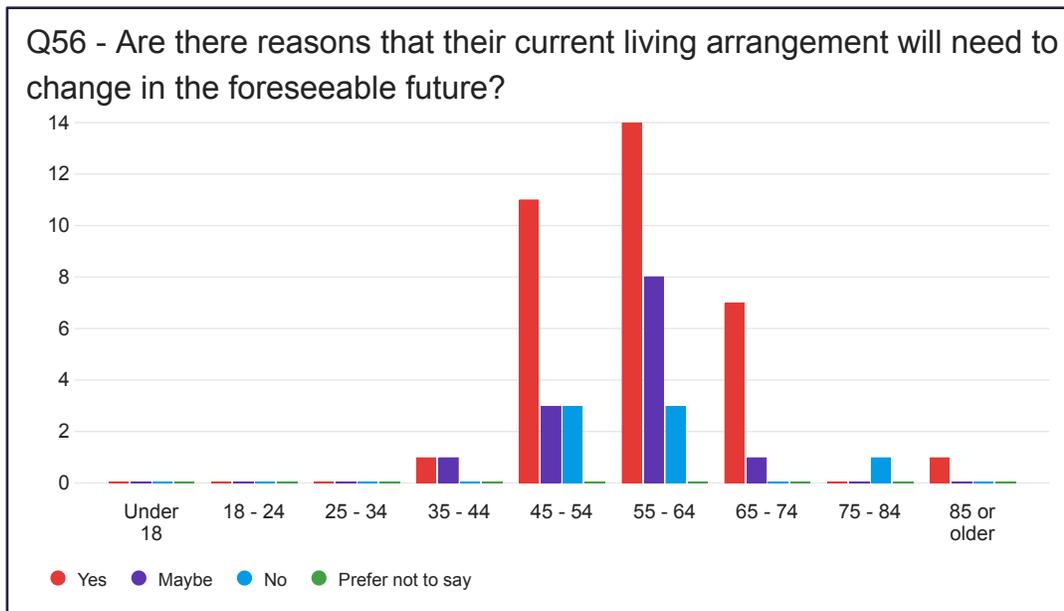


Figure 6.5: Caregiver responses to Q56 with a breakout of the age of caregiver (Q21)

Regarding the reasons Caregivers selected as to why there is a foreseeable need for change in living arrangements, the majority of participants of the Caregiver survey indicated that it is because “current caregivers are ageing/exhausted will be unable to continue” (Q71). When asked whether there are any housing options that can be accessed, the majority of Caregiver participants said “no.” It is instructive to note the large majority of Caregivers who said that the reason for change is aging or exhaustion who also indicated that there are no other housing options available (Q72; see Figure 6.6 below).

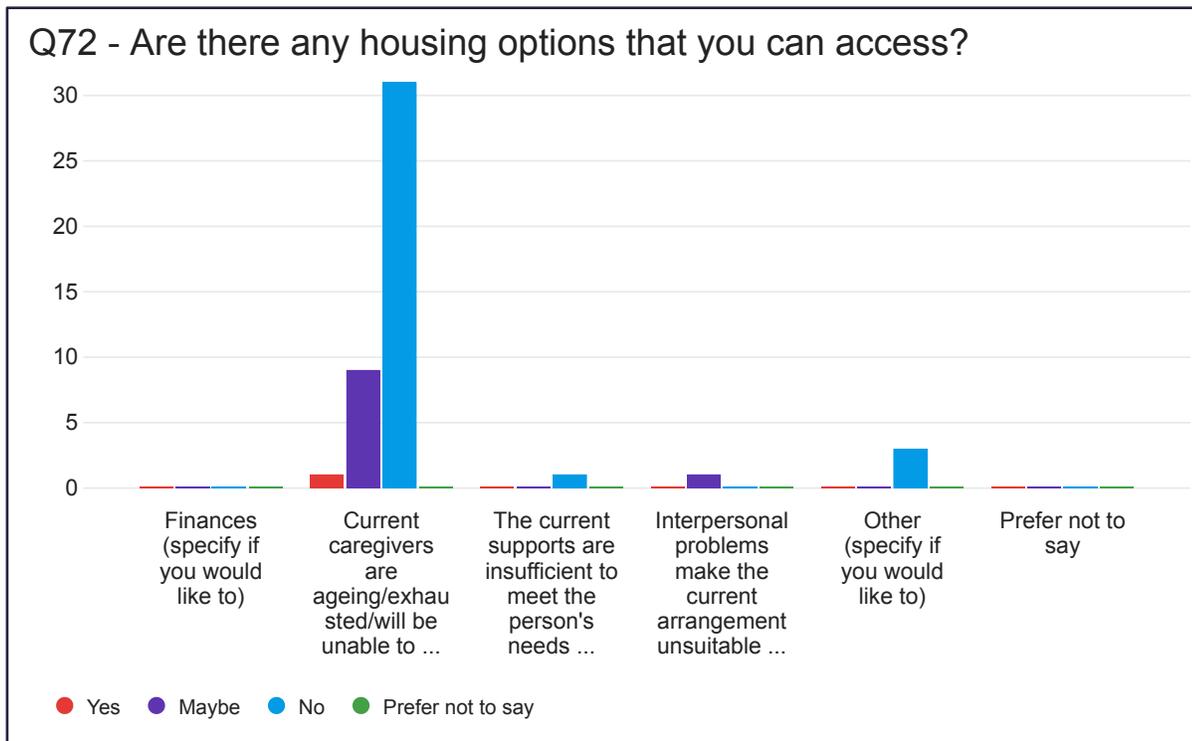


Figure 6.6: Caregiver responses to whether there are any options to access (Q72) with a breakout of the reasons indicated for foreseeable change (Q71)

Furthermore, when viewing the reasons for foreseeable change sorted by the current accommodations, of those participants who care for an adult with developmental disabilities and high-complex needs at home, the most frequent reason given for a foreseeable need to change accommodations was that “current caregivers are aging/exhausted/will be unable to continue” (see Figure 6.7 below). Of the Individuals with high, complex needs who answered the question “what are or might be the reasons that your current living arrangement may need to change?” (Q48), one mentioned to gain greater independence. Relatedly, a Caregiver participant noted that the downside of not securing other living arrangements was the lack of opportunity for their son or daughter to develop new skills and grow in independence. Answers such as these draw attention to the larger scope of adults’ lives that are impacted by changing their housing situations.

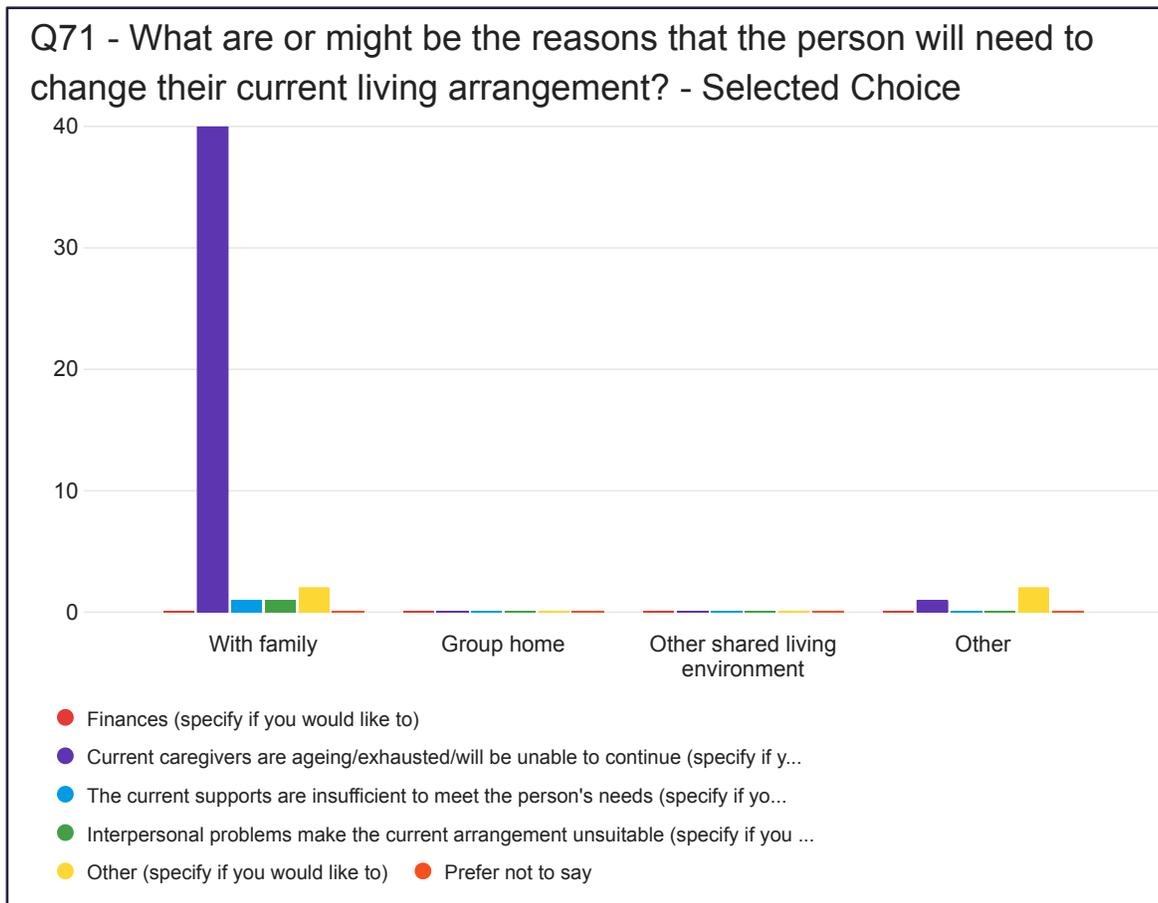


Figure 6.7: Caregiver responses to reasons for change (Q71) with a breakout of where the individual with high, complex needs currently lives (Q36)

When these reasons for foreseeable change (Caregiver survey Q71) are analyzed through the filter of the age of the Caregiver (Q21), we see that “current caregivers are ageing/exhausted/will be unable to continue” is not limited to a particular age category (see Figure 6.8 below). It is the reason for change selected most often throughout each of the age groups of Caregivers who participated in the survey. Continuing the focus on age, the reported lack of housing options is not limited to one age group of adults with developmental disabilities and high, complex needs. Caregivers who support an adult with high complex needs between 18-24 years old reported the highest comparative distribution of “no” for indicating whether there are possible housing options they can access (see Figure 6.10 below). And as noted above, Caregivers of 18-24-year-old individuals reported high rates of having a foreseeable change of living arrangements in the future (see Figure 6.4 below). Once again, this demonstrates that the indicating that current living arrangement is unsustainable is more an indication of the strain of providing 24/7 supports than merely of the ages of those involved.

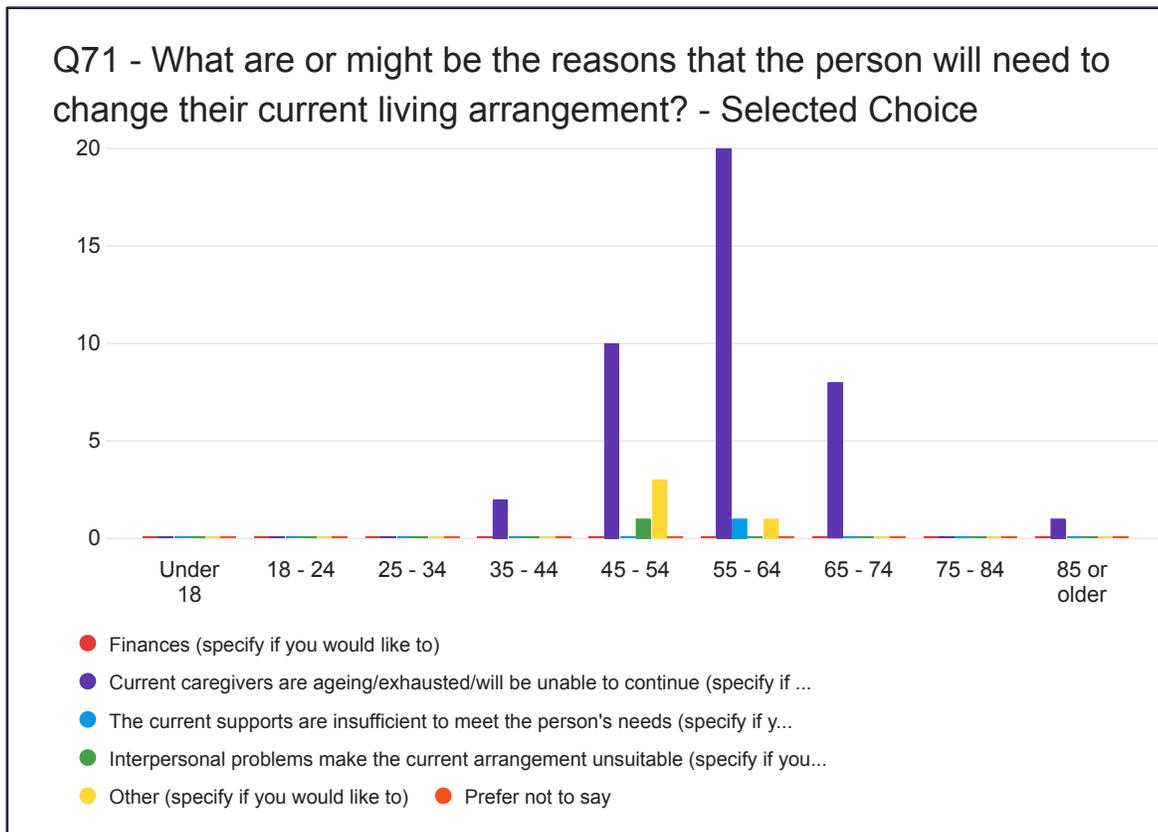


Figure 6.8: Caregiver responses to Q71 with a breakout of caregiver age (Q21)

Given the discussion on the kinds of support provided to make an adult's home function well, it is not a surprise that Caregivers identified that this impacts their lives "a great deal" (Q61 "How much does living with and/or caring for someone with high complex needs affect your daily life?" see Figure 6.9 below). It is worth noting that it is not only when adults live with family that providing support for them impacts the Caregivers' daily lives "a great deal," possibly referring to the high involvement of the Caregiver to plan for and provide care whether or not the adult lives at home.

