

A REPORT ON INCLUSIVE HOUSING NEEDS IN BC 2020



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Executive Summary

Based on the [2018 Inclusive Housing Task Force report](#), a follow-up survey and focus groups specific to the housing needs of individuals with developmental disabilities was conducted in 2019/20. This report summarizes the findings from over 800 survey respondents and focus group participants. We hope this report will help inform local governments, community planners, developers and non-profit housing providers to include homes for people with developmental disabilities in their housing plans and projects. Throughout the report, we prioritize the voices of individuals with developmental disabilities and what they had to say about their needs and their preferences for housing.

This Executive Summary highlights some of the key findings the data told us. Among the many themes we found throughout the course of this research, the following came up frequently:

- For many individuals with developmental disabilities and their families, there is a strong desire for more independent living. While this does depend on the level of support the individual requires, in most cases, people with developmental disabilities want to move to more independent living arrangements. For instance, people with developmental disabilities frequently live with their parents and are getting to an age (average age: 29) where they are seeking more independence from the family home. They want to start leading lives for themselves with supports built around that independence.
- Many structural factors continue to work against the goal of independent living. There is a lack of affordable and accessible housing options in communities in B.C., and especially in rural and more remote communities. The cost of rent in most regions has well exceeded the resources available to most individuals with disabilities from government assistance and employment income. The timing of available housing and available supports do not always coincide, making independent living more difficult to achieve.
- People with developmental disabilities want the same housing as everyone else. They want their housing and neighbourhoods to have social connections and activities, good transportation, leisure opportunities, amenities and decent housing that doesn't cost too much.
- More independent housing tends to foster even more independent living. Frequently, parents have perceptions about what their children are or are not capable of. Many families who have seen an adult child move to inclusive housing and more independent living arrangements see a significant progression in that adult child being more independent.
- Many families do not have housing plans for their adult children that articulate where, how and when their loved ones will live after they are no longer able to support them. There needs to be more supports created to help families and individuals develop these plans.
- There is significant demand for inclusive housing for individuals with developmental disabilities, both from individuals and families. Surveys, focus groups and service and aging data indicate that approximately 5,000 individuals with developmental disabilities need and will want to move to new housing situations within the next five years.



Throughout the report, we prioritize the voices of individuals with developmental disabilities and what they had to say about their needs and their preferences for housing.

Introduction

In 2017, Inclusion BC and Community Living BC (CLBC) came together over the shared issue of inclusive housing for people with developmental disabilities. Together, they formed the Inclusive Housing Task Force made up of people with lived and professional experience with inclusive housing. The Task Force drew upon the expertise of approximately 80 individuals from around the province through a Housing Forum held in January 2018. The Task Force was charged with developing a set of strategies to increase inclusive housing options and to look at promising practices in B.C. and in other jurisdictions. The Task Force produced a report, "[Home is Where Our Story Begins](#)" that outlines actions to increase access to inclusive housing.

A key action identified in the Inclusive Housing Taskforce Report was to conduct research collaboratively with partners in the housing and community living sectors to develop relevant and accurate data that outlines the current and future demand for inclusive housing in B.C. The Report also identified that research should examine issues such as the housing situations people with developmental disabilities currently live, where people would like to live, the connections between quality of life, housing and residential support models, and demographic information.

To help carry out this objective, CLBC and Inclusion BC partnered with BC Non-Profit Housing Association (BCNPHA) to initiate the research program. A committee was set up with key organizations, self-advocates and family members to guide the research process. During 2019 and 2020, BCNPHA and the advisory committee developed and implemented an online survey to solicit feedback from individuals, their family members and unpaid and paid supports to better understand housing need and demand. In addition, BCNPHA conducted several interviews and focus groups with self-advocates and family members in different regions across the province to supplement the survey data with more qualitative information.

This research shows that there are diverse experiences related to housing for individuals with developmental disabilities and their families. Differences in geographical location, level of need, types and forms of housing that work well and material resources that individuals and families have access to are some of the factors that shape housing need and demand for individuals. While there are diverse experiences, this research has also showed many shared themes in housing for individuals with developmental disabilities and their loved ones. These are broadly consistent with the inclusive housing definition contained in the Inclusive Housing Taskforce report noted above.

The current COVID-19 pandemic has amplified the importance of having a safe and stable home and strong social connections. While most individuals and families participating in this research did so before the pandemic took hold, the themes of comments and conversations take on added meaning in our current environment.

What is Inclusive Housing?

- 1. Choice and Control:** Choice and control over living space is fundamental to the concept of home and to quality of life.
- 2. Accessibility:** Housing must meet basic requirements that give people access to both their homes and to their community.
- 3. Avoiding Congregation:** Inclusion is not defined by a hard ratio and is dependent on the size of the development, the neighbourhood location and how opportunities for inclusion are built in and created.
- 4. Diversity:** Individuals have a wide range of interests, preferences, disability related support needs and backgrounds.
- 5. Sustainability:** Housing needs to provide a sense of stability to individuals and be amenable to supports being provided in a quality and cost-effective manner.

Report Method and Structure

The information contained in this report is based on two main sources of data. Between August 2019 and June 2020, BCNPHA developed and administered an online survey to collect information from individuals with developmental disabilities, their family or unpaid support and paid support. The survey asked questions about current housing arrangements, preferences for future housing and living arrangements, barriers to housing, accessibility needs and supports. Over 800 people participated in the survey, providing the quantitative basis for this report.

In addition to the survey, BCNPHA led a variety of focus groups and interviews with people with developmental disabilities and their family members in regions across the province. The purpose of these focus groups was to delve deeper into issues that were uncovered through the survey and ask participants “why” questions that emerged from the data to help uncover more qualitative aspects related to housing needs. Unfortunately, the COVID-19 pandemic presented unique challenges for assembling large groups of people in person, so some of the focus groups were conducted over the phone.

This report weaves together information from both the survey and the focus groups to develop a picture about the diversity and commonalities of experiences related to housing for individuals with developmental disabilities and their families. The report will first provide an overview of the survey as well as some methodological considerations and will then launch into providing some

key demographic information of the individuals and families who participated, followed by a more integrated discussion of the survey data and focus groups.

Limitations and Need for Future Research

There are various limitations associated with the report, which highlight the need future research. Many questions emerged throughout the research process, which points to a need for more housing research related to people with developmental disabilities in the Canadian context, since currently there is little literature on the matter.

As well, as discussed later there are small samples from survey participants who identified as Indigenous and those who live in Northern communities. More research to understand the needs of urban and rural Indigenous people and the unique challenges faced by residents of Northern communities is needed.

Also, while the survey managed to garner responses from a range of household income types, the focus groups tended to attract higher-wealth and higher-income families who likely have different experiences related to housing need and demand than low-income families.¹ This includes differences related to the capacity for families to leverage personal home equity, pay for housing or other material advantages associated with higher wealth and income. While the survey does capture some nuance related to low-income experiences, more research in this vein would also be useful.

¹ While we did not ask about the wealth or income of participants who participated in the focus group, it was inferred from references to home ownership and capacity to leverage home equity relating to housing, or references to professional jobs.

CLBC's Quality of Life Survey

In addition to the survey and focus group data gathered by BCNPHA, this report uses data gathered by CLBC on the provision of residential services and from answers to questions from *include Me!*, CLBC's quality of life survey.

As of March 31, 2020, CLBC provided supports and services to 23,389 individuals with developmental disabilities and autism and fetal alcohol spectrum disorders. Of this total number, the largest age cohorts were those between ages 20-29 and 30-39 (see Figure 1). In fact, together these two age cohorts comprise 63% of individuals served.