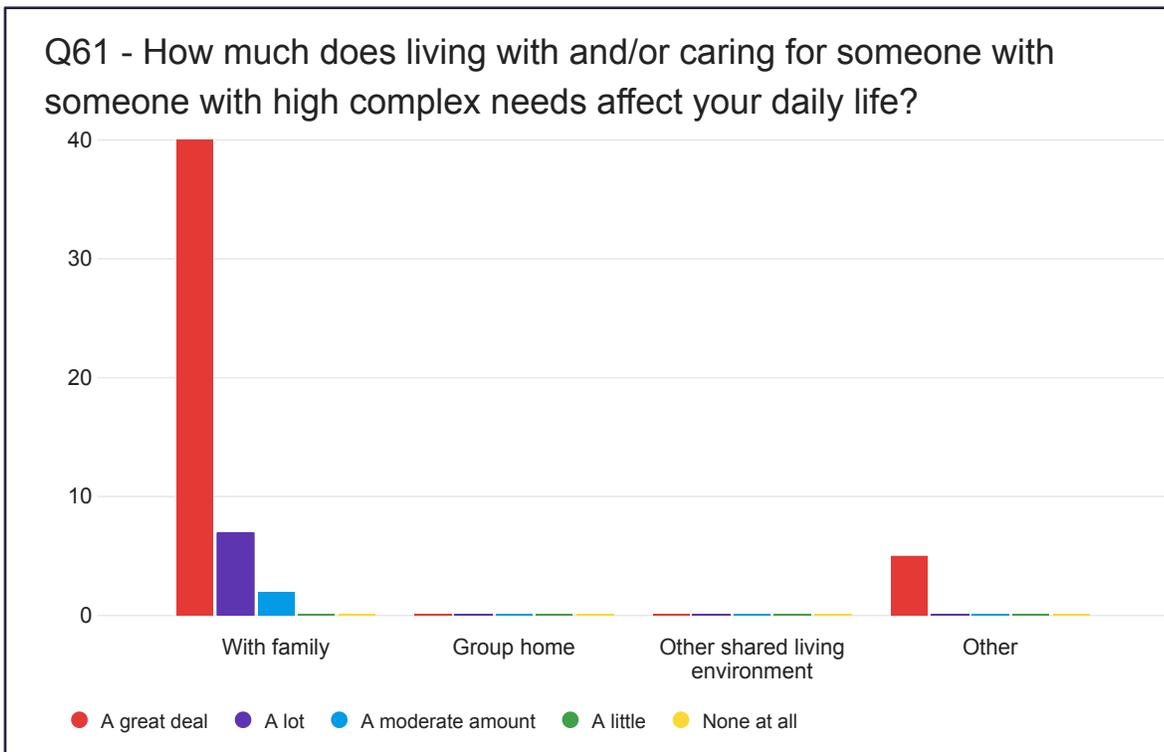


Figure 6.9: Caregiver responses to Q61, with breakout of *where* the adult currently lives (Q36)

Looking more broadly at the challenges mentioned by Caregivers in surveys and interviews that likely relate to selecting that they will be unable to continue in their role, Caregivers identified a variety of economic, emotional and physical health strains involved in caregiving. Also, given that the majority of primary Caregivers are women, the results of this study confirm previous findings that women are reported to spend “more time on care tasks” such as personal and medical care “that tend to be more time consuming and to allow for less flexible scheduling.”<sup>9</sup> This has clear implications for Caregiver’s professional lives. Caregivers mentioned constraints on their professional lives in the form of lack of ability to travel for work, restricted work availability, and having to leave employment altogether to provide care. Some Caregivers noted that this has resulted in financial constraints, leading to a decreased ability to hire additional support staff. When this decreased ability to hire additional help is combined with Caregiver comments about burnout, sleep deprivation, illness, and injury, some of the contributing factors captured in a response of “caregiver is aging/exhausted/will be unable to continue” become clearer.

To reiterate, it is not *only* aging parents with aging individuals with high, complex needs who foresee a change in living arrangements due to aging and burnout. Although aging

<sup>9</sup> Fast, “Caregiving for Older Adults with Disabilities,” 4.

obviously presents unique difficulties and considerations, advanced age itself is not necessary for burnout and unsustainability of living arrangements. Rather, Caregivers of a range of ages, providing care to adults over a wide range of ages, foresee a need for change of living arrangements due to being “aging/exhausted/will be unable to continue,” and they also perceive an absence of options to make the change.

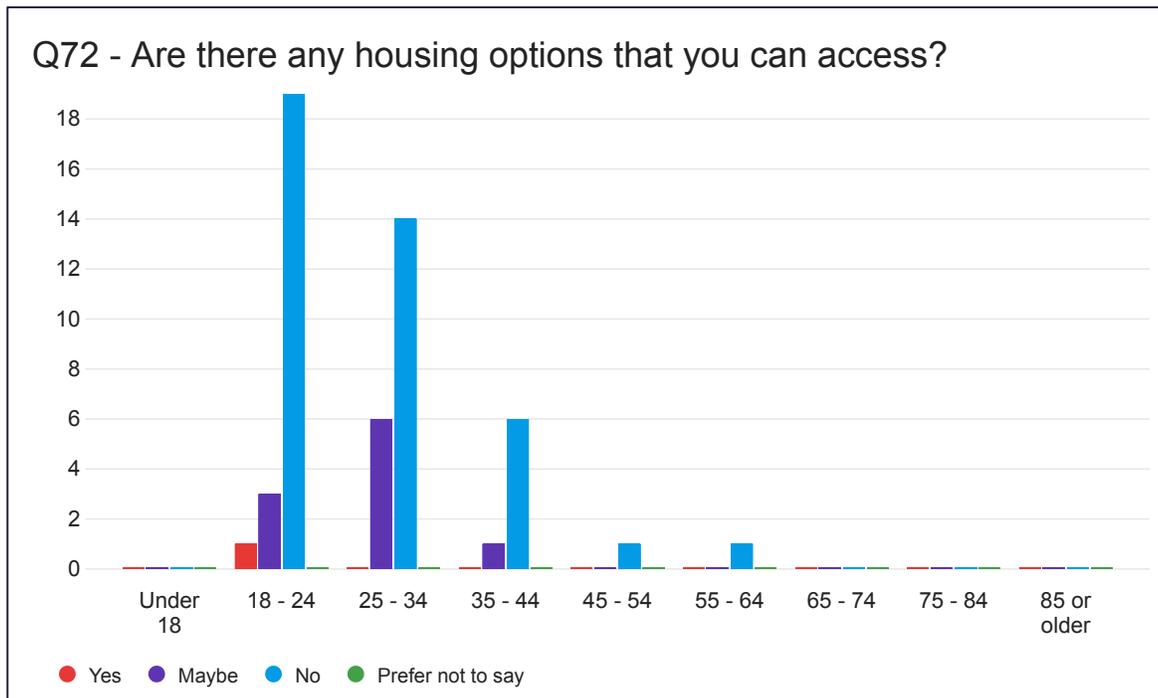


Figure 6.10: Caregiver response to whether there are housing options (Q72), with a breakout of the individual's age (Q4)

## Discussion

Drawing these answers together with previous results, the majority of Caregivers who participated in this study provide responsive and proactive support in the family home that impacts their daily lives a great deal. The majority of Caregivers have a foreseeable need to change living accommodations due to aging or Caregiver burnout, which is not restricted by age of Caregiver or of the adult they provide care for, but most do not perceive any viable options. This paints a picture that is all too similar to the Ombudsmen's 2016 report.

## 7. ALTERNATIVES

In order to gather insight into what housing options, if available, would be viable solutions, the surveys and interviews asked what other housing experiences individuals have had and the outcomes of those experiences.

Of the Caregivers who participated in the survey, 31% of them indicated that the adult with high, complex needs has experience living in arrangements other than the current ones (see Figure 7.1 below; the current living situation being predominantly at home (91% in Caregiver survey)).

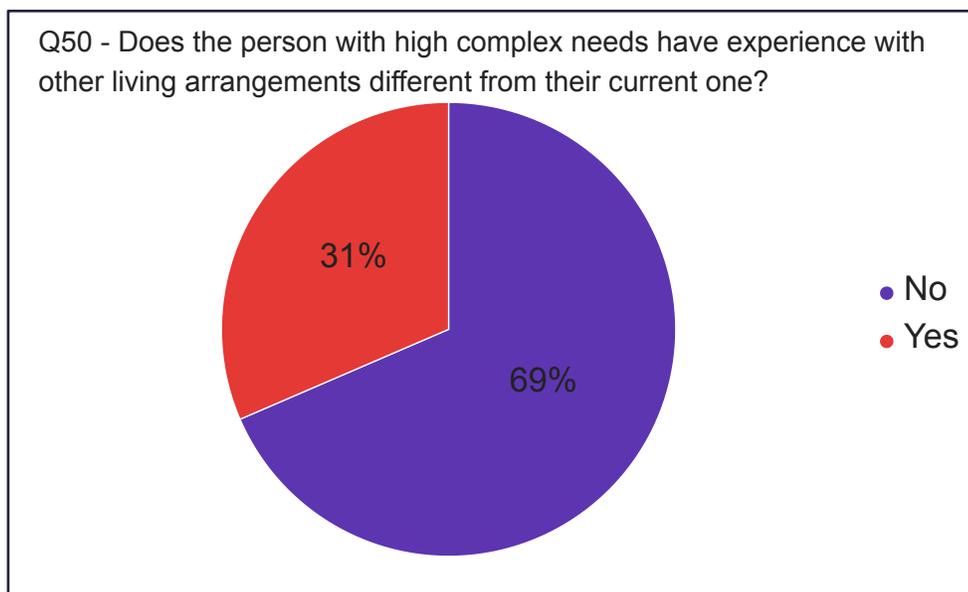


Figure 7.1: Caregiver responses to Q50

Of the 31% of Caregivers who said the adult for whom they provide care has lived elsewhere, participants indicated the adult they support has experience with a range of accommodations (see Figure 7.2 below).