The biggest age cohorts served by CLBC who do not receive any residential services track closely to overall numbers. As of March 31, 2020, 14,368 individuals served by CLBC received no residential services. Individuals between ages 20-39 comprise 74% of those receiving only non-residential services.

CLBC caseloads increase an average 5% per year, with transitioning youth comprising the majority of newly eligible individuals. This is reflected in larger numbers of young adults, providing an important demographic backdrop to housing survey findings.

In addition to CLBC service data, in 2019/20, CLBC worked with R.A. Malatest and Associates to add additional housing-related questions to the *include Me!* survey. *Include Me!* is a CLBC project which invites individuals to participate in a survey that measures quality of life from their perspective. Since 2012/13 over 7,000 surveys have been completed. In this last survey year, when the survey administration concluded in January 2020, data had been collected from, or on behalf of, 1,131 individuals, of which 1,082 answered additional housing-related questions. The *include Me!* survey is based on the *My Life: Personal Outcomes Index™ (My Life)*, a framework developed by internationally

Figure 1: Number of Individuals Served by CLBC By Age Cohort

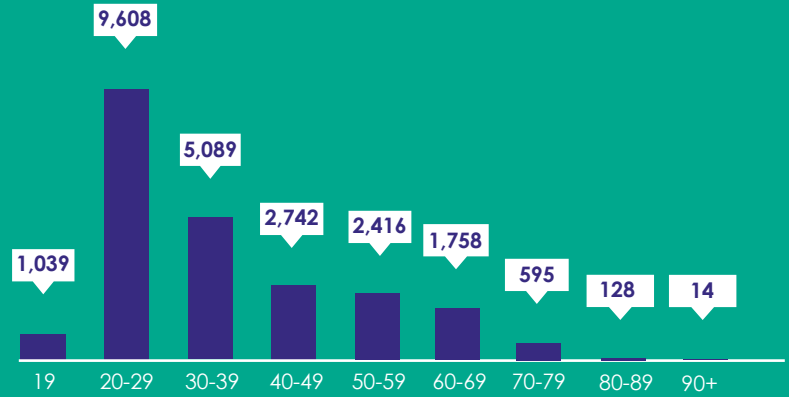
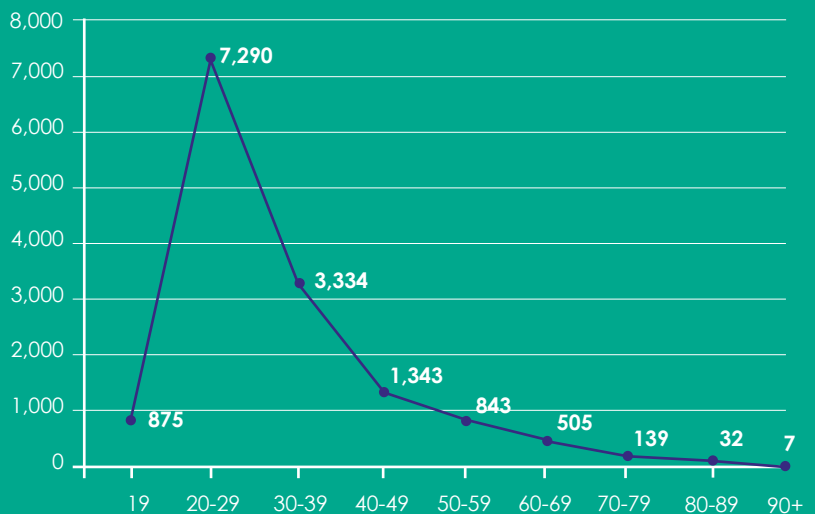


Figure 2: Individuals Receiving Non-Residential Services By Age Cohort



renowned Dr. Robert Schalock to measure quality of life for persons with developmental disabilities. The *My Life* framework is based on eight quality of life domains, which are grouped into three key factors: *Well-Being, Independence, and Social Participation* (see Table 1).

A question regarding housing satisfaction was analyzed to determine how this factor may impact other quality of life domains for *include Me!* respondents. Housing satisfaction was correlated with all but one of the quality of life domains (See Table 2). This reflects the importance of housing in the lives of individuals with developmental disabilities and reinforces themes from focus groups.

Housing Survey Data – Overview

The survey was the first component of this research initiative. It provides a baseline for understanding various issues related to demographics, housing arrangements and preferences and supports for individuals with developmental disabilities, their families and their paid support. The survey asked participants to identify which group they identified with, and framed specific questions for each group:

1. Individuals with a developmental disability, autism or fetal alcohol spectrum disorders who are eligible for CLBC services
2. Family members/unpaid support
3. Paid caregivers/support

In total, the survey gathered responses from 810 individuals. Figure 3 breaks out the total responses by group.

The survey sought to solicit feedback from individuals with developmental disabilities themselves, as family members and paid caregivers may not always reflect or understand their concerns, preferences and lived experiences related to housing. Self-advocates (people with developmental disabilities advocating for themselves) also participated in question design and testing of the survey's language, visuals and survey logic.

Of the 162 individuals above who identified as having a disability, 107 said that they qualified for supports for persons with a developmental disability, 23 qualified under the personal supports initiative, 19 stated

Table 1 - My Life: Personal Outcomes Index™ Key Factors and Associated Domains

WELL-BEING	INDEPENDENCE	SOCIAL PARTICIPATION
Emotional Well-Being Physical Well-Being Material Well-Being	Personal Development Self-Determination	Rights Interpersonal Relations Social Inclusion

Table 2 - Domain Correlations with the include Me! Housing Question

Quality of Life Framework		2019/20 Domain Scores Correlation with: <i>Likes the room where they live</i> n=1,082
Factor	Domain	
Well-being	Emotional Well-Being	0.392
	Physical Well-Being	0.412
	Material Well-Being	0.328
Independence	Personal Development	0.301
	Self-Determination	0.271
Social participation	Rights	0.239
	Interpersonal Relations	0.249
	Social Inclusion	Weak
Moderate Association .2 ≤ r < .5		Large Association r ≤ .5

Source: Survey 2019/20

Note: This report focuses primarily on the responses from individuals and families / unpaid support, as these two groups play the most important part in shaping housing outcomes for people with developmental disabilities.

they did not qualify for CLBC supports and 16 did not know or preferred not to answer.²

A majority of survey respondents (479) were family members or unpaid caregivers who provided for well over half (59%) of all responses. Paid caregivers provided another 169 responses to the survey, while 51 responses (not shown in the Figure 3 above) came from “other” categories, such as social workers, service providers and health professionals.³ Given that this report centres the voice of people with developmental disabilities and their families, the paid caregiver data is not factored as heavily into the descriptive analysis below.

Figure 4 shows the breakdown of survey respondents who indicated they have a developmental disability, based on which CLBC funding stream they are eligible for. In total, 130 individuals were eligible for CLBC services.⁴

Note: In the sections below, participants were given the choice on each question “I prefer not to answer”. As such, while 130 individuals with developmental disabilities completed the survey, the totals below do not always add up to exactly 130. The same goes for family and paid caregiver responses.

Demographic Picture

The survey asked demographic information of its participants, including age, gender, income and employment. This section of the report provides a snapshot of the various demographic variables that were captured in the survey, providing a picture of

² For the individuals who indicated that they did not know which stream they fit under, the survey prompted another window which asked the participants to identify which group they most closely identified with.

³ For those who selected “other”, there was room to leave comments and thoughts surrounding housing for people with developmental disabilities.