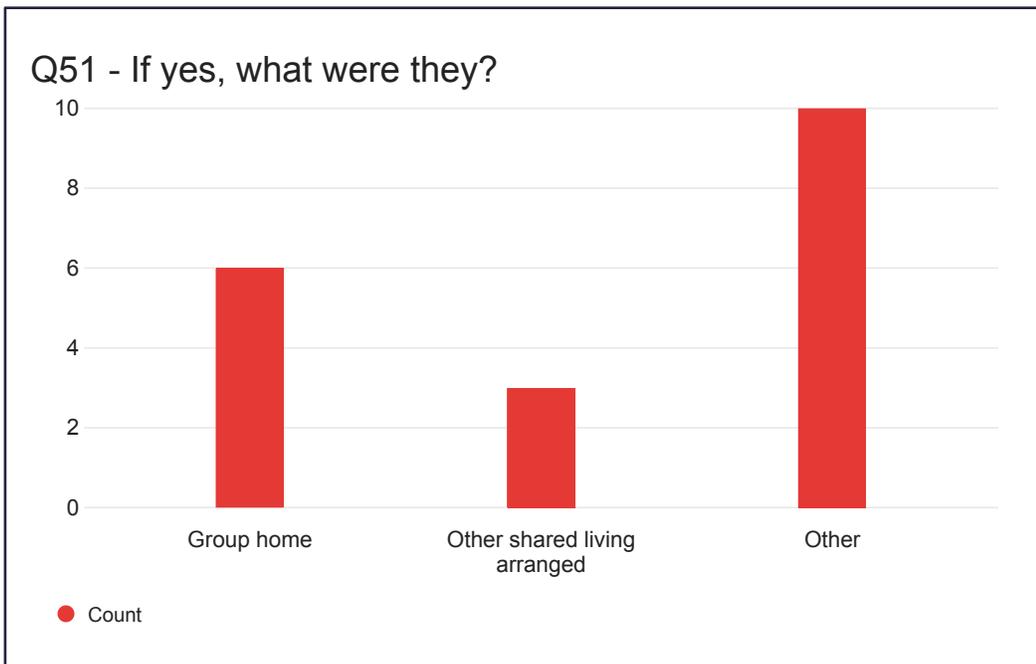


Figure 7.2: Caregiver responses to Q51 (check all that apply), those who answered “Yes” to Q50 (Figure 7.1)

When Caregivers were asked the nature of the “Other” living arrangements the adult has had, participants described a diverse range of scenarios. Some answers point to the adult having experience living in healthcare settings, such as in an “acute care hospital,” and “longterm [sic] care hospital on the complex care floor.” Some responses mentioned other institutional settings, such as adults having lived in a “[r]esidential school,” and a “facility/institution.” The answers given by some participants indicated that the adult for whom they provide care has lived in places that corresponded with the person’s age, such as a specialized “[c]hildren’s mental health centre,” whereas others described multiple changes in accommodation were neither obviously age related nor explicitly explained to be such by the participant.

Other Caregivers described the alternative living experience as an arrangement for respite. One Caregiver said that the adult for whom they provide support has experience with “monthly respite outside the home in a ‘group home’ like setting.” Other participants described temporary arrangements such as “[f]oster families,” or “[g]roup foster home,” which by name seem to imply their non-permanent nature, but not necessarily for the purpose of respite. Alternative arrangements within a family context were also mentioned, such as a Caregiver who mentioned that the adult has lived with birth parents prior to their current arrangement.

Some prior living arrangements were described as experiences of seeking to organize long-term, or permanent, living arrangements. For instance, one participant described the experience of having “[p]urchased a house with two other families and partnered with [an agency] to initially provide weekend respite with a view to transitioning the 3 young [individuals] to live there full time.” Another participant described a similar process as that was highly individualized for the residents, and “very much parent-driven and parent-involved.”

Caregivers were asked to describe the benefits of the previous living arrangement (Q52), and when relevant specifically asking what benefits they identified for the adult they care for when living in group homes, other shared living, and other living accommodation (Q51). Some Caregivers were clear that there were no benefits to the adult. One participant simply responded with “nothing,” and another said, “none for [him/her].” But of the positive responses, there were two main themes mentioned.

First, some Caregivers reported the different living arrangements offered the adult an enjoyable experience in multiple ways, including skill building and socialization. In particular, Caregiver participants mentioned positive features such as how the adult “really enjoys being away from home and looks forward to going back to respite,” and that the adults benefit from “community involvement, individual and group activity,” “play, social skills, practice self-help-skills, [and a] change of scenery.”

The second main noted benefit was that the arrangement offered respite for the Caregiver, something that “allows my partner and I and my other child to live a normal life...[we] can breathe a little and not be so vigilant.” It is interesting to note that this response indicates respite from both responsive and proactive forms of caregiving (see §4 for more details).

Of Individuals with high, complex needs who have experienced different living situations, one reported that a benefit of the experience was to have come into contact with professionals with relevant expertise related to their disorder, and that these positive connections continued beyond the change in living arrangement.

When asked to describe the *challenges* of the previous living arrangement (Q63), Caregiver responses reflected a wide range of experience. Some Caregivers didn’t identify

any challenges. For others, the challenges were not to do with the quality of the accommodations, but with their availability. One participant said that the challenge of the alternative living arrangement was that it was “short term,” implying a permanent arrangement is needed, not a temporary one. The prohibitive cost associated with the alternative living arrangement was also highlighted as a challenge. As one Caregiver participant explained, the “lack of access to any long term sustainable funding to transition the [individuals] to living [in the shared living arrangement] full time was the biggest roadblock.” See Section 9 for more about barriers to adequate housing.

Several Caregivers, however, described the challenges of previous living arrangements as the result of inadequate support for the adult with high, complex needs. For example, mentioned challenges included “[l]ack of accountability,” “[l]ack of supervision,” “[s]afety concerns,” and that the “level of care [was] not up to my standard, personal hygiene [was] not taken care of properly.” One Caregiver highlighted the serious consequences of inadequate safety and security support when they described how their son or daughter went missing from the accommodations and needed to be located by police. Another Caregiver noted both a “[l]ack of full understanding of complexity of needs” as well as the “[i]nability to provide [the] level of care required” for the adult to be adequately supported. Another Caregiver indicated a different sort of inadequacy in the support provided, saying that the group home “failed to provide the individualized care” for their son or daughter. An Individual with high, complex needs who had experience in alternative living arrangements addressed the lack of appropriate healthcare support when they noted that they were often over medicated in a previous living arrangement.

Some Caregivers identified the lack of emotional and social support as a challenge to alternative arrangements. Caregivers described a negative emotional experience for their son or daughter due to missing family, and the challenge of being “non-verbal...making [themselves] understood,” and in one case there was a “[l]ack of ongoing attachment” in the living arrangements. Distance was identified as a challenge by a Caregiver, likely referring to the geographic distance of the accommodations from the individual’s community, but in such a way that would likely have negative impact on the adult’s relationships by being far from family and friends. And as one of the Individuals with high, complex needs who completed the survey noted, the challenges of previous living arrangements included that they “hated being away from home,” as these other living arrangements “felt like jails.”

## Discussion

Although only 31% of the adults for whom the Caregiver participant provided care had experience living elsewhere, the experiences varied widely and there is much to learn from the outcomes. When they were good, the benefits of the previous living arrangements included not only providing adequate support for high, complex needs, but also aspects such as skill building, socialization, and community involvement. These are important elements to highlight as requirements for future initiatives to provide homes.

There is also much to learn from the challenges associated with the previous living arrangements, the most common one being that there was not an adequate level of support. In addition to highlighting the importance of meeting physical needs (personal care, physical safety etc.), they highlight the seriousness of a lack of emotional attachment, communication support, and connection to family and friends. It is presumably the latter sort of failing more than the former that would result in living arrangements feeling “like jails.”

## 8. HOUSING PREFERENCES

This section gathers together the responses from Individuals and Caregivers that offer a picture of what kind of living accommodations are needed and desired, in a way that addresses aspects other than providing adequate support covered in Section 5.

### Individual Results

Individuals who self-identified as having developmental disabilities and high, complex needs who completed the survey were asked “what living accommodations would you most like?” requesting the participant to “select all that apply.” These results show that Individuals who answered this question have a range of preferences for housing options (see Figure 8.1 below). When offered the chance to describe preferences, one Individual reported that they would prefer: “Living with others my own age As [sic] independent as possible knowing I’m in a safe environment.” Another Individual highlighted the importance of personal choice when they stated that, “I want to pick my place.”

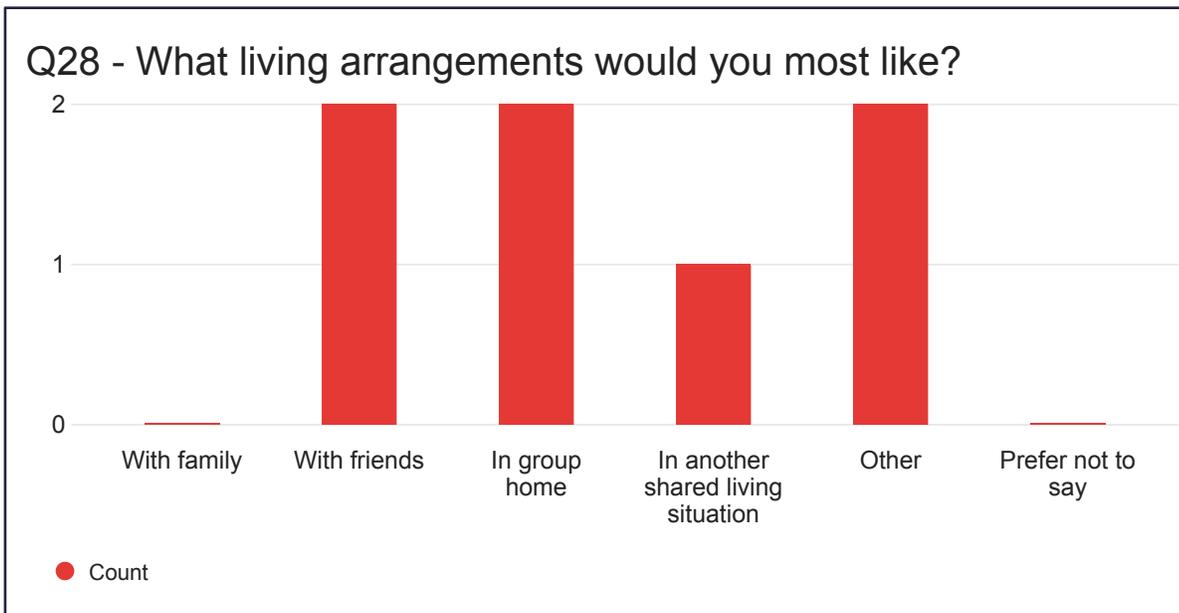


Figure 8.1: Individual responses to Q28

## Caregiver Results

Caregivers who participated in the surveys and interviews offered many general remarks about what was important for any potential living arrangement to have, beyond the need for the sorts of supports already considered. The affordability of the home was mentioned as an important factor, along with the residents having discretionary funds. Social opportunities for the residents was often noted, including community involvement and being close to family and friends. Caregivers also mentioned the importance of the resident's having access to new experiences and learning opportunities, such as social activities in their community, as well as the resident being able to maintain their established personal interests (e.g., music, art, religious observance). The routine and structure of the home was noted as important, as were physical activity/sports, social time, and also the opportunity to be quiet. Also mentioned were that the home itself be physically accessible, safe, and close to services.

## Group Homes

When considering comments made about certain kinds of living arrangements, the most common arrangement referred to by Caregivers was a group home. Comments Caregivers made about group homes fell roughly within the categories of, (1) being neutral due to circumstances, (2) being positive but heavily qualified, and (3) not perceiving them to be a viable living option for the adult for whom they provide care.

## Neutral

Some participants seemed to be neutral to the idea of a group home as a possible living arrangement. Typically, this was due either to being unsure of other options, or because the urgency of the need for alternative accommodations. For example, one Caregiver reported that, “[a]t this point in time, that’s all I’ve ever really thought I had as an option was group homes. It’s just there’s not that many and they can be years and [...], I don’t know how many years we have.”

## Positive but qualified

Of the Caregivers who voiced their opinions in terms of what living option they would like to see most, one said that a “group home setting within or close to our community would be ideal,” hence qualifying that the location of the home is necessary for it to be a positive choice. Other participants spoke about group homes in a positive way, but with qualifications on the *kind* of group home they had in mind as being a good option: for instance, one that offered choice and flexibility for the residents, community connection, and that provided the required support in a *caring* way.

Regarding the need for flexibility in an acceptable group home, one Caregiver noted that for a group home to be a good option it would need to provide a level of individual choice for the residents, and that it be “a community that is flexible such that the group doesn’t have to do everything together.” Another participant noted that the structure group homes provide is positive since their “[son/daughter] really need[s] to kind of know what’s going to happen next and chaotic wouldn’t be useful for [them],” but that it needs to be “structured in a way that’s structured around [their] activity and what [they] want to do.” Here we see that some Caregivers consider a group home as a positive option so long as it achieves this balance of structure and choice for the residents.

One participant shared that they saw a group home as a positive choice, given financial constraints, since “[t]he group home model is a viable cost-effective option for adults with high complex needs. Of course, with unlimited funding a very individualized housing option is ideal for everyone.”

It seems fair to conclude on this basis that in the opinion even of Caregivers who say that group homes might be a suitable home for the person they care for there are substantial

concerns about the suitability of most existing group homes. These are substantial qualifications: the group homes would need *caring* staff who are sufficiently trained to provide adequate support for someone with high, complex needs, but also there would be a need for suitably individualized support and activity, and a degree of autonomy, for residents. However, several participants voiced their doubt that group homes could meet these requirements to provide adequate care and support. For some Caregivers, however, their situation is such that they would be willing to transfer their son or daughter to a group home because of their urgent need for a change in living arrangements, even though they don't have much hope that it would be a positive choice.

### No to group homes

Some Caregivers reported that group home arrangements won't work for the adult with high complex needs that they care for, regardless of the qualifications, due to particular aspects of the adult's high complex needs. For instance, one participant said that:

...because of [their] high sensitivity in terms of [their] sensory needs with noise, and because some of the things that trigger [them], such as, wheelchairs, it's been very clear to us for many years why some of the traditional systems are not going to work for [them].