⁴ The total in Figure 2 adds to 165 individuals. This is because 3 individuals initially identified as 3 “self-advocates”, and were then prompted to identify which group they were most closely associated with, which prompted them to select “individual with a developmental disability”. This added three responses to the totals in Figure 2.

Figure 3 – Survey Responses: Respondent Distribution

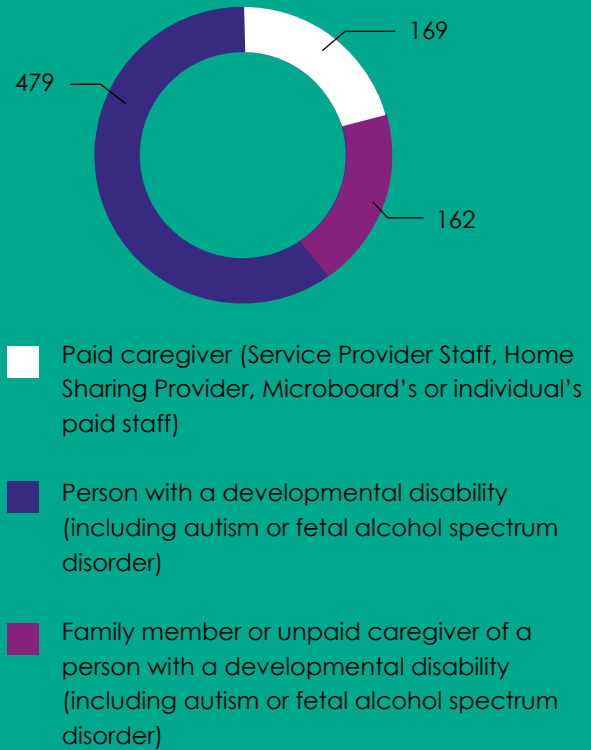
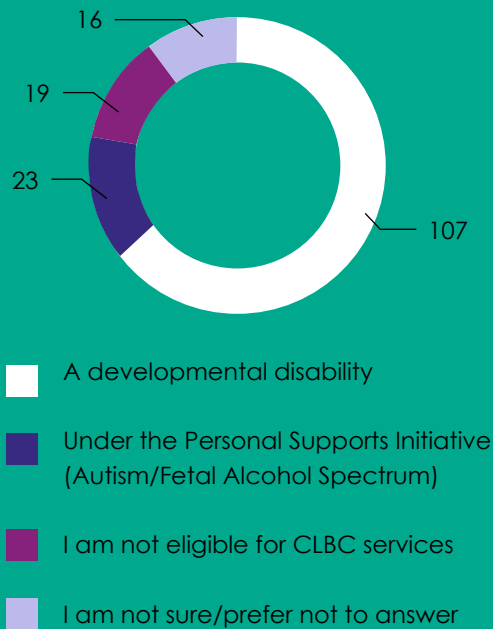


Figure 4 – Individuals Who Identified Having a Disability, by CLBC funding stream



who the individuals with developmental disabilities and their families are. It is important to note that not all of the demographic questions were asked to the families, given the report wanted to focus more prominently on individuals with developmental disabilities themselves. The survey did not ask for demographic information from the paid caregivers.

Location

The tables below show the different regions that individuals and families who completed the survey reside in. It should be noted that the regions listed do not strictly align with CLBC service regions. Table 3 provides an overview of where individuals were located and Table 4 shows where family members/unpaid support were located. The responses are only shown for those who decided to answer the question.

Gender

The survey asked individuals with a developmental disability about their age and gender. Of 117 responses,

there was a near even split between those identifying as men (50%) and women (47%), with the other 3% of responses for individuals identifying as non-binary/gender fluid, and others preferring not to answer the question. The survey did not ask family members or paid caregivers to state their gender, as this was not directly relevant to understanding housing needs of individuals with disabilities.

Age

The survey asked both individuals and family members/unpaid support to state their age. The median age for individuals participating in the survey was 29, while the median age for family members/unpaid support was 55 years old.

As discussed further below, parents overwhelmingly tend to be the primary caregivers of individuals with developmental disabilities. These figures show a general trend that parents are moving into their senior years and getting to an age where they are worried about their capacity to care for their loved ones, while many

Table 3 – Respondents by region (individuals)

	Number	Proportion
Vancouver Coastal (Greater Vancouver, North Shore)	54	54%
Interior (Kelowna, Kamloops, Coldstream, Trail)	17	17%
Island (Victoria, Nanaimo, Duncan, Parksville)	15	15%
Fraser (Abbotsford, Chilliwack)	8	8%
North (Prince Rupert, Fort St. John, Prince George)	6	6%
TOTAL	100	100%

Table 4 – Location of Family Respondents

	Number	Proportion
Vancouver Coastal Region	126	43%
Interior	95	30%
Island	48	15%
Fraser	28	9%
North	20	6%
TOTAL	317	100%

individuals with disabilities are at an age where they want more independence and control of their lives, desiring different living arrangements. Many family members articulated significant stress, anxiety and concern about aging and the implications this has for housing their loved ones and the increased limitations on being the primary caregiver. They are worried about the future.

The following quotes from the survey and focus groups help to demonstrate how this is a persistent issue:

Concern Over Aging and Housing Arrangements

Group: Family Members

"[My loved one] is 23 and would like to experience independence from the parent - but need supports around shopping, meal preparation, needs a roommate as doesn't like being alone and also needs support around medical [appointments] and issues - they know that I am getting older and cannot sustain the level of support due to my own health issues."

"She doesn't want to live in her parent's home forever. She wants to be like other 31 year olds."

"I am aging with my own disabilities. I want my daughter to be settled in her own home in a supported Community. When something happens to me I want to know that her life won't go into a tailspin. She wants to live in a community with her peers. With supports. Without old sick parents."

Group: Individuals

"I am thirty years old and no longer want to live with Mom or Dad."

"I'm 28 years old. I want to be able to move out and have more freedom and become an adult."

Indigenous

Of 117 individuals who answered the question, eight individuals identified as Indigenous. Of these eight participants, five identified as First Nation, two identified as Metis and one identified as Inuit. Six of these individuals indicated that they lived off-reserve, while one indicated they live on-reserve, and another preferring not to answer the question.

Additional research is required to further understand the diversity of housing needs and preferences for those urban and rural Indigenous people across B.C. who have developmental disabilities.

Employment and Income Individuals

Individuals were asked about where they derive their sources of income to provide an indicator of their capacity to pay for housing. Individuals were allowed to select multiple answers, and the data showed that of 117 responses, 68% indicated that they received Persons With Disability (PWD) assistance from the provincial government, 23% indicated they receive money from employment, 3% from trust funds and 6% indicated that they do not receive income sources from any of the above.

In addition, respondents were asked if they have a Registered Disability Savings Plan (RDSP), to which 55% of individuals and 65% of families said that they did have one. This shows that there is some financial planning on behalf of individuals and families for securing future income sources, and that efforts to allow these savings plans to be used toward down payments on homes could be an effective policy tool for increasing housing options for more moderate- and higher-income households who tend to take advantage of the program.

A theme to emerge from both the survey and focus groups is the inability for individuals to pay for housing, given that the shelter component of provincial disability assistance is the most prominent source of income. Provincial disability assistance rates are set at just over \$1,180 for a single individual, of which \$375 is designated toward shelter costs. Individuals and families noted how this acts a structural barrier to more independent living, as the only housing that is affordable at this cost are home sharing arrangements or subsidized units in non-profits and co-operatives that are in limited supply.

Families



Lack of Money Through PWD as Barrier to Housing

Group: Family Members

"We have ALWAYS needed to supplement our loved one's living expenses as the PWD Benefits are ludicrously too low to live on."

"\$375 makes housing unaffordable. My son cannot find a rental that is appropriate or affordable. There are no housing choices available in my community."

Group: Individuals

"Government doesn't pay enough in pwd for me to live on my own. I'm lucky I have my mom but I'd really like to be able to live independently. Rent has gone up in BC but pwd hasn't, not nearly enough."

"PWD and limited funds will not be able to afford to live in North Vancouver with 375.00 monthly as given today."

"Lots of people want to be more independent but cant afford to or live in a safe environment and so many people on PWD are vulnerable."

Family members were asked to state their overall household income. As can be seen in Figure 5, there is a broad diversity in the income composition of families who participated in the survey. This shows the range of capacity for families to support their loved ones with material resources to afford housing. While some families have sufficiently high wealth and income, many do not.

When compared to family income groupings contained in the 2016 census (Figure 6), these two data sets show similarity up until the higher income

Figure 5 – Income Groupings of Families, N=317

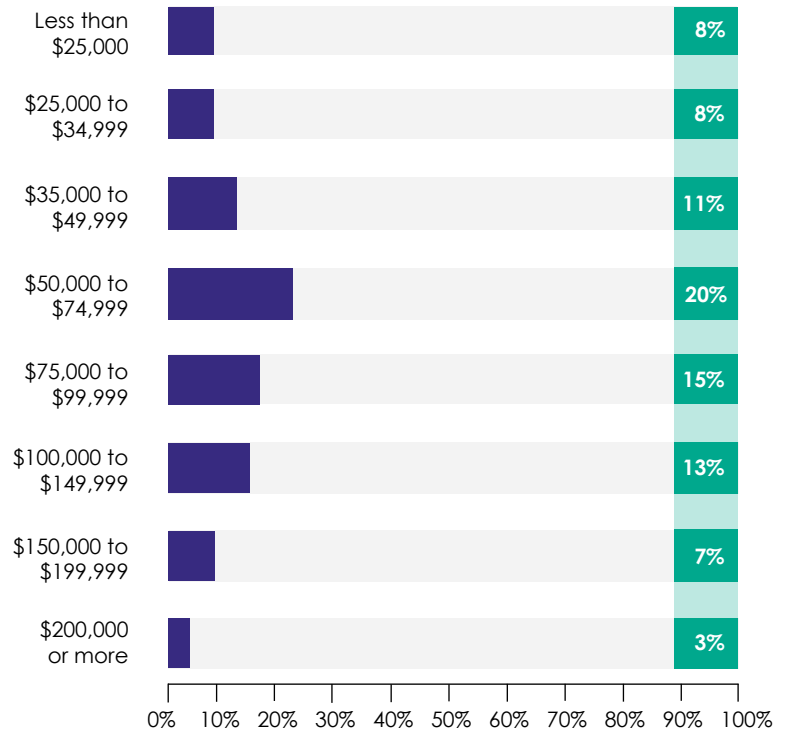
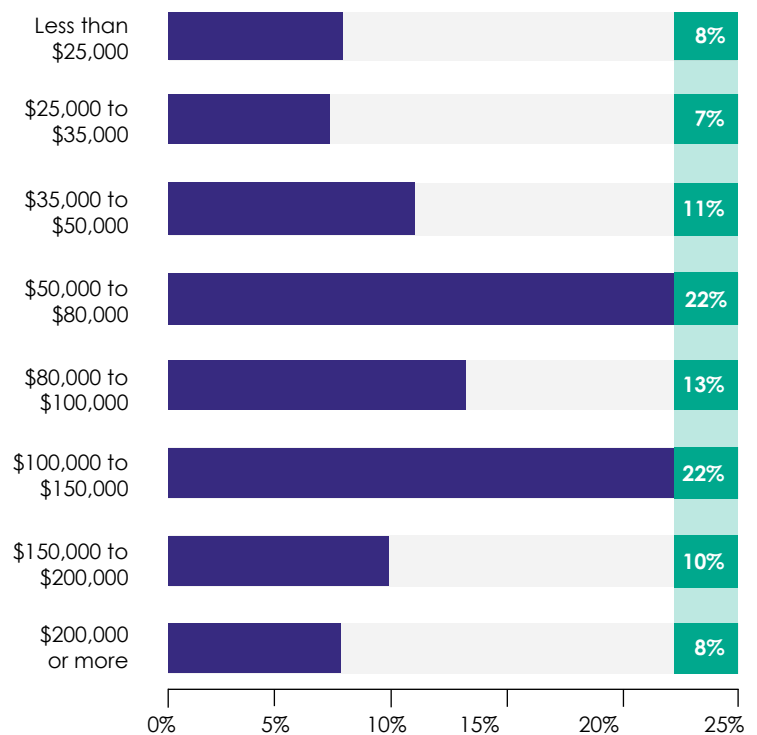


Figure 6 – Income Distribution of All Households in BC, 2016 Census: Before-tax Census-Family Income Groupings, BC 2015 ⁵



⁵ 2016 census, Beyond 20/20 table 98-400-X2016104

Table 5 – Average Housing Cost by Family Income Grouping, and Range of Housing Cost-to-Income Ratios

Income	Average housing cost	Housing cost to income ratio
\$25,000 or less	\$1,670	83% or more
\$25,000 - \$35,000	\$1,727	83% - 59%
\$35,000 - \$50,000	\$2,057	59% - 49%
\$50,000 - \$75,000	\$2,415	41% - 30%
\$75,000 - \$100,000	\$2,398	28% - 29%
\$100,000 - 150,000	\$3,287	21% - 26%
\$150,000 - 200,000	\$3,600	14% - 22%
\$200,000	\$3,900	14% or less

Figure 7 – What is Your Current Living Arrangement?—Individuals



- With my parent(s) or step-parent(s)
- With my brother(s) or sister(s)
- With my grandparent, aunt/uncle or other family members
- With my husband, wife, or partner
- With a roommate/non-related friend
- With a paid caregiver or home sharing provider
- In a group home
- In an assisted living facility or long term care facility

bands, diverging at \$100-\$150,000. This could indicate that the survey tended to attract more middle-income people, although more analysis is necessary.⁶

Families were also asked to state how much their monthly housing costs were on average. As can be seen from Table 5, families with income below \$50,000 tend to experience high housing costs that will on average take up a much higher proportion of their income, ranging from just under half (49%) to 83% or more.⁷ This brings into question the material resources that low-income families have to support the housing choices of their loved ones with developmental disabilities if they themselves are severely cost burdened.

Living Arrangements

The survey asked individuals to identify what their current housing arrangement was. Of 126 responses, a majority of respondents (54%) indicated they lived with their parents or step-parents, while 16% indicated that they live with siblings. The rest of the responses were split between partners other family members like grandparents, aunts or uncles, or with roommates. Figure 7 provides a summary of the responses to this question by individuals. It shows that approximately 70% of individuals in this sample are living with their families. This is consistent with studies in Canada and the U.S. that indicate that 70-80% of adults with developmental disabilities live with family members (CAACL, 2008; Braddock, et al, 2015; CQL & The Arc, 2019).

Similarly, individuals were asked what the most important

⁶ Refers to gross income. Note that the census income groupings do not completely align with the income groupings the survey collected.

⁷ Housing costs includes renter and ownership costs, as participants had a mix of tenures.