Another Caregiver noted that a group home would not be a feasible option since the adult for whom they provide care has a strong desire to live independently or with a chosen roommate, and have the support provided in their home.

## Alternatives

Individuals who identify as having high, complex needs and Caregivers described several housing arrangements that they see as the best options, but that do not fall within the traditional group home approach. Caregivers also identified several options of other kinds of living accommodations they saw as viable solutions, though not ideal. Participants from both groups (Caregiver and Individual) saw someone living at home in their own house or apartment with at most one roommate, with support to meet their needs coming into the home, as a viable, and even a preferred, option. A Caregiver identified shared living (i.e., multiple non-related residents with disabilities in one home) with community connection as an

ideal living arrangement. Related to these kinds of proposed solutions, Caregivers noted the significant need for operational funding and support that could keep the home running smoothly even after the parents are no longer living.

Of the Individual participants who identified as having high, complex needs who selected “other” to Q28 (see Figure 8.1 above, “Where would you like to live?”), explained these “other” arrangements as, living “on my own with support and family coming into my space to support me. A little support delivered from my family and the majority from people within my age group.” They added “I want to continue living in my own home with individualized support.” Another Individual noted that adding a roommate to their living situation was a possibility, but that this must be approached carefully: “If it seems wise to offer a home to another person or two, it’s important that we be kindred spirits and that the sharing works well for us all.”

## Discussion

Much of what Caregivers shared about housing options was described by referring to group homes as the comparison. However, when describing group homes (by name or otherwise) the participants did not define what they meant by this. Nevertheless, the varied meanings they presumed can be inferred by analyzing the responses.

The way Caregivers used the term “group home” seemed to refer to a home owned and equipped with appropriate staff and support that is operated by a third party (often an “agency”) It also seemed to be generally presumed that the home has multiple residents, all of whom have similar needs, but the residents are not involved in selecting who else lives there. Some Caregivers expressed a strong need for this form of group home. At times, such statements seemed to be out of desperation, such as when one participant acknowledged that it is not an ideal option, but crisis makes it necessary. In contrast, some participants – both Caregiver and Individual participants – expressed a preference for group home living. When expressed as a preference, it was most often explicitly qualified by specific, presumably atypical, features a group home must have. In particular, it must be one where support is provided in a genuinely caring way, with adequately trained staff, and offering meaningful choices for the residents, as well as having practical features such as the home properly maintained and is financially affordable. These were also key features identified by

respondents who did not want a group home, but instead wanted what was called a “shared living environment.” The main difference between the two sorts of living arrangement seems to come down to the degree of control over who shares the space (i.e., entrance into the physical house itself, selection of fellow residents) and who are the parties responsible for the practical running of the home (house maintenance, staffing etc.). In the case of a group home, the selection of residents and practical running of the home are the responsibility of a third-party. Some participants explicitly identified third-party handling of these responsibilities as a desirable quality.

For those wanting to organize shared living (i.e., not third party operated) arrangements, the responsibility of staffing is a large component of this. Some Caregiver participants indicated that they are willing to take on the task of house maintenance and staffing etc. but need increased ongoing financial support to do so. Others are not willing or not able to take on that responsibility, regardless of financial support. Further, some Caregiver participants acknowledged that while they are willing to accept the responsibility of staffing for the time being, it will inevitably need to be passed on as they age and become unable to do so personally.

Some Caregiver and Individual participants expressed that they, or the adult they care for, have a strong preference for independent living, or living at most with one other roommate. Control over one’s environment to suit an adult’s needs and the opportunity to make personal choices were highlighted as motivating reasons. Other Caregiver participants expressed that the adults in their lives are not well suited for group home *or* shared living. The higher the degree of control over a living space required to accommodate the adult’s particular needs (medical fragility, extreme sensory sensitivity, etc.), the less likely it is that the particular configuration of the living space will also accommodate the needs of other residents. Even the highly qualified version of a group home (i.e., with high degrees of caring, choice) was not perceived by Caregivers as a viable option for these adults. It is important to acknowledge this diversity. As one participant noted, “[w]e need different solutions for different circumstances.” See Figure 8.2 in appendices for more information on what Caregiver participants identified as required in a successful living arrangement, and how these requirements were perceived to fit within the options of group homes, shared living, and living independently.

## 9. COMMON BARRIERS

Analysis of participant responses within the Caregiver survey and qualitative interviews revealed common themes about what factors stand in the way of increased availability of suitable options for homes. We describe four of them: inadequate funding, lack of adequately trained support workers, social tensions arising when pursuing solutions, and the stress of not having a plan for the future of the adult with high complex needs they are caring for.<sup>10</sup>

### Funding

Lack of funding was mentioned consistently through the responses of Caregivers within the surveys and the interviews as a barrier to creating successful homes, in ways ranging from not having the funding to hire adequate support in present daily life, to insufficient funding to be able to pursue alternative housing options. For example, one participant recognized that lack of funding (whether provided by the government or privately) negatively impacts the ability to offer individual choice to the adult with developmental disabilities and high, complex needs:

...you maybe have to be more creative and spend a little bit more money to achieve that vision of individual choice. You have to be really on-guard to make sure that that is preserved because that's probably the first thing that will go if you are trying to save money...

Overall, financial limitations were identified by Caregivers as a main obstacle to adequate living arrangements. Caregiver participants identified this consistently, and directly, particularly when answering the interview question “what are the obstacles to achieving this desired living arrangement?” A Caregivers stated that, “[p]robably the most obvious one is financial.” Another participant said that the obstacles are:

Absolutely financial. There's no funding that we can take advantage of. I would add that often government funding comes with strings attached that don't work for what you're trying to achieve.

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<sup>10</sup> For a thematic map of common barriers to housing, see Figure 9.1 in appendices.

Even for Caregivers who could foresee initiating the process of trying to set up their desired living arrangement, such as purchasing a home in which the adult could live, they recognize that “[t]he challenge comes in the on-going funding for staffing which I don’t know if I have the resources to keep continue doing that.” Hence financial barriers prevent people from pursuing alternative housing arrangements, and also threaten the long-term success of these arrangements if they are initiated.

## Support Worker Industry

Caregivers mentioned the support worker industry throughout the surveys and interviews. This industry refers to personal support workers (PSWs) and those in similar roles who are paid to either come into the home to provide care for the adult with high complex needs, or to support the individual to participate in activities in their community. While involving PSWs is a benefit to the Caregiver as well as the adult, the task of recruiting, hiring, and scheduling this kind of help is time consuming and not without complications. Participants in the Caregiver survey and interviews indicated that particular aspects of this industry negatively impact what living arrangements are possible for adults they care for. The most common aspects mentioned by participants were the lack of availability of support workers (shortage), inadequate training, and how lack of finances impact availability and quality of service.

One Caregiver connected financial restrictions with the quality of support provided, stating that “...we choose to pay our workers a little more to find good workers, because good workers are hard to find.” A Caregiver participant also connected this to the quality of a group home, saying that “[g]roup homes are great, there’s good ones, there’s bad ones. Lot of it has to do with staffing, whether the staff are overstressed or overworked, and possibly underpaid, or under supported...” Financial barriers are directly related to the quality of care provided for adults with developmental disabilities and high, complex needs, both in the family home and in group home arrangements. When the support staff are stretched too thin (either understaffed, underpaid, or both) this negatively impacts the level and quality of support the adult receives.

Other Caregivers noted that part of the challenge is the lack of available support staff. “There’s not enough PSWs” said one participant, while another stated that “there’s a total shortage of PSWs or even just workers who do the same thing. A total shortage.” With

respect to the support staff who are working, one Caregiver said “[m]ost of these workers, they do it as a part time job. They have another job. So, it’s difficult for them to free up time to be able to do that.” This is compounded with financial issues, as in times of competition people who can offer higher wages are more likely to be able to attract and employ support staff. These factors make securing support in the home for the adult, especially at desired times (e.g., for the caregivers to attend events etc.), very difficult.

The degree to which adults with developmental disabilities and high, complex needs have access to “informal” (i.e., unpaid) supports is variable, but for the population of interest in this study the need for paid supports is universal. As noted above, many of the homes of people involved in the study rely heavily on unpaid support from family members, and these sources of support are viewed as unsustainable by those involved precisely because of the exhausting nature of providing the degree of support involved. Establishing the social connections that may result in new friendships or acquaintances that might become additional informal supports requires either additional effort from family members or paid supports. Furthermore, for many of adults with developmental disabilities and high, complex needs considered in the study, the complexity of their needs is such that it is unlikely that any non-family informal supporter will be able to entirely meet them.

## **Tension Between Perspectives**

Several participants in the Caregiver surveys and interviews identified tension within and between disability communities when discussing possible housing solutions, and that this tension has had a negative impact on securing preferred future living arrangements. For instance, one shared that “...I feel like the push back in their attempt for people not to be in group homes anymore, they’ve taken away our choice. And, it’s all about choice.” Another noted that “...there’s competing ideas on housing out there. There’s a [...] group [who are] very negative in [Ontario] who doesn’t think the same way we do.” The participant goes on to describe an experience where people within a local disability community were negative towards a particular housing option that the Caregiver was pursuing.

Some Caregivers expressed a desire to shift the nature of the dialogue about options. For instance, one said that,

I would like the conversation [about housing] to be not negative, that group living is bad. How can we improve on it? How can we make it better? How can we make it more individualized? Why can't we have that conversation instead?

Another Caregiver stated that “[i]t is about choice” and the blanket rejection of group living takes away a choice that they think ought to remain available.

## Dealing with the Unknown and Limited Options

Some Caregivers identified the lack of ability to plan for future housing as an additional complication that they see as likely to negatively impact the success of the inevitable transition. One Caregiver noted that,

I wouldn't want this transition into a new home be during a time of crisis. And that be the only cause and be wherever there is a spot available. I would like to be able to plan, be able to talk to my [son/daughter], talk about what we want, make some choices...

Another noted a similar struggle since, “if [they] are less stressed about the change, [they are] more able to participate in the decision making around the changes that are about to come and we want [them] to be able to do that.” This is not currently available given the limited options and unlikelihood of securing living arrangements in one's own community.

Caregivers also spoke about the nature of waiting lists for the existing options, and that they are actually “expressions of interest” and an adult's name is likely to stay on the list upwards of 10 years, unless a crisis occurs. Furthermore, Caregivers also noted long lists for receiving even temporary living arrangements in the form of respite accommodations for the adult they care for.

Other Caregivers identified a disconnect between the advice they receive from the government and similar sources, and their situations. What is often promoted does not fit their circumstances. For example, one Caregiver stated that

...there has been a push by [an agency] for families to create their own housing options. That becomes problematic when you're dealing with somebody who has a higher level of need. Personally, the only housing options that I have seen a family be able to create have been for individuals who are extremely high-functioning.

This thought was shared by other Caregivers, as one noted that

...what we found was that the conversation around residential models was not fitting our [adult children]. It seemed to be more for more able-bodied [people, such as] someone who is social, can maybe do a volunteer position, part time job, could use a cell phone, could be left at home for a few hours.

Several participants were aware of the possibility of potentially having to abandon their son or daughter due to the lack of housing and respite options. Such situations have resulted in Caregivers accepting living arrangements that they do not approve of, as one participant mentioned that “[w]e have been very upset and felt guilty that we need to leave [them] in that organization, simply because there is no other alternative.” Other caregivers are aware of this very possibility, when they state that, “[o]nce we go there’s no turning back. Our children might be unhappy for the rest of their life and there’s not a thing we can do about it.”

The lack of options also poses problems for the emotional connections of the adult with high, complex needs, and any social or community support they have established in their home area. As one Caregiver reported, in order to “have [them] in ANY supported living situation, we had to agree to have [them] live in a different region,” which is an hour each way from their family home. Many Caregivers are acutely aware of the likelihood of having to be geographically separated from the adult for whom they provide care, which would be negative for their immediate family relationships, and would mean that the adult “would lose [their] day programs, networks, and so on.”

## Discussion

Caregivers identified a host of barriers to securing adequate living arrangements for the adults they care for that are beyond just securing adequate support to meet adults' high, complex needs. Lack of adequate finances or funding was a consistent barrier and

contributing factor to nearly all of the challenges listed by Caregiver participants. As with any community, there are differing perspectives on what viable solutions should be funded by the government, making the tensions regarding possible solutions directly related to financial issues.

Caregivers consistently connected the lack of financial means (personal or government funds) to hindering adequate care in the family home and in group homes. Further, given the lack of PSWs, even if a family had financial means to employ a support worker who met their standards of care by offering them a competitive wage, there may not be enough PSWs available. Issues of retainment in the PSW industry, which likely include issues of compensation, have a direct negative impact to the availability and quality of care an adult receives.