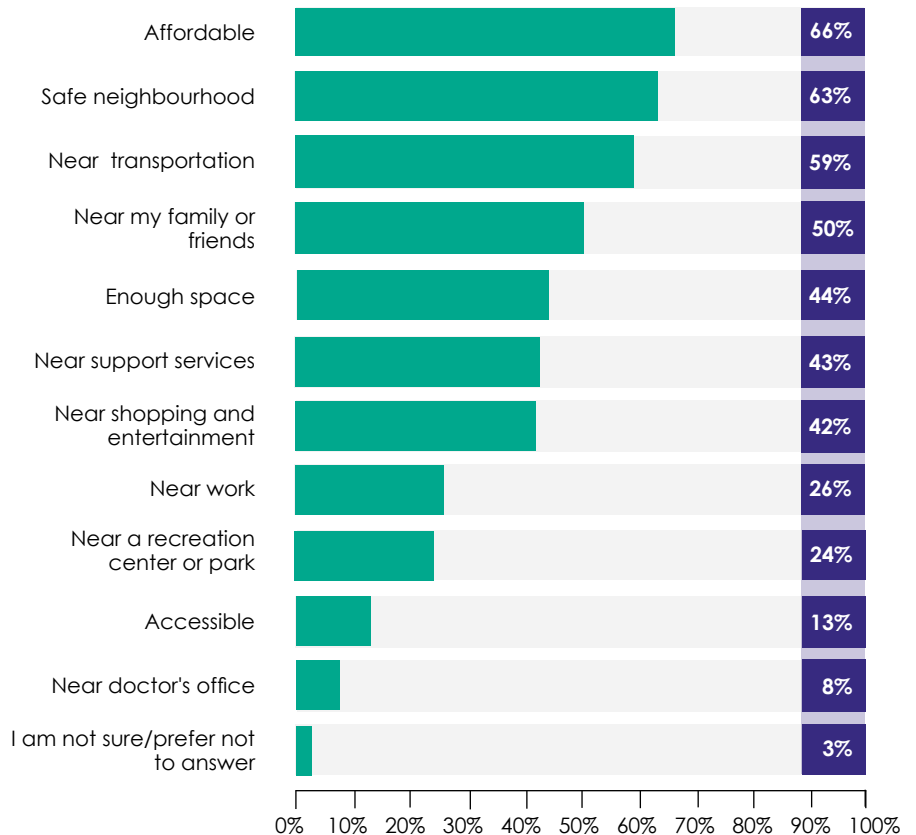
Individuals were asked what the best thing about their current living arrangement was. Participants were allowed to check multiple answers. Figure 8, shows many items are weighted similarly:

Figure 8 – What are the best things about where you live now?



aspects of housing were, not just of their current home, but of housing in general. Participants were allowed to select multiple responses (Figure 9). A strong majority (66%) of individuals noted that affordability was a key concern, followed by safety (63%), being close to transportation (59%), being near family and friends (50%), and living with enough space (44%).

Figure 9 – What is most important for your housing arrangement? - Individuals



Preferences for Housing

Individuals and families were asked if they would choose a different living situation than their current one. Of the 117 individuals who responded to the question, 44% indicated "no," while 49% indicated "yes," with the rest choosing not to answer the question. Of the 454 family members who responded to the question regarding their adult child, sibling, or loved one, 33% indicated "no," and 54% indicated "yes," with the rest indicating they preferred not to answer the question or choosing "other."⁸ These responses indicate that a near majority of individuals, and a majority of families see the current housing arrangement as not being the best suited for them. A small number of individuals currently in Home Sharing arrangements

⁸ For those who selected "other", a common theme was that their present housing situation was working well, but in the future they would need another arrangement.

responded to the survey (12 individuals) and 50% indicated a desire to move into independent housing. Given the small sample size however, more research is recommended in this area.

It is clear that there is a desire for more housing options and different living arrangements for individuals with developmental disabilities and their families. The survey showed differences in opinion however between individuals and families about which types of housing are preferred.

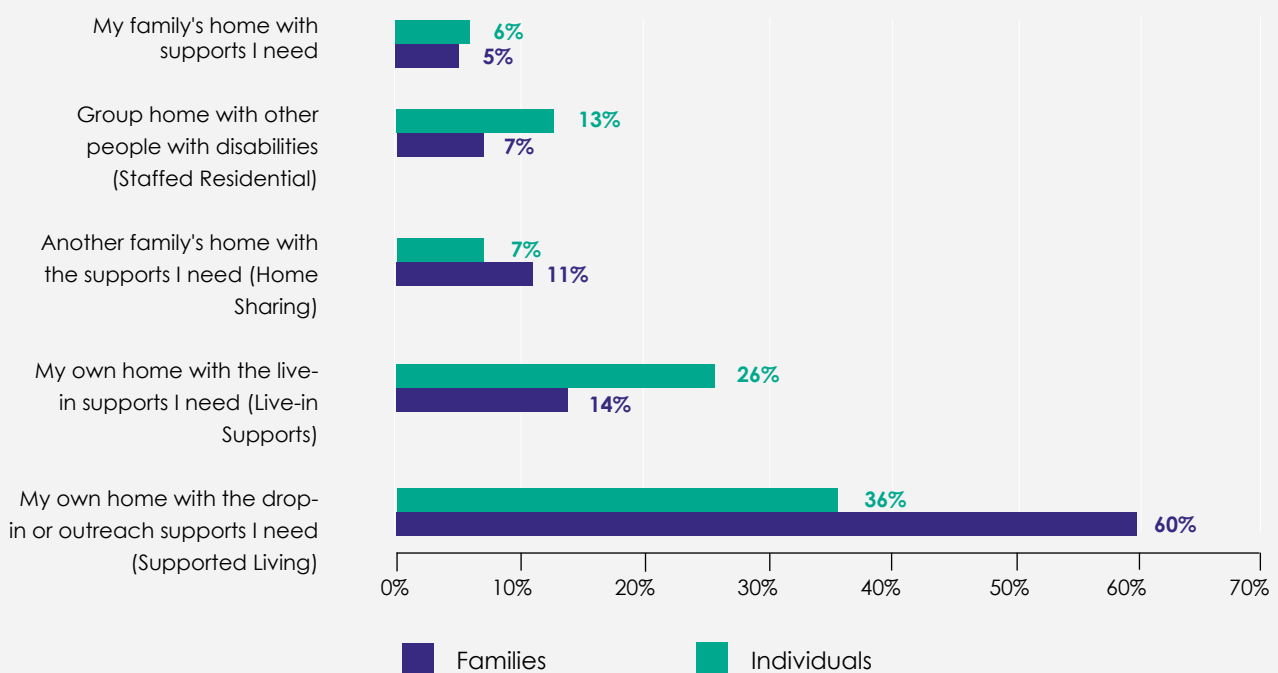
Figure 10 compares the responses between individuals and families about which type of housing option each prefers.⁹ Individuals were much more likely than family members to select living in their own home with drop-in or outreach supports, with 60% of individuals preferring this option and only 36% of family members preferring this option. Families on the other hand were more likely to prefer live-in supports or group homes for their loved one.

These results show that while independent housing is a preference for many families and individuals, there is some divergence in opinion about what the best housing and support options are. The focus groups further elaborated on these differences in opinions. Many families feel as though their loved ones need more support, and living independently is simply not an option:

“Another big factor for our daughter is that she shouldn't be home alone ever, and I think that will exist to her senior years. She'll put an element on and put a pot on, go to the bathroom and it could cause a fire. She has to have caregivers living in the same facility, whereas that wouldn't necessarily be true for other people's kids.”

This sentiment was continually repeated and demonstrates that the individual's level of need is

Figure 10 – Comparison of which housing option families and individuals would choose



⁹ This question was only asked to those who indicated "yes" to wanting another living arrangement.

related to what the family thinks is best for them and therefore influenced by their awareness of various housing and service models. Families often referred to health and safety-related concerns, while individuals stressed their desire for independence and the ability to make their own life choices.

At the same time, a major theme to emerge from the focus groups was how independent living fosters more independence. Family members whose loved ones were living independently, frequently commented how they saw growth in their ability to live and act independently. One family member, who has seen their child get their own independent housing stated: *"I never thought this would happen, but she started cooking!"* The participant was genuinely surprised that their child could ever be independent enough to cook on their own.

One parent commenting on their perception of their child's independence mentioned: *"I think a lot of the time it's in your head ... sometimes we're our own worst enemy. You think your child can't [be more independent], but they can. I think a lot of the time it's in your own head. For instance, I think that my daughter can't take the bus alone so I'll drive her, when really, she can take the bus alone."*

Similarly, another parent seeing their child move into more independent living said: *"I don't think we give our kids enough credit for being capable. Yeah, I think backing away is something important we've learned."*

Another person remarked: *"My daughter has physical disabilities as well and for her entire life I had to wash her hair Within two weeks of living by herself, she figured out how to wash her hair herself."*

Family members who had seen their loved ones move into more independent living arrangements, indicated many times they saw it translate into the person with developmental disabilities becoming more independent. This finding is obviously closely related to the needs and capabilities of the individual and more independent living is not always a realistic option. However, in many cases there are benefits to more independent living.

Moving

In addition to asking individuals about their satisfaction with their current housing, and whether they would choose a different living situation the survey asked individuals if they were thinking of actively moving from their current home. Of 117 responses, 48% of individuals indicated that they were seeking to move, while 38% said they were not, and 15% declined to answer the question (Figure 11 following).

Of the individuals who responded "yes" to wanting to move, the survey asked when they were planning to

Figure 11 – Are you thinking about moving from your current home? - Individuals

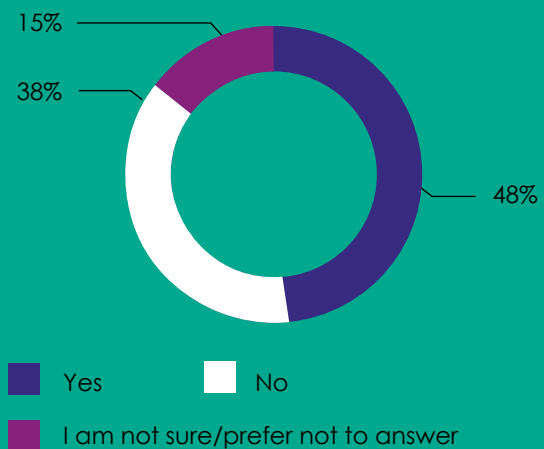
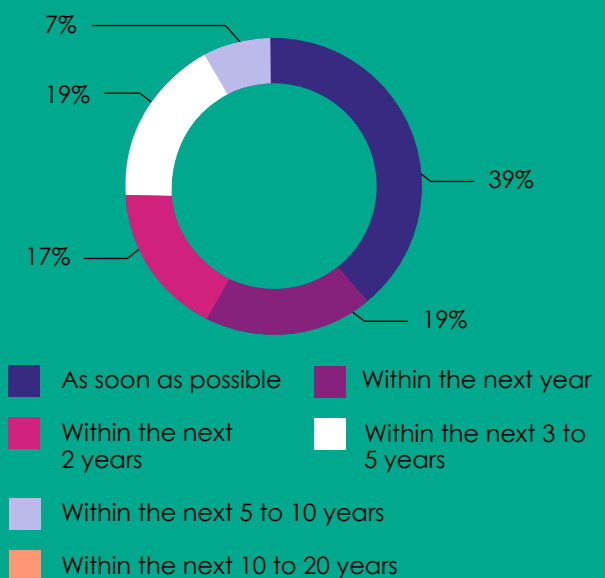


Figure 12 – When would you want to move? - Individuals



do so (Figure 12). Of the 56 individuals who indicated they wanted to move, 39% said as soon as possible, 19% indicated within the next year, 17% within the next two years, and the remaining respondents indicated three years or more. In other words, 75% of respondents who want to move, want to do so within the next two years. Once again, this was consistent with family member responses about their adult children, sibling, or loved one.

The survey also provided the opportunity for individuals, family members and paid caregivers to comment on reasons for individuals wanting to move out of their current living arrangements. There were many themes that were reinforced through these answers, including the desire for increased independence, choice and control over their housing situations.

Independence

Group: Individuals

"To achieve my goal to live on my own & prepare myself for living on my home."

"I want to live with friends."

"More independence."

"To be more independent."

"I want to be like everyone else. I want a girlfriend and to have privacy. I want to do things my way in my own place."

"I would enjoy making the decisions that govern my daily life. I want more than just my bedroom as my only unshared space."

"Personal space. Privacy. Family too much involved."

"To be more independent by living away from parents."

"I need my own space. Living with my brother or more than 1 person triggers and agitates me."

"I would like to try living on in my own home, not right next door to mom and dad but with my supports so i can be a normal adult like everyone else."

Affordability and Suitability of Housing

Group: Individuals

"My house is old, falling apart, moldy, critters in attic, etc."

"Unsafe conditions, fires, no maintenance, mean landlord, no pets, no guests, no bath, like a prison."

"The area I live in has a lot of hills and I need flatter surfaces for my wheelchair use as I am hypersensitive."

"It's very small for four people."

"I don't feel safe here and the constant noise is ruining my life/sleep."

Group: Paid Caregivers

"The duplex is very old, has had issues with rodents, mold. Costs over 50% of their income and the place is shared."

"Living conditions are poor, typically the affordable housing for a person living on a fixed income like PWD is sub-standard housing. However, there are limited to no other options within our community (Kootenays)."

"The individual would like to be more independent and have more freedom."

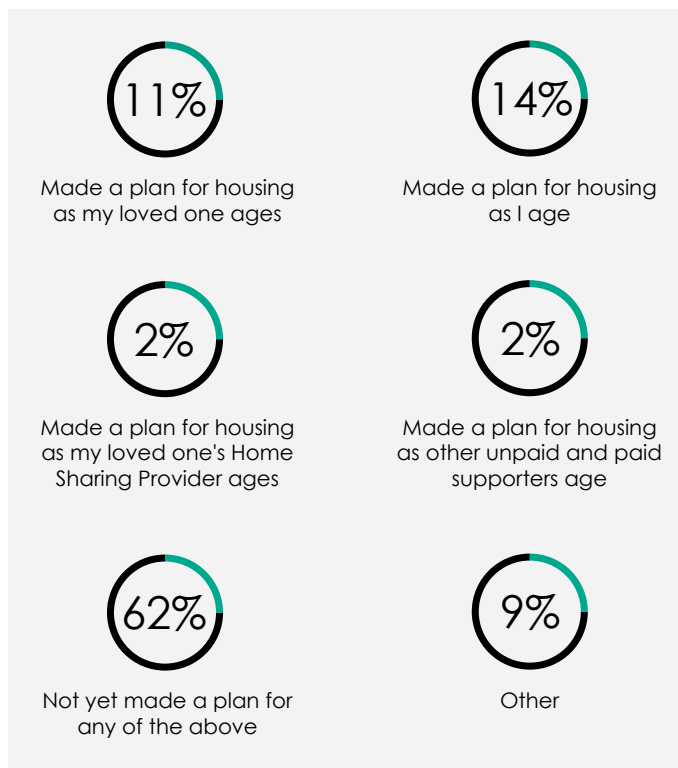
"Would like to live independently from his family; would like to get married and have children in his own home."