Due to the overarching financial restrictions, the few possible solutions are not feasible for Caregivers, even if they are preferred, or even suitable, to them and the adult they care for. For those who are not financially restricted in this way, and can implement individualized options, a similar question arises when caregivers consider who will maintain the living arrangements after they pass away.

## 10. CONCLUSIONS

The results of this study show that for adults with developmental disabilities and high, complex needs the lack of housing is an urgent situation.<sup>11</sup> Caregivers indicated a foreseeable need for alternative housing options for the adults for whom they are the primary caregiver (which takes place, for the most part, in the family home), due to the fact that, as primary Caregivers, they are “ageing/exhausted/will be unable to continue” providing care. This was selected as the reason for foreseeable change by Caregivers in all but one of the age groups surveyed, and not just by aging Caregivers as one might assume. The majority of Caregivers provide care at home for their son or daughter, and don’t see any feasible options

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<sup>11</sup> As noted above, this research was carried out prior to the vast changes brought about by the COVID-19 pandemic. We acknowledge that had this research taken place after March 2020, participants of the surveys and interviews may have said things differently, as the pandemic has changed so much of daily life. The barriers people face to achieving housing solutions highlighted in this report (e.g., financial barriers, lack of available and qualified personal support workers) have likely been exacerbated. However, we can only analyze and draw conclusions from what was reported at the time, and the considerations drawn from this study remain true: people’s needs for adequate housing, and the lack of available options.

for a change in accommodations in the future. With the urgency of the problem in view, key lessons that can be drawn from this study are as follows:

**1. The housing challenge for people with developmental disabilities and high, complex needs is uniquely challenging.**

This housing challenge is in important ways different from the general shortage of affordable housing, or even of accessible affordable housing designed for others with developmental disabilities. In particular, due to their high, complex needs, people need homes with:

- 24/7 support that is “never more than arms’ length away”
- continual and pro-active support (e.g., monitoring of environment)
- supports tailored to the complexities of the particular individual

**2. Conceptual clarity regarding *group homes* may help discussions about solutions move forward.**

The term *group home* suggests different things to different people, and these differences of understanding drive quite different responses to the question of whether group homes are an acceptable home for adults with developmental disabilities and high, complex needs. Clarity regarding what people see as the main benefits of different arrangements, or even different conceptions of a group home, can help draw attention to what makes options viable and even preferred for future possibilities.

- The negative aspects of group homes that Individuals and Caregivers most frequently cited were that they do not offer adequate levels of care, and that they are not sufficiently person-centred.
- For many Caregivers, the benefits of a group home are the transfer of primary caregiving responsibility. For some, this made a group home an option, but not a preferred option.
- Positive features of group homes for the adults (i.e., possible residents) included social connections and growth in independence.
- Some Caregivers reject the idea of group homes but are open to shared living arrangements.
- For some adults, shared living is not an option, and this might be the case for those with extreme sensitivity to noise, difficulty with changes of routine, and so on.

**3. People are interested in “creative options,” but there are barriers.**

As noted, some Caregivers shared that options besides group homes have not previously been on their radar. This is not surprising, given the level of stress and time involved in being

a caregiver. Many, though, perceive a push for families to create their own housing options.

Respondents identified a number of challenges to doing so.

- Finances. Being creative, especially given the need for individualization and significant supports identified above, will require money, which is not available. Moreover, Caregiver participants noted that often government funding comes with strings attached that don't work for what someone is trying to achieve.
- Personal support workers are needed to make many options viable. But good ones are in short supply because they are generally underpaid, overworked, and their training can be inconsistent.
- There is a lack of information about options.
- The options and models touted as possibilities are aimed at a different population than those with developmental disabilities and high, complex needs. The options on offer presume that people are "higher functioning," more physically able, more social, or in other ways easier to fit into an arrangement involving others who need support than are the adults that are the focus of this study.

#### **4. The emotional cost of uncertainty.**

Regardless of the preferences expressed for future living accommodations for the adults they care for (e.g., group home, shared living, or supported independent living), the majority of Caregivers consistently stressed the total lack of feasible housing options. The uncertainty regarding one's ability to secure future adequate living arrangements causes additional stress on the Caregiver, and often the adult, in the present. As one Caregiver noted, "...it's still that uncertain future that can really weigh parents down," and as another said, "I know there's the piece of worry that we carry. The emotional stress around what does the future hold for [them] and us and the whole living situation piece. I think the emotional stress is costly."