"They are isolated, living in an affordable basement suite that is out of town, sharing with a roommate they don't like to afford rent, and their limited mobility means they can't get down their front stairs independently."

Housing Plans

To understand the extent to which families are planning for future housing arrangements, the survey asked family members if they have a housing plan for their loved one.¹⁰ As shown in Figure 13 following, of 499 responses, 62% of family members/unpaid support indicated that they do not have a housing plan at all, 27% do have some form of a plan, while 11% indicated “other” choosing to add text answers to the question.

Figure 13 – Housing Plans



As can be seen from the data, there is a general lack of family planning around housing. Survey respondents and family members in the focus groups elaborated on why this was the case. These are elaborated further below.

A Lack of Planning Resources

"The reason people don't have plans is the lack of information out there."



"I think the family has some responsibility [for housing plans], however their facilitator needs to tell them what's available."

"I think roughly me and [my] wife are aware of different housing options, but we don't know the pluses and minuses of each option."

"I am very uncertain about what is out there in terms of options."

Structural Barriers (lack of affordable housing supply, necessary income)

"Can't move forward with the plan to live independent with minimal support as there are too many barriers to inclusive affordable housing. So, I guess one could say we do not have a plan."

"I want to have a plan for him for housing in case something happens to me but find it really difficult in this town to find any kind of solutions."

"We have a plan but it's aspirational i.e., the plan can only unfold once the circumstances exist to support it."

"Want to make a plan but nothing affordable available."

Lack of Supports

"We've made a plan but we as parents are paying for it, using our retirement savings. Not an adequate plan but there is no other option."

"The plan has to be supported by CLBC. So far... no current model to match our vision."

"Trying to make a plan for housing as I age, but services do not currently exist".

"I can make all the plans I want, but if the supports are not available to us, there is no point."

¹⁰ Respondents were allowed to check all that applied, given that more than one planning scenario could apply to a family's particular context.

“ ”
Stress

“Some people are so exhausted and feel paralyzed—they are working and can't even take the time to think about it; they are living day-by-day.”

Different need between families and individuals

“We are developing a plan that works for both us as retiring parents and our kids. We have very different needs and wants, so it's challenging. Right now, we are considering many options and looking to meet other families who might like to develop a plan together.”

Siblings Within the Context of Housing Plans

Given that siblings were identified in the survey as the second largest source of support for individuals with developmental disabilities, the focus groups asked about their experiences with how they would be involved with housing planning after their parents were no longer able to provide care.

Some siblings expressed anxiety about the future: “I’ve definitely thought about what happens when our parents pass away... I wonder how to manage the logistics... I can't imagine being there seven days a week.” Siblings can feel that they cannot be as heavily involved in supporting their sibling with developmental disabilities as their parents, and that there is a considerable amount of uncertainty about the future. This indicates that support planning is not always thought about. Another parent also commented to this effect:

“My kids are really afraid of death because I’m a single parent. They are freaked out, because I’ve been mom, dad, and everything. I’m terrified that I won’t be able to do it anymore. I cannot let go for one minute because who is going to look after them? It affects the second generation, the siblings. You know, my one son says, “I can never take a job outside of Vancouver, because I have to be here with them.”

This helps to indicate that that more supports are required for siblings related to housing planning. Given an aging parent population, siblings will frequently be relied on to find housing and support solutions for their siblings and this may require targeted education and outreach.

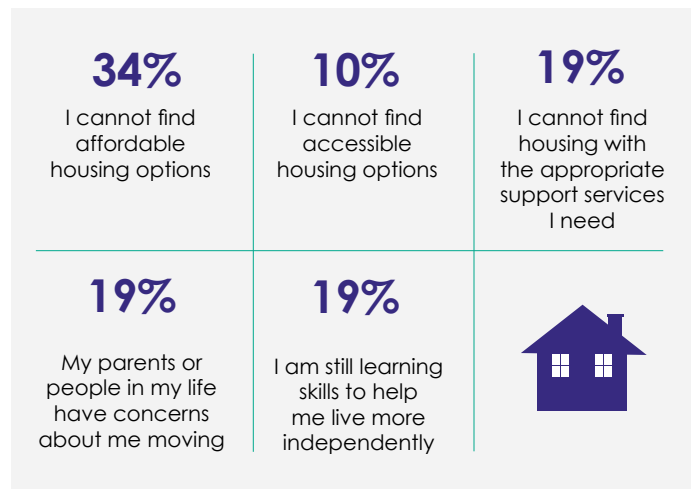
It was also identified through the focus groups that families need help accessing resources. An advocate who participated in one of the focus groups articulated the need for a central resource hub for the entire province, for individuals to call in to access information on housing options for loved ones.

Barriers to Housing

Individuals were asked about the biggest barriers to finding housing. Of 102 responses (Figure 14), 34% indicated that finding affordable housing was the biggest barrier, followed by not finding housing with appropriate supports nearby (19%), having parents or people in their lives concerned about them moving (19%), still learning skills to live more independently (19%), followed by a lack of accessible housing options (10%).

When families were asked about how much their loved one could afford, of 458 responses, 50% indicated they could only afford less than \$375 per month, while another 35% indicated that they could afford a housing cost of less than \$500 per month (Figure 15). In other words, 85% of family members indicated that their loved ones can only afford \$500 or less per month. This puts independent housing out of reach for many people with developmental disabilities.

Figure 14 – Barriers to Housing - Individuals



One individual encapsulated these barriers in their response: "I can't find housing that is even humane to live in at a decent price in a good neighbourhood, and I need it to be with the proper support systems and close to my jobs and medical clinics and people who are helping me."

This indicates that it is more than just affordability acting as a barrier for people with developmental disabilities accessing housing, there are also overlapping issues of suitability, physical accessibility, proximity to nearby supports, and issues with family members having concerns about people with developmental disabilities living by themselves.

These themes related to housing barriers were further elaborated in the focus groups and survey:

Figure 15 – How much could your loved one afford? - Individuals



Lack of Affordable and Suitable Housing Supply

Group: Individuals

"There is not enough low-income housing place for people like me."

"I can't afford to live on my own, so I will have to move in with someone."

"I need a new two-bedroom accessible house with a close accessible parking spot ... It is extremely hard to hire caregivers with a driver's licence for 17.75/hr."

"I want a co-op arrangement where I can meet friends and learn independence."

"The 375.00 needs to change. Fragmented government policies are one of largest barriers to individuals living a happy, inclusive life. Let's work hard, think smart and address the need for affordable housing."

Restrictions on Pets

Group: Individuals

"I have to keep my pets, even though I have too many for anywhere. It would be traumatic to be forced to give up one and I have PTSD."

Desire for Independence

Group: Individuals

"I don't want a caregiver who tells me what to do, when to go to bed, what to eat etc. I can make those decisions myself."

"I would live in a shack or a shed if I could own it and have some privacy, a garden and a pet. Help us!"

"I would like to live independently but I also need support."

Lack of Supports

Group: Family members

"He is in his early 30's and as a normal part of his maturation has wanted to move out since his 20s. Not having adequate supports has been the main barrier."

Supports

The survey asked individuals if they require help with daily living activities such as cooking, laundry, personal care and financial management. Of 117 responses, 77% of individuals indicated that they require help with daily living, 17% indicated that they do not receive help and 6% preferred not to answer the question.

To determine whether support systems are primarily in the family or with roommates, the survey asked individuals who are the main people in their lives who provide them with supports. Respondents were able to check multiple responses. Of 113 responses, 61% indicated their parents or step parents were their main supports, followed by siblings at 25%, partners (5%), roommates (4%) and other family members (4%). In other words, the vast majority of support was contained within the structure of the family, with a small minority coming from roommates.