# 11. APPENDICES

## Figures

Figure 3.1: Caregiver response to Q21

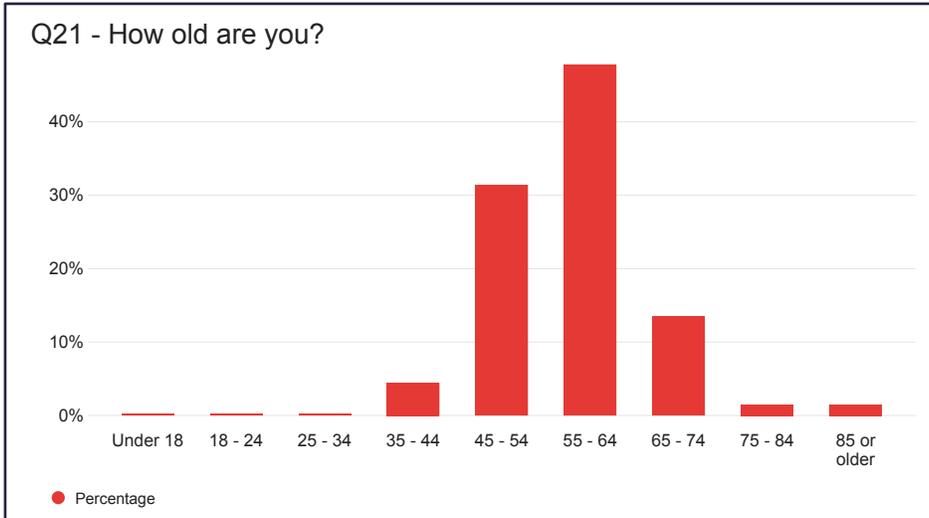


Figure 3.2 Caregiver responses to Q4

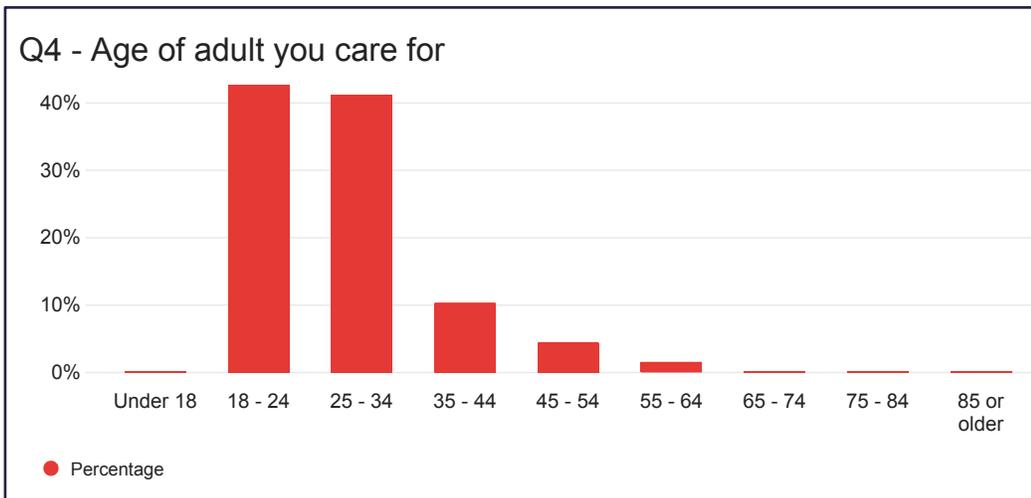


Figure 3.3: Caregiver responses to Q22



Figure 3.4: Caregiver responses Q16

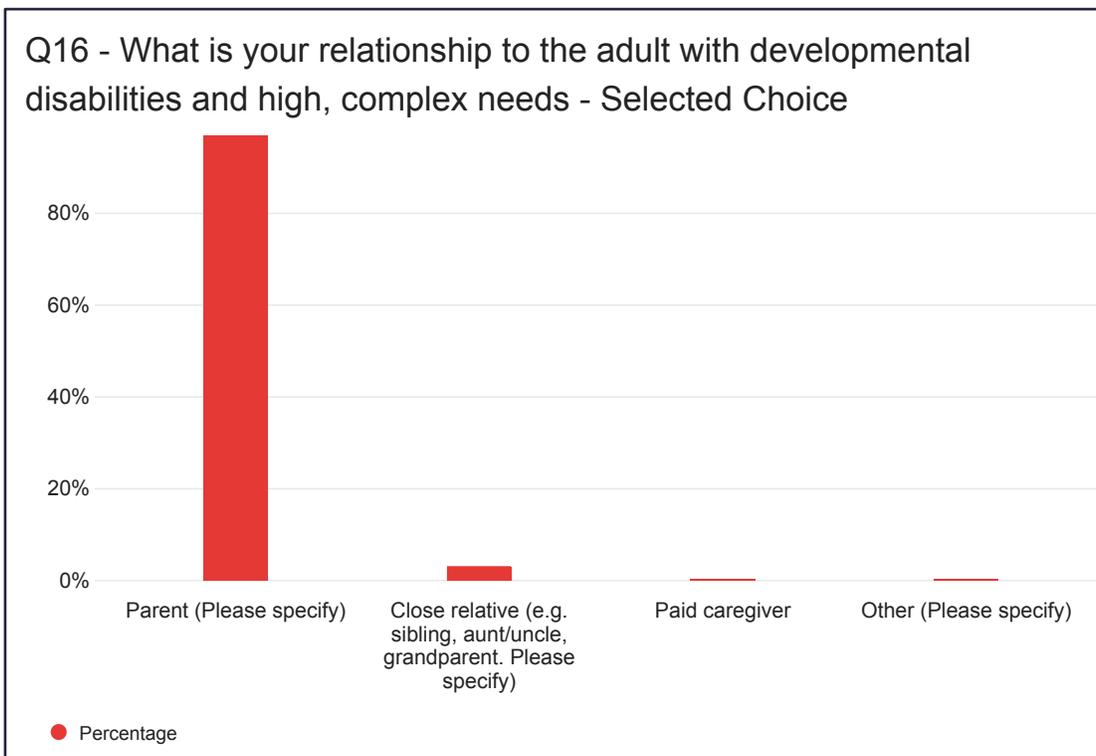


Figure 3.5: Caregiver responses to Q5

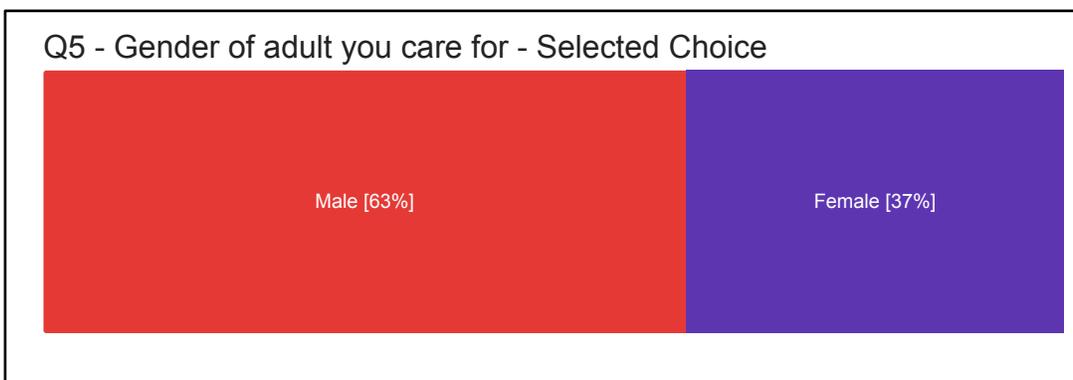


Figure 3.6: Caregiver responses to Q6

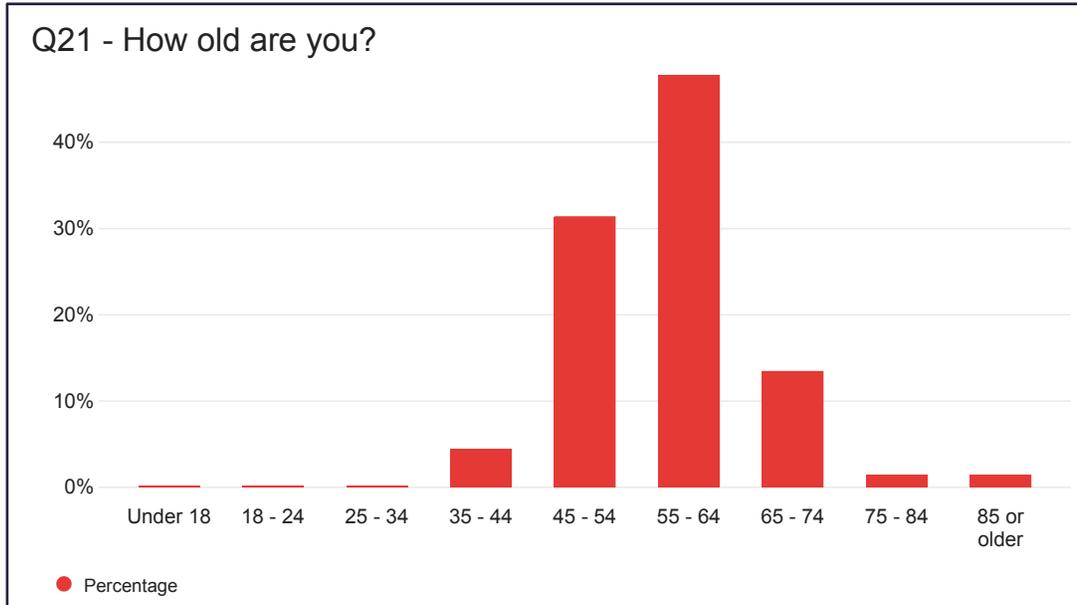


Figure 3.7: Caregiver responses to Q36

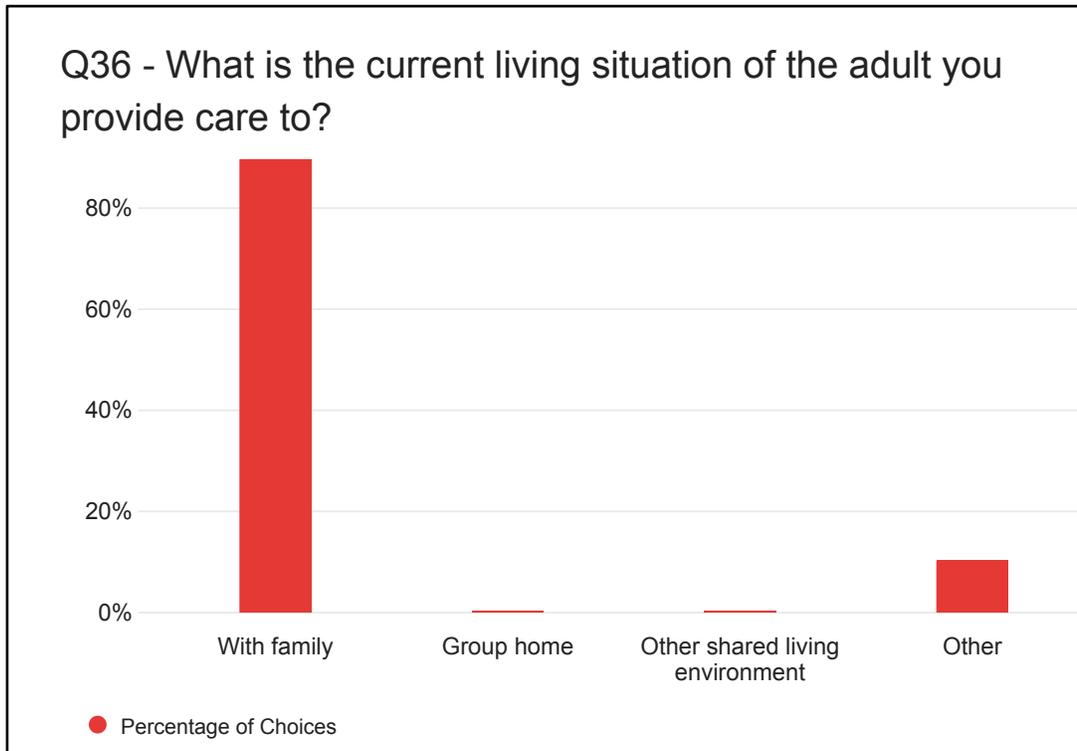


Figure 3.8: Caregiver responses to Q4 with a breakout of Q36 (“What is the current living situation of the adult you provide care to?”)