The type of supports was also broad ranging from getting to appointments or running errands (20%), preparing meals (19%), looking after personal finances (18%), everyday housework (18%), personal care (12%), basic medical care (1%) and others such as doing social activities and making friends (1%).

Social Activity and Connection

A recurring theme to emerge from the focus groups related to support, for both individuals and families, was around social activities and connection in housing arrangements. Having opportunity to make friends, spend time with neighbours, have regular social outings and meaningful social connection was a major theme for housing planning. Many family members and unpaid support are concerned that their loved ones will be isolated if they move into more independent living arrangements. This theme was recurrent.

"We provide a nice home for [children's name], but it's boring for them. We're old, and they are not old. And we think we're pretty cool and exciting, but I guess we're not. So, their biggest need that we don't provide is the social need they need."

In the focus groups, individuals who were well supported in inclusive housing, as well as their family members, spoke about their social connections with neighbours and friends, and their active social lives. One participant,

who had their daughter move into independent living talked about the difference since moving in: *"I feel like I barely see my daughter anymore since moving [laughs] ... she is so busy with her friends and other sorts of social activities ... my daughter is very proud of living alone."* This supports the idea that social connection can be fostered in independent living arrangements, if it is planned for accordingly.

Accessibility

Individuals were asked about the accessibility of their homes to determine their suitability for those who may have both a physical and a developmental disability. Of 117 respondents, 11% indicated they did need physically accessible housing, while another 10% indicated that they do not need it now but will in the future.

Those who indicated they required physically accessible housing were asked how accessible their current home was. 40% indicated that their current home is fully accessible, 24% indicated that their home is only partly accessible and 28% indicated that their home was not accessible at all.

The respondents who said they needed physically accessible housing were asked what type of features would be required to make it accessible (Figure 16).

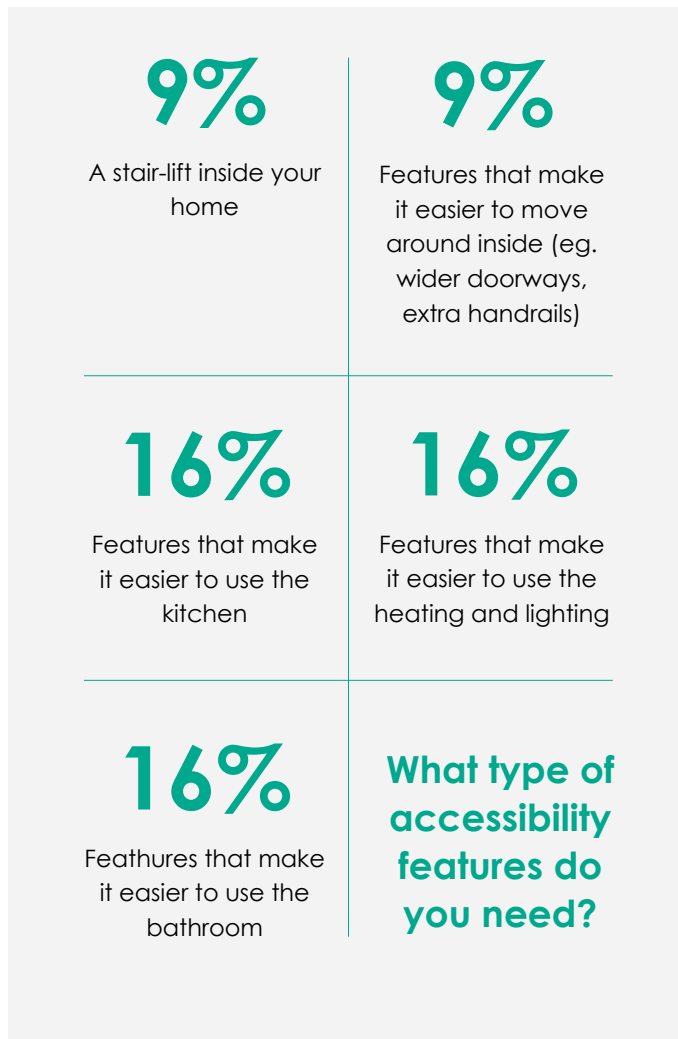
Figure 16 – What type of accessibility features do you need?

16%

Step-free access (no stairs) at the front of your home

16%

Automated doors



Housing Demand Estimates and Themes

As already noted, 70% of individuals responding to the housing survey report living with family members and 48% indicate a desire to move from their current housing situation. Of those wishing to move, 93% indicate a preference to move within the next five years with more than half (58%) preferring a timeline of either “as soon as possible” or within the next year. Statistics Canada research on adults living with parents shows that the age of adult children living at home has increased over recent years with close to 1.9 million people in Canada, or 9% of the adult population aged 25 to 64, living with one or more of their parents in 2017. This was more than double the figure in 1995 (StatsCan, 2019).

In focus groups, individuals with developmental disabilities and their families discussed having similar housing goals and timelines as their non-disabled siblings and peers, and such normative practices are consistent with best practices in the field of Community Living (Wolfensburger, 1970; Cocks, 2001; Wong & Stanhope, 2007). Taken with CLBC demographic and service information, it is conservatively estimated that 5,000 individuals with developmental disabilities will need housing over the next five years.

Conclusion

This research uncovered many commonalities and recurrent themes related to the housing needs, demands and preferences for people living with developmental disabilities and their families. Respondents came from all over the province and there were many common themes highlighted, which are summarized in the sections below.

Both individuals and family member survey-respondents and focus group participants indicated that **the most desirable housing and support model is having their own home with drop-in or outreach supports to meet their needs**. This preferred model was followed by having their own home with live-in caregiver supports to meet their needs. Taken together, 74% of individuals and 62% of families who responded to the question preferred a housing and support model in which they or their loved one lived in independent housing. Independent housing models support the “unbundling” of housing and services, meaning that an individual can change the organization that provides their supports without having to change their home, which is consistent with the principles of self-determination.

While the desire for independent living does depend on the level of support an individual requires, **in a lot of cases, people with developmental disabilities want to move to more independent living arrangements**. For instance, people with developmental disabilities are frequently living with their parents and are getting to an age (survey respondent average age: 29) where they are seeking more independence from the family home. They want to start leading lives for themselves, with supports built around that independence.

Many structural factors continue to work against the goal of independent living. There is a lack of affordable and accessible housing options in communities

throughout B.C., and especially in rural and more remote communities. The cost of rent in most regions of B.C. has well exceeded the resources available to most individuals with disabilities from government assistance and employment income. The timing of available housing and available supports do not always coincide, making independent living more difficult to achieve.

People with developmental disabilities want the same housing as everyone else. They want their housing and neighbourhoods to have social connections and activities, good transportation, leisure opportunities, amenities and decent housing that doesn't cost too much.

More independent living tends to foster more independent living. Frequently parents have perceptions about what their children are, or are not, capable of in terms of independence. **Many of the family members who have now seen their adult children move to inclusive housing and more independent living arrangements see a significant progression in that adult child being more independent**.

Many families do not have housing plans for their children that articulate where, how, and when their loved ones will live after they are no longer able to support them. **There needs to be more supports created to help families and individuals develop housing plans**.

Once again, there is significant demand for inclusive housing for individuals with developmental disabilities, both from individuals and families. **Surveys, focus groups, and non-residential service and aging data indicate that approximately 5,000 individuals with developmental disabilities need and want to move to new housing situations within the next five years**.

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