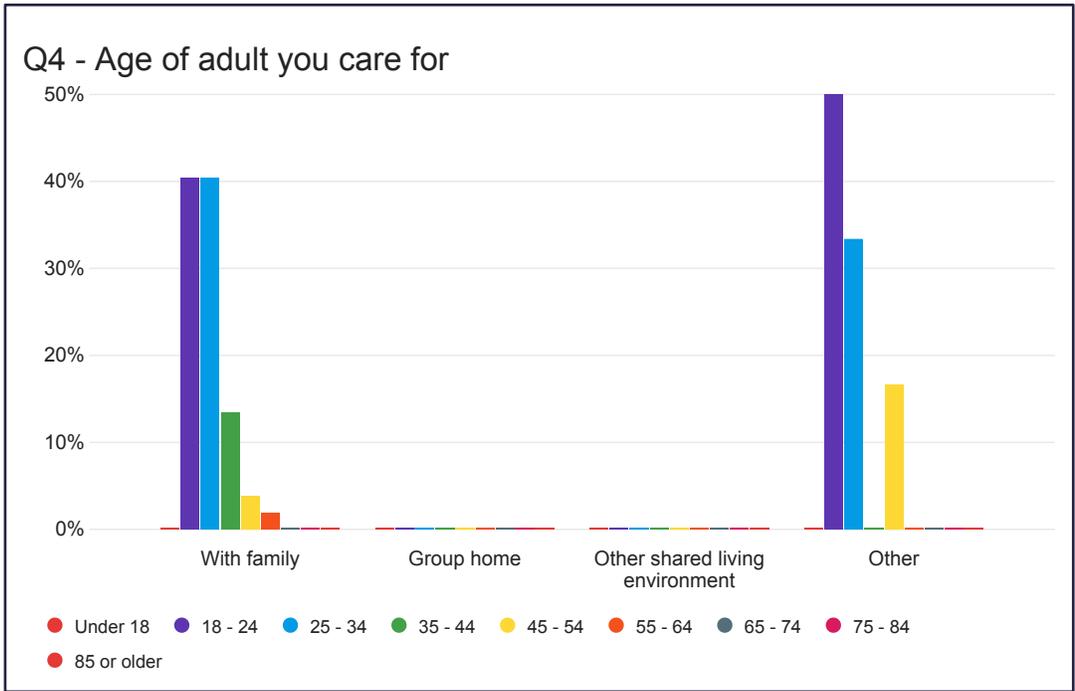


Figure 3.9: Caregiver responses to Q35

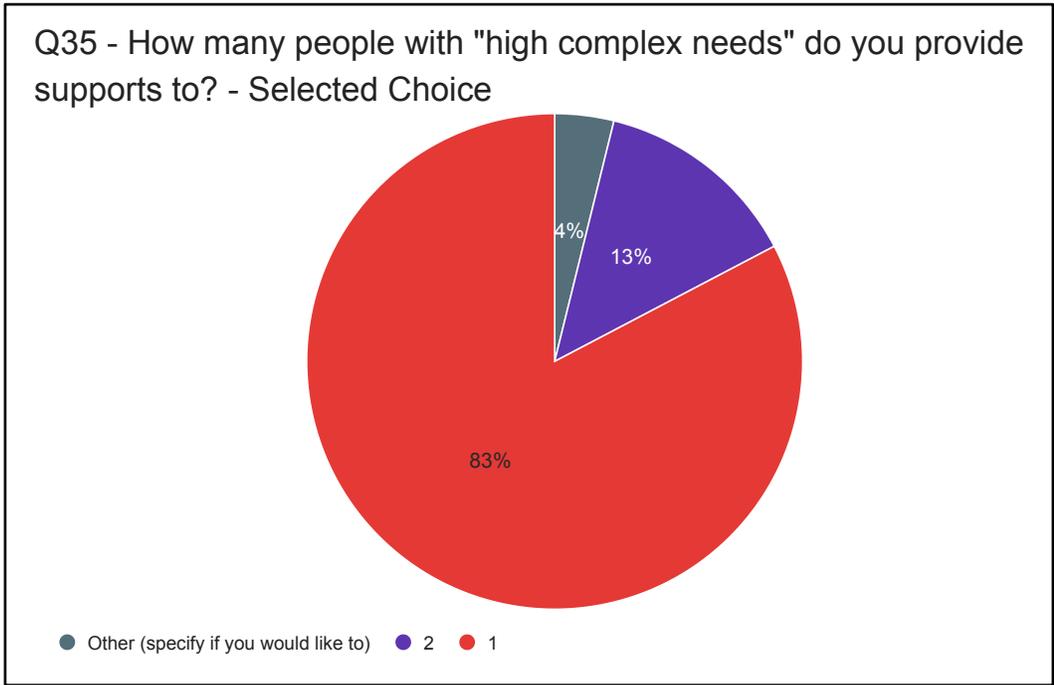


Figure 3.10: Individual responses to Q4

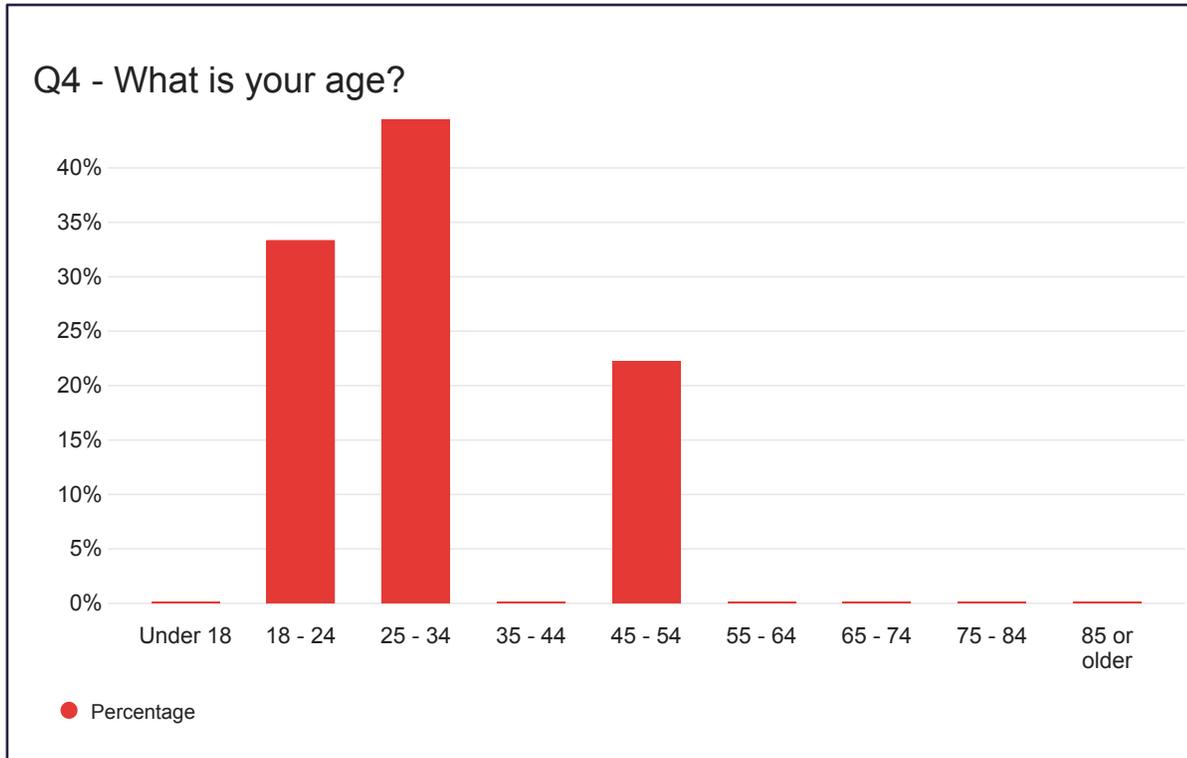


Figure 3.11: Individual responses to Q11

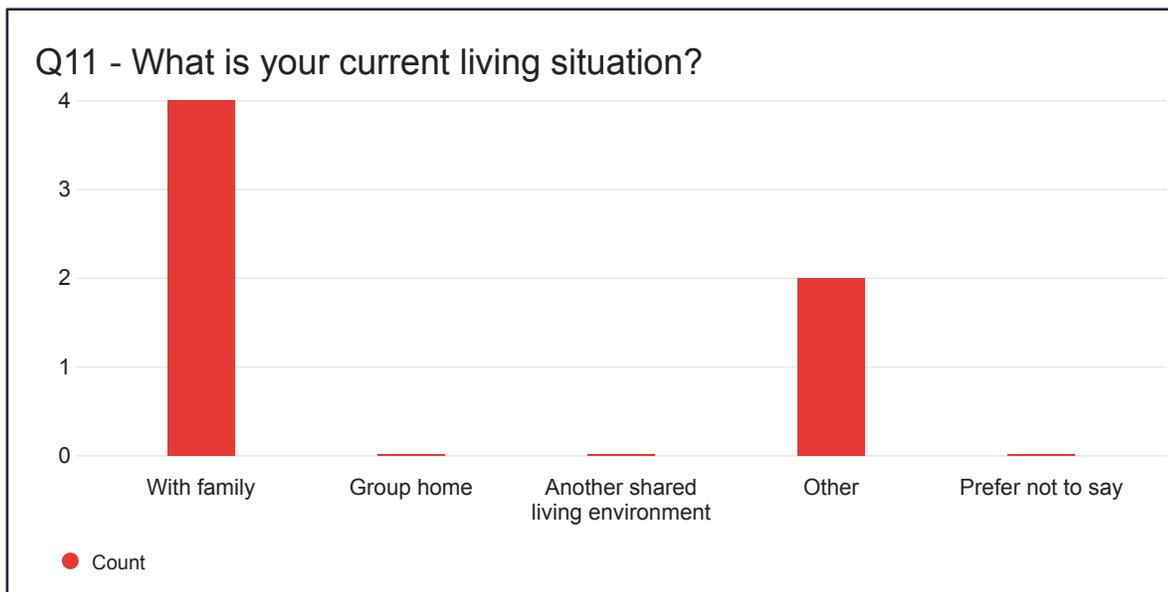


Figure 3.12: Individual responses to Q5

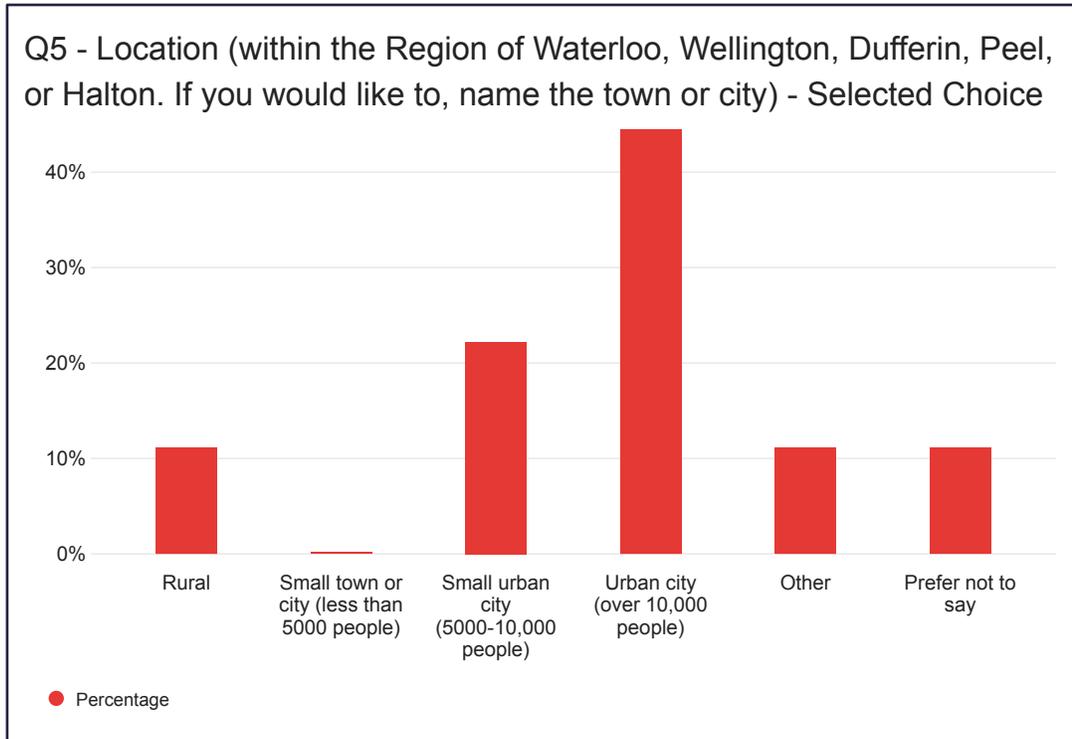


Figure 6.1: Caregiver responses to Q56

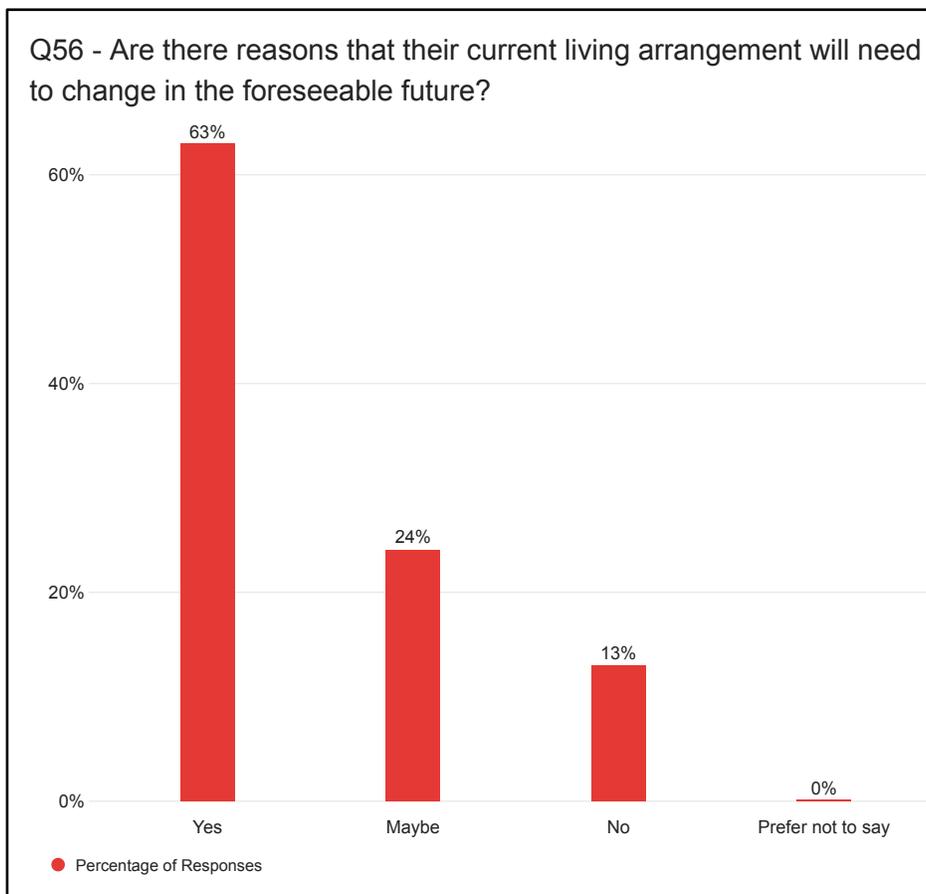


Figure 6.2: Individual responses to Q27 with a breakout of Q11 (“What is your current living situation?”)

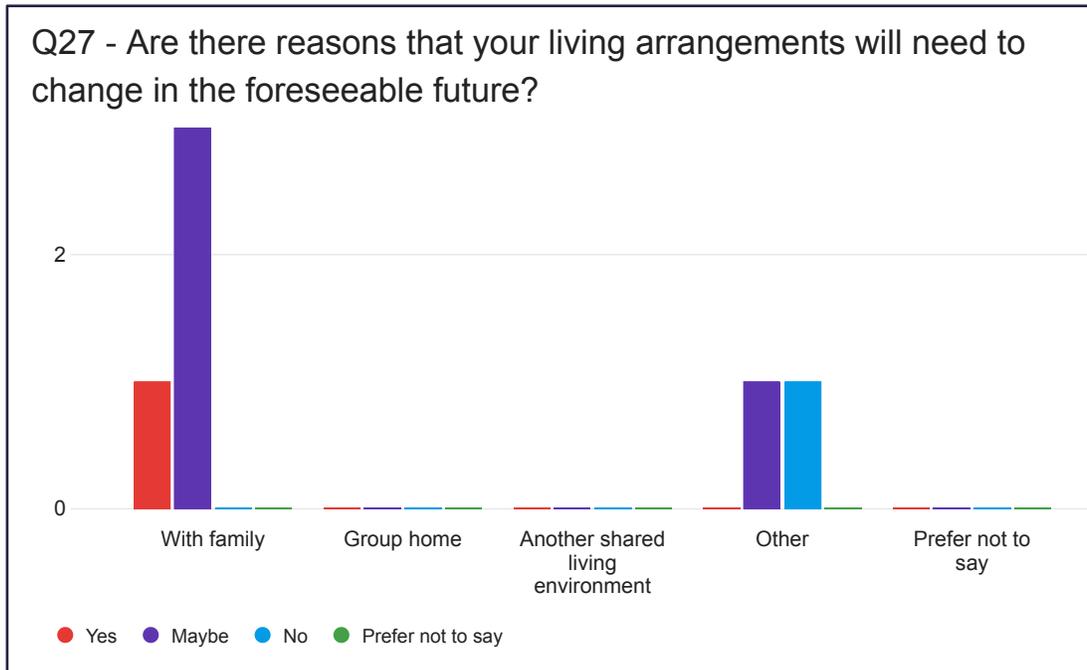


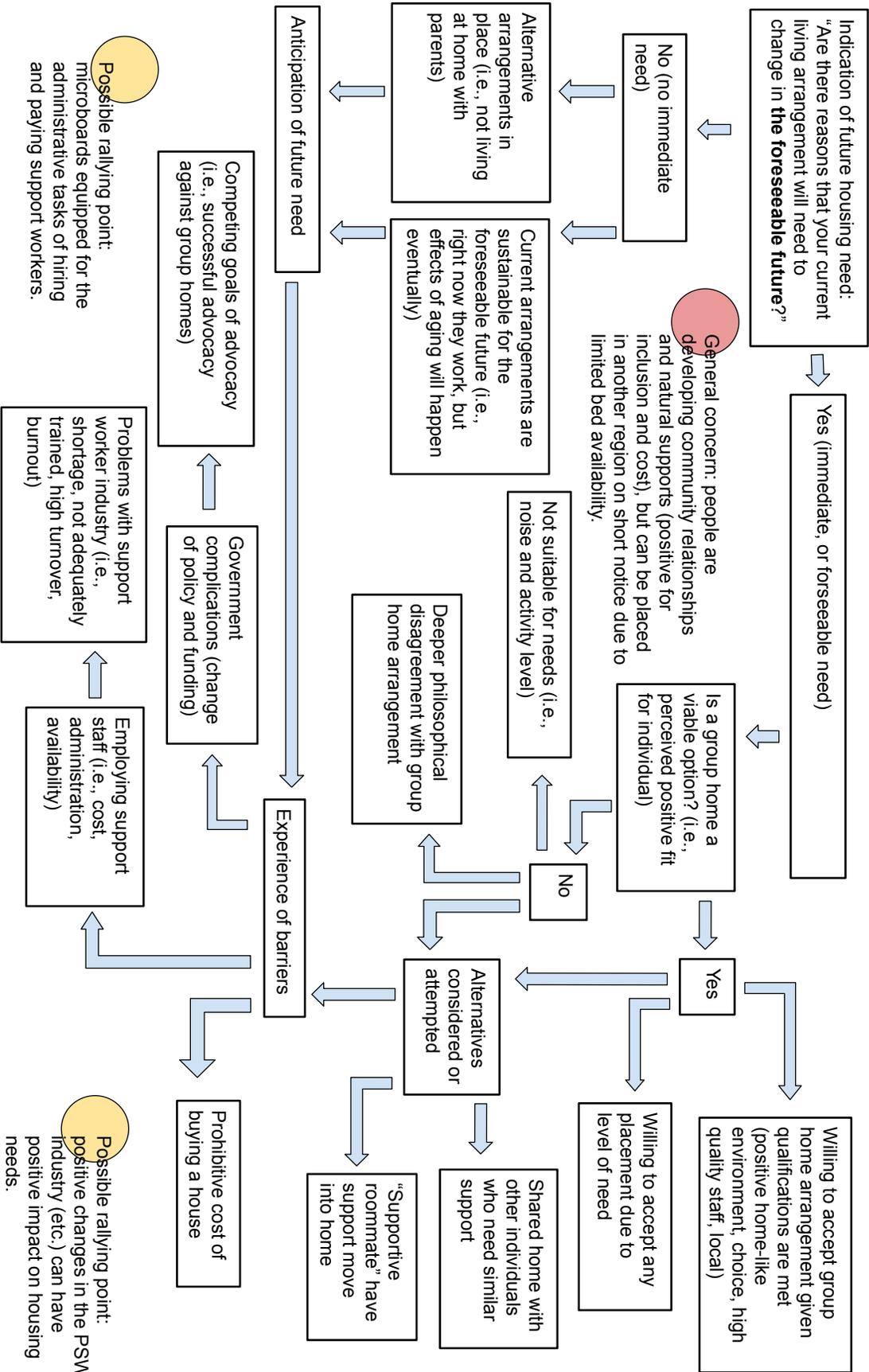
Figure 8.2: Chart of participant responses (caregiver and individual) compared to three categories of housing options.

Important Features of a Home	Reality GH= Group Home SL= Shared Living IL= Independent Living
Safety (e.g., supervision, upkeep of building)	GH: Often bare minimum but present SL and IL: responsibility of caregivers
Health care support	GH: Often bare minimum, staff might not be equipped for level of medical need SL and IL: responsibility of caregivers to provide or secure healthcare staff
Dietary support	GH: Often bare minimum, likely to have restricted options SL and IL: responsibility of caregivers
Learning opportunities	GH: Not guaranteed

	SL and IL: can be implemented to suit individuals (finances permitting)
Physical activity	GH: Some, not guaranteed to suit individual's desired level or kind of activity SL and IL: can be implemented to suit individuals (finances permitting)
Community involvement/social activities	GH: Individual may need to move away into a new community, particular homes may not invest in the amount/kinds of involvement or activities a person wants SL and IL: can be implemented to suit individuals (finances permitting)
Personal interests (e.g., music, religious practices)	GH: Not all homes offer level suited to individual SL and IL: can be implemented to suit individuals (finances permitting)
Physically accessible	GH: Legal requirement SL and IL: accommodations made to suit individuals (to the degree finances permit)
Close to family/friends	GH: People might have to move far away for a group home SL and IL: more likely to choose a home in proximity to family and friends (to the degree finances and availability permit)
Opportunity to be quiet (own space)	GH: Not all residences allow for this, SL: Likely achieved, part of how fellow residents are selected IL: Guaranteed
Affordable	GH: Government subsidized SL: Large barrier (housing costs and staffing etc.) subject to change given involvement of multiple parties IL: Large barrier (housing costs and staffing etc.)
Routine/Structure	GH: Present but, unlikely to suit everyone (or anyone?) SL: Can be implemented, may still clash with needs of other residents IL: Guaranteed
Caring/supportive	GH: Dependent on the home, is subject to change SH and IL: Within control of those choosing residents and staff

Adequately trained staff	GH: Dependent on the home, is subject to change SH and IL: Within control of those choosing staff (to the degree finances permit)
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Figure 9.1: Thematic map of caregiver responses to surveys and interviews.



## Caregiver Survey

### Survey Questionnaire for Creative Housing Options for Primary Caregivers for an Adult with Developmental Disabilities and High Complex Needs

[Questions are on separate pages from the Information Letter and Consent page and tick box. Only if someone self identifies as the primary caregiver of an adult with developmental disabilities and high, complex needs AND they live in our study's region will the rest of the survey open. If they click "no" to either of these questions, the survey will close, thanking them for their time and saying they can contact us if they have any questions:]

#### Eligibility questions:

- 1.) I am a primary caregiver for an adult with a developmental disability and high complex needs (yes/no)
- 2.) I currently live within the Region of Waterloo, Wellington, Dufferin, Peel or Halton (yes/no)

#### Demographic Questions of individual they care for:

Some of the demographic information is sought because we think that certain characteristics may increase challenges in accessing supports or providing them oneself. You are free to leave any question blank.

- 1.) Age of the adult in question:
  - 2.) Gender of the adult in question:
- 1) Location where this adult lives (Radio buttons with options, we'll also give them the option to write in the town's name)
    - Rural
    - small town or city (population less than 5000)
    - small urban (population 5000-100,000)
    - urban (population over 10000)
  - 2) First language of the adult in question:
  - 3) Education of the adult in question:
    - Elementary school
    - High school
    - Trade school
    - College or University

#### Demographic questions about the caregiver:

Some of the demographic information is sought because we think that certain characteristics may increase challenges in accessing supports or providing them oneself. You are free to leave any question blank.

- 4) Relationship to the adult in question:
- Parent or close relative. Please specify
    - As a close relative (other than a parent), how long have you been providing care to this individual?
  - Paid caregiver
    - How long have you been a paid caregiver for this individual?
    - How often do you provide care to this individual?
      - Daily
      - 2-3 times a week
      - 4-6 times a week
      - Biweekly
      - Monthly
      - Other
      - Prefer not to say
  - Other
    - Please specify:
- 5) Age:
- 6) Gender:
- 7) First Language:
- 8) Education:
- Elementary school
  - High school
  - Trade school
  - College
  - University
    - Undergraduate
    - Graduate
- 9) Children:
- 10) Dependents:

[Separate page]

### Research Questions:

- 11) In some of the questions below, we ask for your perceptions about, for instance, the desires of the person in question. Please briefly explain how you know what they might desire with regards to living arrangements:
- 12) We have given a definition of what we mean by high complex needs: we define **high complex needs** as: A person has *high, complex needs* if, as a result of health and neuro-developmental disorders and social and communication challenges, they need 24/7 support where support is “never more than arms-length” away, that is, the person needs supports to be constantly at the ready, e.g. the person cannot be left alone in a house, even for a short time.

If your definition is different, how do you define “high complex needs?”

13) Are there other people in your household or to whom you provide supports who you would classify as having “high complex needs”?

14) What is the current living situation of the adult in question?

- With family
  - How many people currently live in the person’s home?
  - Are there others living in their home who have support needs that affect the ability to provide the support the person in question needs?
  - Are there multiple generations in the household? Yes/No
    - If yes, does this affect the preferred housing arrangements for the individual with high complex needs?
      - How?
        - Group home
        - Other shared living environment (please explain)
        - Other (please explain)

15) What supports does the person need in order to make their current housing arrangement work?

- Healthcare supports?
- Dietary supports?
- Safety and security issues?
- Other supports?
  - Please briefly explain the nature of the supports that the individual with high, complex needs requires:

16) Does the person in question have experience with living arrangements different from the current one?

- Yes
  - 28) If yes, what were they?
  - 29) What were the benefits and problems with those arrangements?
- No

17) How long has the person been living in their current living situation?

18) Are there reasons that their living arrangements might need to change in the foreseeable future?

- Yes
- Maybe
  - If yes or maybe are selected - what are or might be the reasons that the person will need to change their current living arrangement?
    - Finances
    - Current caregivers are aging/exhausted/will be unable to continue

- The current supports are insufficient to meet the person's needs
  - Interpersonal problems make the current arrangement unsuitable
  - Other
  - Prefer not to say
- No
- 19) Are there any housing options that you can access?
- Yes
  - Maybe
  - No
    - Would those housing options meet the individual's needs?
- 20) What living arrangements would the person prefer? What would the person want in a home of their own?
- 21) In your opinion, what are the things that would be necessary to make a good home for the person in question?
- 22) How much does living/caring for someone with high complex needs affect *your* daily life?
- A great deal
  - A lot
  - A moderate amount
  - A little
  - None at all
  - Prefer not to say
    - Please briefly describe how living and/or caring for someone with high, complex needs affects your daily life
- 23) If the person you care for is currently living with more than one family members, how many family members live in the same home, and how do you share the job of providing supports for the adult with high, complex needs in the family home?
- 24) Do you or others in your household who are providing supports also provide support to other people as well? Please briefly describe.
- 25) Has the person in question completed the Supports Intensity Scale (a "SIS Assessment")?
- Yes
    - If yes, when?
    - Did it reveal anything useful in relation to housing needs and desires?
  - No
    - If no, do they plan to?
    - If they plan to, why?
    - If they do not plan to, why not?
  - Unsure/Maybe

Is there anything else you would like to tell us with respect to living arrangements for the person in question, or more generally about homes for adults with developmental disability and high complex needs?

[Separate page]

### **Interested in learning more?**

If you are interested in learning more about our follow-up interviews, please provide us with a contact email where we can reach you. We will not use this email for any other purpose, and it will not be stored with your other answers once we have made decisions about who to interview. Email addresses will be removed from the survey data and replaced with pseudonyms assigned by the researchers. Interview participants will be selected based on their survey responses. Please NOTE: due to time constraints of the study, not everyone will receive a follow up email about the interviews.

Email:

## **Individual Survey**

### **Survey Questionnaire for Creative Housing Options for Adults with Developmental Disabilities and High Complex Needs**

[Questions are on separate pages from the Information Letter and Consent page and tick box. Only if someone self identifies as an individual with developmental disabilities and high complex needs AND they currently live in our study's region will the rest of the survey open. If they click "no" to either of these questions, the survey will close, thanking them for their time and saying they can contact us if they have any questions:]

#### **Eligibility questions:**

I consider myself an adult with a developmental disability and high complex needs (yes/no)

I currently live within the Region of Waterloo, Wellington, Dufferin, Peel and Halton (yes/no)

#### **Demographic questions:**

Some of the demographic information is sought because we think that certain characteristics may increase challenges in accessing supports. You are free to leave any question blank.

Age:

Gender:

Location: (radio buttons: rural; small town or city (less than 5000); small urban (5000-100,000); urban (over 10000))

First language:

Education:

- Elementary school
- High school
- Trade school
- College or University

Marital status:

[Separate page]

### Research questions:

We have given a definition of what we mean by high complex needs: we define **high complex needs** as: A person has *high, complex needs* if, as a result of health and neuro-developmental disorders and social and communication challenges, they need 24/7 support where support is “never more than arms-length” away, that is, the person needs supports to be constantly at the ready, e.g. the person cannot be left alone in a house, even for a short time.

If your definition is different, how do you define “high complex needs?”

How many people in your household would you classify as having “high complex needs”?

What is your current living situation?

- With family
  - How many people currently live in your home?

- Are there other family members in your home that have other needs that affect the ability of others to provide the supports you need?
- Group home
- Other shared living environment
  - please explain
- Other
  - please explain

What supports do you need to make your home function well?

- Healthcare supports?
- Dietary supports?
- Safety and security issues?
- Other supports?

Do you have experience living with living arrangements different from the current one?

- Yes
  - If yes, what were they?
  - What were the benefits and problems with that arrangement?
- No

How long have you been living in your current living situation?

Are there reasons that your living arrangements will need to change in the foreseeable future?

- If yes, please explain

What living arrangements would you most like?

- With family
- With friends
- In group home
- In another shared living situation
  - If “other shared living situation” selected: What other shared living situation would you like?
- Other
  - If “other” selected: What “other” living situation would you like?
- Prefer not to say

What would you want in a home of your own?

Have you completed the Supports Intensity Scale (a “SIS Assessment”)?

- Yes
  - If yes, when?
  - Did it reveal anything useful about your housing needs and desires?
- No

- If no, do you plan to?
- If you plan to, why?
- If you do not plan to, why not?

Is there anything else you would like to tell us about what you desire with respect to living arrangements?

[Separate page]

**Interested in learning more?**

If you are interested in learning more about our follow-up interviews, please provide us with a contact email where we can reach you. We will not use this email for any other purpose, and it will not be stored with your other answers once we have made decisions about who to interview. Email addresses will be removed from the survey data and replaced with pseudonyms assigned by the researchers. Interview participants will be selected based on their survey responses. Please NOTE: due to time constraints of the study, not everyone will receive a follow up email about the interviews.

Email:

## Caregiver Interview Questions

### Semi-Structured Interview Schedule

#### Creative Housing Options for Adults with DD and HCN

##### Interviewee: Caregiver

#### 1. Demographic Questions:

Age of adult for whom you provide care:

Gender of that person:

Age of Interviewee:

Gender of interviewee:

Location:

#### 2. What is the current living situation of the person with DD and HCN that you provide care for?

- With family
- Group home
- Other shared living environment (please explain)

- Other (please explain)
3. How long has the person been living in the current living situation?
  4. How sustainable is the current living arrangement?
  5. How urgent is a viable alternative (and why)?
  6. What might put the current living arrangement at risk?
  7. When you think about what is important in a good home for the person you care for, what are some of the things that come to mind as most important?
  8. What are some of the most challenging things when it comes to making the current living arrangement a good one?
  9. What housing options are available near where the person you care about lives?
  10. How satisfactory would those options be, if they were accessible?
  11. What do you think the person you care about would ideally want in a home?
  12. What are the main obstacles to achieving something like this ideal?
    - For example, sustainable funding, access to supports or services, affordable housing, and within the community where the individual currently lives, etc?
  13. Have you (or other people involved in the life of the person you care about) tried to make other living arrangements work for the person? How well did they work, and what barriers did you encounter?
  14. How does caring for someone with high complex needs affect daily life?
    - Has the caregiving impacted your health (physically/mentally)?
    - Have the current arrangements impacted the health of the person you care for?
    - Has it impacted your life style (isolation, loss of friends, loss of freedom)/ finances?
  15. If the person you care about is currently sharing their home with others, is this because it best or because it is most practical?
  16. If sharing with others is important to making a good home, what factors need to be considered in making a shared home a good home for someone with high complex needs?
  17. How important is an individualized daily schedule/routine within a shared living environment?
  18. Anything else you would like to add: