The housing needs and preferences of adults with intellectual disabilities in New Brunswick

A report prepared by
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For Willow Tree Community Inc

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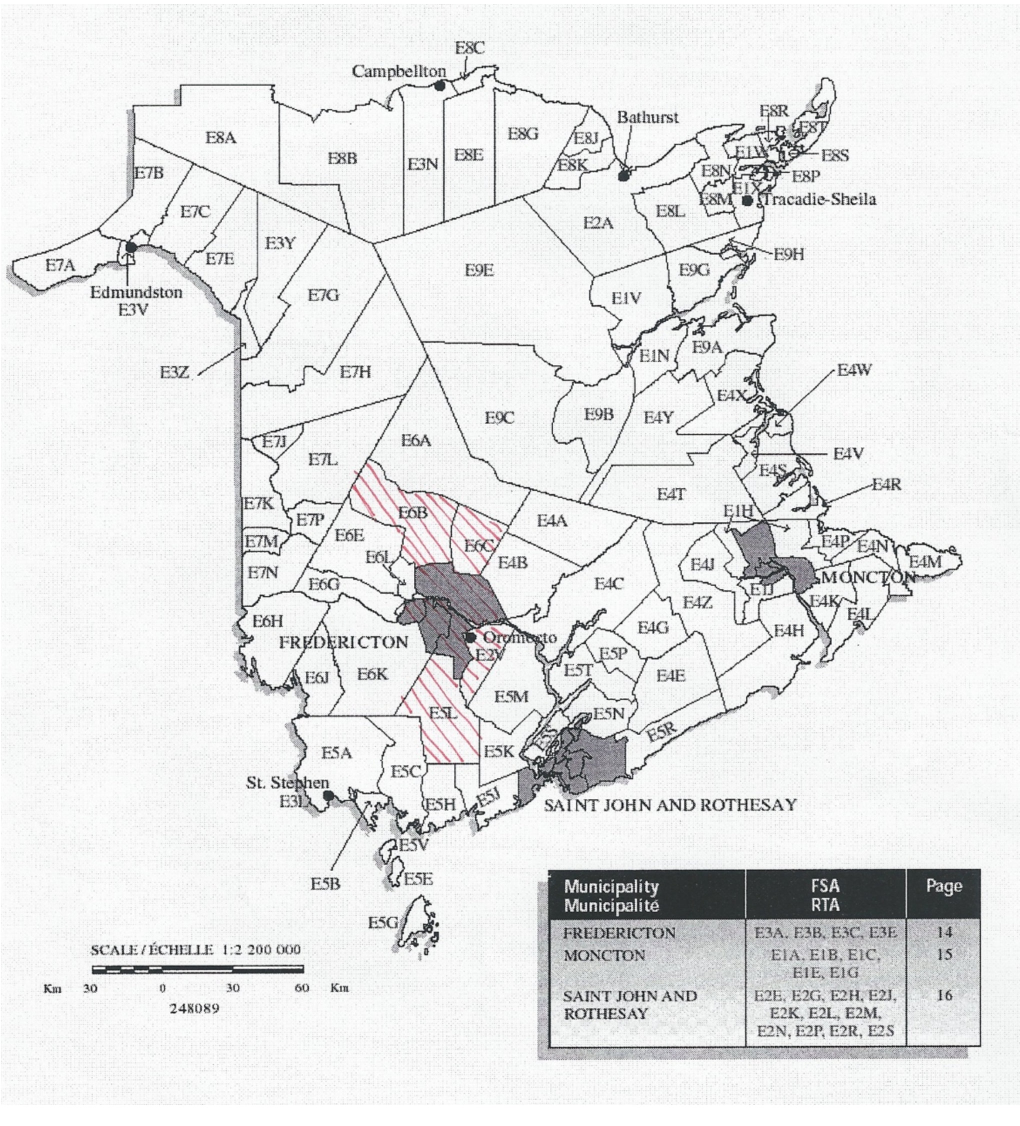
Introduction

Willow Tree Community (WTC) received a grant from Fredericton Community Foundation to undertake a research project to ascertain:

b) the numbers of adults with intellectual disabilities living in the greater Fredericton area;

c) the housing needs and preferences of adults with intellectual disabilities in the area.

For the purposes of this study, the 'greater Fredericton area' was defined as the areas covered by the following postcodes: E3A, E3B, E3C, E3E, E3G, E5L, E6B, E6C, E2V, and Yoho Lake.



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Dr. Clive Baldwin, Canada Research Chair in Narrative Studies, Professor of Social Work, and Director of the Centre for Interdisciplinary Research on Narrative, and Ms. Greason, Research Associate of the Centre for Interdisciplinary Research on Narrative, were engaged to conduct this research on behalf of Willow Tree Community Inc., and a Memorandum of Understanding was drawn up.

Ethics approval was sought and granted from St Thomas University, Research Ethics Board in February 2017. An amendment was sought to modify the process of recruitment to include an advertisement in the press, which was granted.

Methods

The study comprised two parts: a survey, and a qualitative study.

The survey. An online survey was designed in conjunction with WTC. The survey was also available in hard copy and responses were entered into the online database as they were submitted. A copy of the survey appears in the accompanying data file. The survey was designed to allow for completion by only those living within the designated area.

Basic demographic data were collected (age, gender, employment, sexuality etc.), together with information regarding current housing, current involvement in the community, desired future housing arrangements, desired future involvement in the community, and whether or not the individual had heard of L'Arche and would be interested in either living in, or receiving support from a L'Arche community. While most were closed questions, seeking respondents' choice from pre-determined options, a number of open-ended, free-text response questions were also included. A copy of the survey and the summarized data accompany this report.

In cases where family members or carers were completing the survey and/or interview, they were encouraged to respond to the questions in conjunction with the adult with an intellectual disability, so to include him/her as much as possible, and generate responses reflective of his/her thoughts and wishes.

The qualitative study. In order to provide rich data focusing on the lived experience of those with intellectual disabilities, thus fleshing out those gathered in the survey, interviews with individuals with intellectual disabilities and/or their caregivers were undertaken. Interviews were conducted by Dr Clive Baldwin, Ms Michelle Greason, and Anna McCully, research assistant. In all, seventeen interviews, with twenty-eight people, were undertaken. Data were collected regarding 20 individuals with intellectual disabilities. While we would have liked a few more participants, we are of the opinion that we were approaching data saturation (the point at which no new themes were being raised by participants) within these interviews. All save one of these interviews were with family members or carers of an adult with intellectual disabilities - those with intellectual disabilities were present during two interviews. Questions focused initially about the experience of caring, and then moved to explore current and future housing options, and involvement in the community.

Interviews were audio-recorded, transcribed and analyzed for themes, concerns, and issues facing adults with intellectual disabilities with regard to housing and related matters.

At a late stage in the project two self-advocates were identified, one of whom was interviewed, the other, although willing to be interviewed and sign a consent form, was prevented from doing so by his caregiver.

We have taken the liberty to 'clean up' the quotes included in this report by removing the ums, uhs, and ers, simply to make the quotes more readable.

Recruitment

The survey was publicized in a number of ways:

First, a number of agencies working with adults with intellectual disabilities were contacted and asked to issue a call for participants via their electronic mailing lists. Agencies included New Brunswick Association for Community Living (NBACL), Fredericton Association for Community Living (FACL), OPAL Family Services, Autism Connections Fredericton, Oromocto Training and Employment Centre (OTEC), Jobs Unlimited, Willow Tree Community, and Special Olympics. A second call was made approximately three months later.

Second, a number of agencies were asked to include a link to the survey on their website and/or Facebook pages. Agencies included NBACL, FACL, OPAL, Autism Connections Fredericton, Jobs Unlimited, and Willow Tree Community.

Third, 200 hard copies of the survey, together with pre-paid return envelopes, were supplied to Jobs Unlimited for distribution. 50 hard copies were supplied to OTEC.

Fourth, nursing and special care homes in the designated area were contacted directly, and where they agreed, hard copies of the survey were delivered to the home. Some homes were resistant to participating/distributing the survey indicating that any individual with an intellectual disability living in the establishment either did not want to move, or was unable to do so. The sense we had from direct contact with some homes was that the establishment of a L'Arche community might be unwelcome competition.

Fifth, churches in the local area were contacted with a request to draw attention to the survey via newsletters, noticeboards etc.

Sixth, there was some local media coverage of the project – The Daily Gleaner, and CBC community announcements radio. An advertisement was also placed in The Daily Gleaner.

73 people submitted responses to the survey. Of these, three were disqualified due to being outside of the designated area. Nine surveys were incomplete to the extent of providing no usable data. One survey was incomplete but provided enough data to be included in the analysis. 61 surveys are included in the final analysis. The number of respondents to any given question appears in parentheses (n=). While this appears as a relatively small number, it must be remembered that the research population is also estimated to be small (see below). If the research population falls somewhere between the estimate provided by JOBS Unlimited (600) and the calculation of the prevalence of disability based on the numbers and estimates from the Canada Mortgage and Housing Corporation (1300, see next section) then with a sample of 61, the margin of error at a confidence level of 90% is between 10% and 10.3%.

Interview participants were recruited via the survey – anyone interested in being interviewed included their name and contact details on the survey, word of mouth; and personal contacts. In total, seventeen interviews were conducted, involving twenty-eight people, in respect of 20 individuals with intellectual disabilities.

A note on numbers

While part of the remit of this research was to discern the incidence of adults with intellectual disabilities in the greater Fredericton area, it soon became apparent that this would not be possible within the timeframe of the study. This was discussed with the representative of WTC. We understand that the government and Social Development do not distinguish between those with physical and those with intellectual disabilities, categorizing them all under the generic term 'disabilities'. Further, many have co-morbidities, that is have both physical and intellectual disabilities.

Because of the rather generalized categorization of persons with disabilities, to gather information on those with intellectual disabilities would require soliciting numbers from each agency, and then cross-referencing names to avoid duplication. This would have required multiple applications for ethical review, as well as the co-operation of many agencies and individual social workers and support staff. It was agreed early on that this line of research would not be followed due to the time and resource constraints of the study.

When approached, we were informed by JOBS Unlimited that they estimated that there would be around 780 people in the community who qualify for their service under the rubric 'intellectual disabilities'. We were informed that there were approximately 600 individuals aged 19-50 served by JOBS Unlimited, though only around 200 who might fit the criteria for the study. It should be noted, however, that the catchment area for JOBS Unlimited is different to that of this study.

In 2001, the Canada Mortgage and Housing Corporation produced a 'Participation and Activity Limitation Study' (https://www.cmhc-schl.gc.ca/en/inpr/rehi/rehi_020.cfm) which included a profile of housing conditions of Canadians with a learning disability, aged 15 years and older. While the age range in that study is slightly longer than that covered in this report, it is worth noting that in the CMHC study, it was estimated that there were 10,100 persons with a learning disability in New Brunswick[1].

If, however, we use the percentage of the population over 15 years of age with a learning disability calculated from the CMHC study figures – 1.38% - and if the population of the greater Fredericton area is estimated at 94,268 – then the estimated numbers of residents over the age of 15 with a learning disability is approx. 1300. This study focuses on adults (18+) with intellectual disabilities, within the area indicated in the map above, and so the research population is likely to be significantly smaller in number than 1300.

These figures can only provide a very rough estimate of possible numbers.

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[1] The CMHC uses the term learning disability, hence its usage here. For the purposes of this study the two terms, learning disability and intellectual disability are used interchangeably.

Survey data

1. Respondents (n=61)

Adults with intellectual disabilities	5
Family members	53
Friends	3

Age of primary caregiver (n=58)

21 – 29	5
30 – 39	4
40 – 49	9
50 – 59	18
60+	22

Gender of adult with intellectual disabilities (n=60)

Female	25
Male	34
Unknown	1

Marital status (n=60)

Single	55
Married	4
Unknown	1

Language of preference

English	58
French	2

(Though the survey was in English, there was provision made for French speaking respondents to complete a survey over the phone with a French speaker)

2. Current living arrangements

The majority of adults with intellectual disabilities in the survey currently live at home with parents or other family members (42/60). Ten currently live in nursing or special care homes. Of the remaining eight, two live in their own apartments without a live-in caregiver; two in group homes with more than six residents. The remaining four each live in different arrangements: one in a “granny suite”, one with another family, one rents a room without formal support, and one lives in an apartment with a live-in caregiver.

3. *Daily living*

Respondents were asked about the level of support they required in daily life: hearing, seeing, communicating, walking, eating, cooking, dressing, personal hygiene, reading, taking medication, and financial planning.

Few adults with intellectual disabilities required much support with hearing, seeing, walking, eating, and dressing. Many required support with reading, taking medication, cooking, and financial planning. For the other areas, communicating, and personal hygiene, there was a balanced spread of level of support required. This suggests that the required levels of support may well be factored into otherwise independent living situations, rather than the need for residential, twenty-four-hour care.

4. *Employment*

Of the 58 respondents answering this question, the numbers were evenly split 29 employed, 29 not employed. 15 were employed 30 or more hours per week. A number of respondents indicated that while they were employed, they did not necessarily receive a ‘real’ wage – instead, a stipend or honorarium.

16 respondents were engaged in voluntary work, ranging from a few hours a week, to 30 per week.

Of those who then indicated the type of work they do (30), many worked in retail or housekeeping (laundry, cleaning, general household tasks) of some description. A few worked in personal services. These responses, to a large extent aligned with responses to the question, ‘What type of job setting best matches your abilities and interests?’ Other options offered to this question, such as landscaping, woodworking, farming/forestry, and artist workshop elicited little interest or fit with respondents’ abilities. This is, of course, of importance should Willow Tree be contemplating developing a work environment, as is the case with some other L’Arche communities.

5. *Plans to move*

31 respondents indicated that there were plans to move from the current arrangements. The timeline for such moves ranged from the reasonably immediate (1-2 years) to a much longer timeline (10 – 20 years). 12 respondents indicated a move within 1-2 years. Respondents were also asked whether they had started the process. While it is not surprising that those who indicated that a move was planned in the longer-term (3+ years) had not yet started planning for this, of those who indicated that a move was likely in the next 1-2 years, almost half had not yet started the process (5/12). So, while there is a long-term expectation of a move, there does not seem to be any long-range planning on the part of respondents.

When plans to move is cross-referenced with age of caregiver, the same pattern of responses emerges. We find that of the caregivers 60+ (those we might expect to be thinking of the future more), 11 responded as planning a move within five years, of those eleven, five had started the process, and all of these five were planning a move within 1-2 years. Of the 50-59 year-old caregiver group (n=4) none had started the process of planning a move, even if such a move was anticipated within the next 1-2 years.

The responses here suggest that there may be a role for educating family members as to the importance of long-term planning. The number and range of services related to this possible need is relatively limited in NB, and the development of new services may take considerable time.

10 respondents were living in nursing or special care homes at the time of response. Seven of these indicated that they had no plans to move (two hoped to move within five years, and there was one non-response). This might be explained in a number of ways. First, that the level of care these individuals required, particularly around cooking, personal hygiene, reading, taking medications, and financial planning may preclude a move to a less-than-twenty-four-hour supportive environment. Second, given the reticence of residential facilities to participate, and the fact that most of the respondents were acting as proxies for the individual with intellectual disabilities, the response may reflect more the proxy's desire than that of the individual with intellectual disabilities. While there is no way of knowing, it does raise level of required support as a consideration in designing alternative services for those already being served by residential establishments.

6. Preferred housing options and support

Respondents were invited to indicate their top three preferences from a list of possible housing options. Of those respondents who indicated a possible move (n=31) the preferred options in order from most to least popular were:

Supported independent living with a live-in caregiver	15
Living with one other resident (sometimes called co-housing) receiving support from a live-in caregiver	10
Living with a family other than your own	7
Living with one other resident (sometimes called co-housing) receiving support, without a live-in caregiver	7
Home with parents/family	7
"Granny suite" with support from parents/family	7
Supported independent living without a live-in caregiver	6
Group home with 3 to 5 residents	5
Adult residential facility - special care home	4
Renting a room and sharing facilities (e.g. bathroom, kitchen, laundry) in a rooming/boarding house without formal support	3
Group home with 6 or more residents	1
Adult residential facility - Nursing Home	0

Five respondents indicated ‘Other’ – with four of these giving details:

> Autism centre with permanent residential care, continuing education, community activities, and swimming for severely autistic adults.
>
> His wish is to get married and live with his wife independently, but with support.
>
> Own house.
>
> L’Arche community.

52% of respondents (n=56) said they would prefer live-in carers. Almost equally important was the preference for caregivers to be the same person all the time, and someone with professional qualifications (47% and 46% respectively).

Using Q11 ‘Are you able to spend time independently (without assistance)’, as a proxy indicator of a level of disability, we cross-tabulated this response with the housing preferences listed above, clustering those preferences into three groups on the basis of the level of independence, the groups being most independent, some independence, and least independent. There was little difference in the proportion of respondents preferring independent housing between those who were reported as being able to spend time independently, and those reported as being unable to do so. This suggests that desire for independence cuts across level of disability.

A second proxy indicator of the level of disability was calculated by adding together the scores on Q10, which asked for the level of support required for a number of activities. Each respondent thus had a score on a rage of 0 – 55. We then cross-tabulated these scores with the three clusters of housing options (most independence, some independence, least independent) to see if there was any correlation between level of disability and housing preference. 42 respondents completed both Q10 and Q27 (ranking housing options in order of preference).

While there was a general trend that those with higher levels of disability indicated a preference for more supported/lower independence housing options, this was not so for all respondents. Two individuals with relatively low scores on Q10 (16 and 17 out of 55) stated a preference for the least independent housing options, and two with higher scores on Q10 (indicating a higher level of disability) - scores of 39 and 40 out of 55 – stated a preference for the most independent housing options. This suggests that there is still a desire for independence among some individuals with higher levels of disability.

Taken together, these two findings suggest that independent housing options are to be considered for individuals across levels of disability, and not simply for those who are relatively able to perform activities of daily living for themselves.

From the above, it seems reasonable to draw the following:

1. That preferred housing options among adults with intellectual disabilities are as varied as those among adults without intellectual disabilities. In order to meet the differing needs and desires of adults with intellectual disabilities it is therefore necessary to design a range of services.

2. That there is a general preference for independent, small scale housing options. 60% of respondents (n=54) stated that they would prefer to live alone or with one other person. This preference is strong among those who are able to spend time independently, and those who are not.
3. That family or family type support remains important when thinking about future possible housing options.
4. That while live-in support is indicated as important, if there is a choice between independence and live-in support, independence is preferred. (When asked to rank their three options in order of priority, respondents ranked ‘supported independent living without a live-in caregiver’ over ‘living with one other resident receiving support from a live-in caregiver).

Thirty of the thirty-one respondents indicated their reasons for considering new living arrangements:

- 22 wanted more independence,
- 19 were considering moving due to ageing caregivers,
- 11 wanted more community involvements (and nine wanted to be closer to existing activities and friends), and
- 11 were anticipating needs for new or increased supports in the future.

When thinking about new living arrangements, participants were asked about the possible challenges that such arrangements might pose. 52 responses were received. By far, the perceived greatest challenges were financial, caregiver support (though, from the interview data we might suppose that these are linked), and personal safety. 73% of respondents foresaw financial challenges, with 32 respondents, reporting that financial concerns were preventing them from accessing their preferred housing option:

> *Not enough funds to make living independently a success,*
>
> *Only receiving disability pension. Amount is too small to pay for housing and other living expenses.*
>
> *The live-in stipend, and hourly rate for respite, are barely adequate with the parent's present involvement. When the parents are no longer involved, the stipend won't be sufficient.*

75% of respondents foresaw challenges with caregiver support (see later discussion of interview data) reflected in the following free-text responses:

> *Lack of necessary expertise in autism management and care.*
>
> *Making sure the staff are properly trained*
>
> *No appropriate places or properly trained staff to meet his needs and provide quality of life and if he only qualifies for an institution that is even worse.*
>
> *The Caregiver support is the biggest problem.*

71% saw personal safety as an issue. For example, the desire for: "*A place that is well monitored and secure", "privacy and security",* and, *"accessibility. safe, quiet building"*

When asked about how important having one's own bedroom, bathroom, kitchen, living space, and laundry were, respondents were overwhelmingly desirous of their own bedroom and bathroom. Responses were more evenly split in the desire for one's own living area, with 33% (n=59) saying this was very important and 28% saying it was not at all important, with an even spread between. The majority of respondents were not particularly desirous of having their own kitchen or laundry. This lack of desire of one's own kitchen ties in with a further question about whether or not sharing meals was desirable, to which 87% of respondents said it was.

When asked about whether the person with intellectual disabilities would want to be involved in the management of their housing, responses were split 60% positive, and 40% negative.

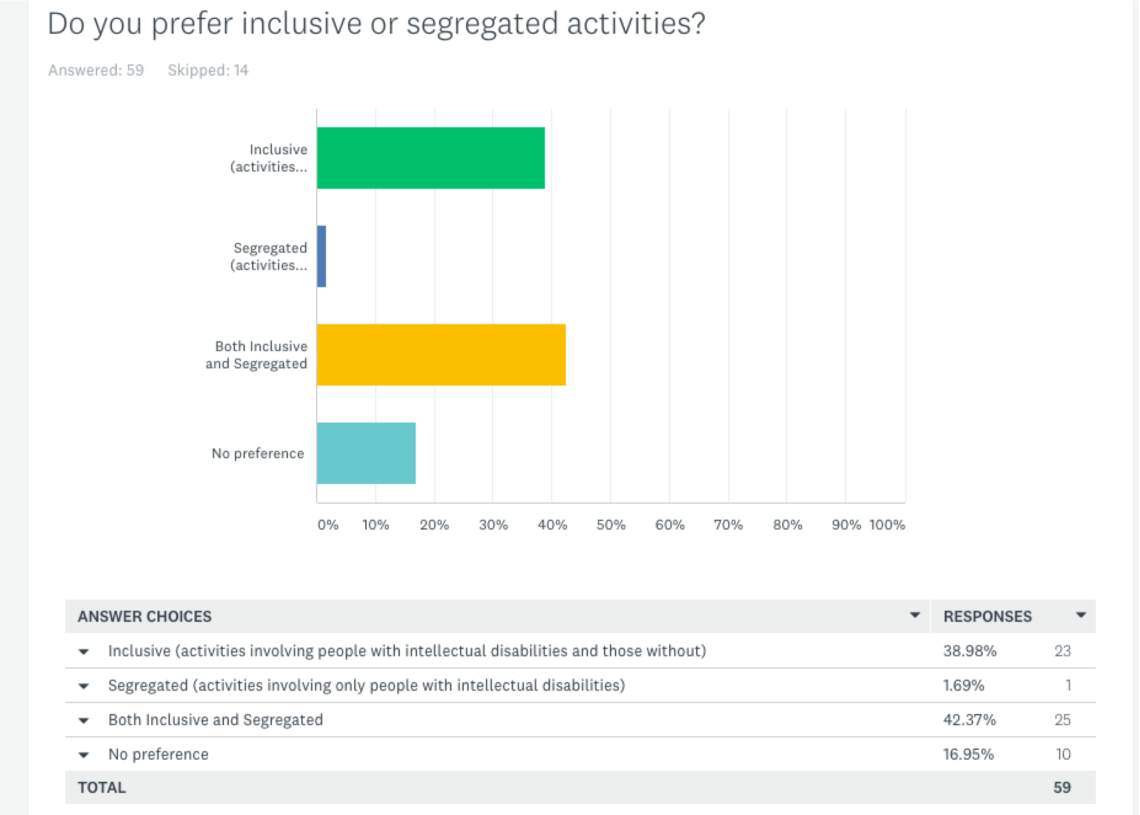
A number of other considerations seen as important were presented in the free text responses: location, proximity to transport, quality of physical surroundings, quiet, and sociability and emotional support:

> *In town near work and activities*
>
> *Bus route close to store and work*
>
> *I'd like to be close to public places by bus/walking*
>
> *Location near bus route, walking trail, quiet*
>
> *Public transit access, internet,*
>
> *Uncluttered, relatively quiet, peaceful.*
>
> *Should provide activities - outings and social gatherings*
>
> *Friendly, routine, lots of kindness*
>
> *Having the other members of the house understand me and my needs*
>
> *We want our son to have a place to belong, a place where people form strong relationships, who connect with him, who would care for him as we do now, at home, proper nutrition, with medical and dental coverage, haircuts, modern clothing etc. A place where he is loved and well cared for, where he matters*

7. Sports, hobbies, and social programs

Popular sports and hobbies among respondents (n=59) were music, church attendance, bowling, and swimming. When asked about other sports and hobbies in which they would like to participate, these remained popular, but theatre, cooking and fitness classes also featured prominently, suggesting a desire for further community-based activities and skill development.

With regard to social programs (Special Olympics, Best Buddies, and Opal Drop-in) these are both currently popular, and are programs in which people would like to participate.



Do you prefer inclusive or segregated activities?

Answered: 59 Skipped: 14

ANSWER CHOICES	RESPONSES	
Inclusive (activities involving people with intellectual disabilities and those without)	38.98%	23
Segregated (activities involving only people with intellectual disabilities)	1.69%	1
Both Inclusive and Segregated	42.37%	25
No preference	16.95%	10
TOTAL		59

Twenty-three of fifty-nine respondents preferred inclusive activities, with twenty-five respondents preferring to have a mixture of inclusive and segregated activities. Only one respondent preferred solely segregated activities. Of the six respondents with the highest level of disability, two preferred solely inclusive activities, while four preferred both inclusive ad segregated activities.

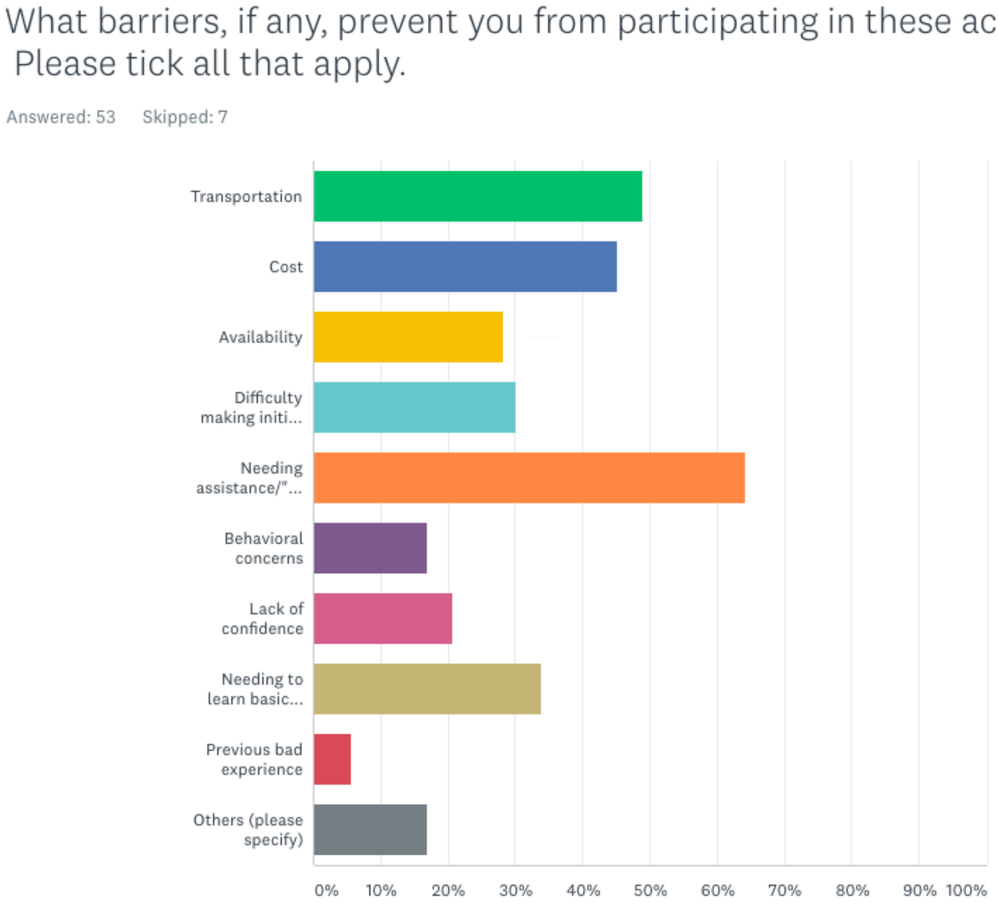
A number of respondents emphasized their desire for social activities. For example:

> *I like socializing with all aspects of society.*
>
> *I am very sociable & friendly. I really like being around people. I really like different cultures & learning about different cultures.*

Of those preferring a mixture of inclusive and segregated activities, the free-text comments pointed to competition being a factor in sometimes preferring segregated activities:

> *Sometimes I just can't compete with "normal people", and I want to quit because I feel like I am not as good as them, I like to be with people like me sometimes.*
>
> *When possible he loves to participate in an inclusive environment but in some cases his skill level is not high enough to be able to keep up with others - ex.: hockey*

We would suggest that the desire to compete with others at a similar skill level is not restricted to those with intellectual disabilities, but is a common trait regardless.



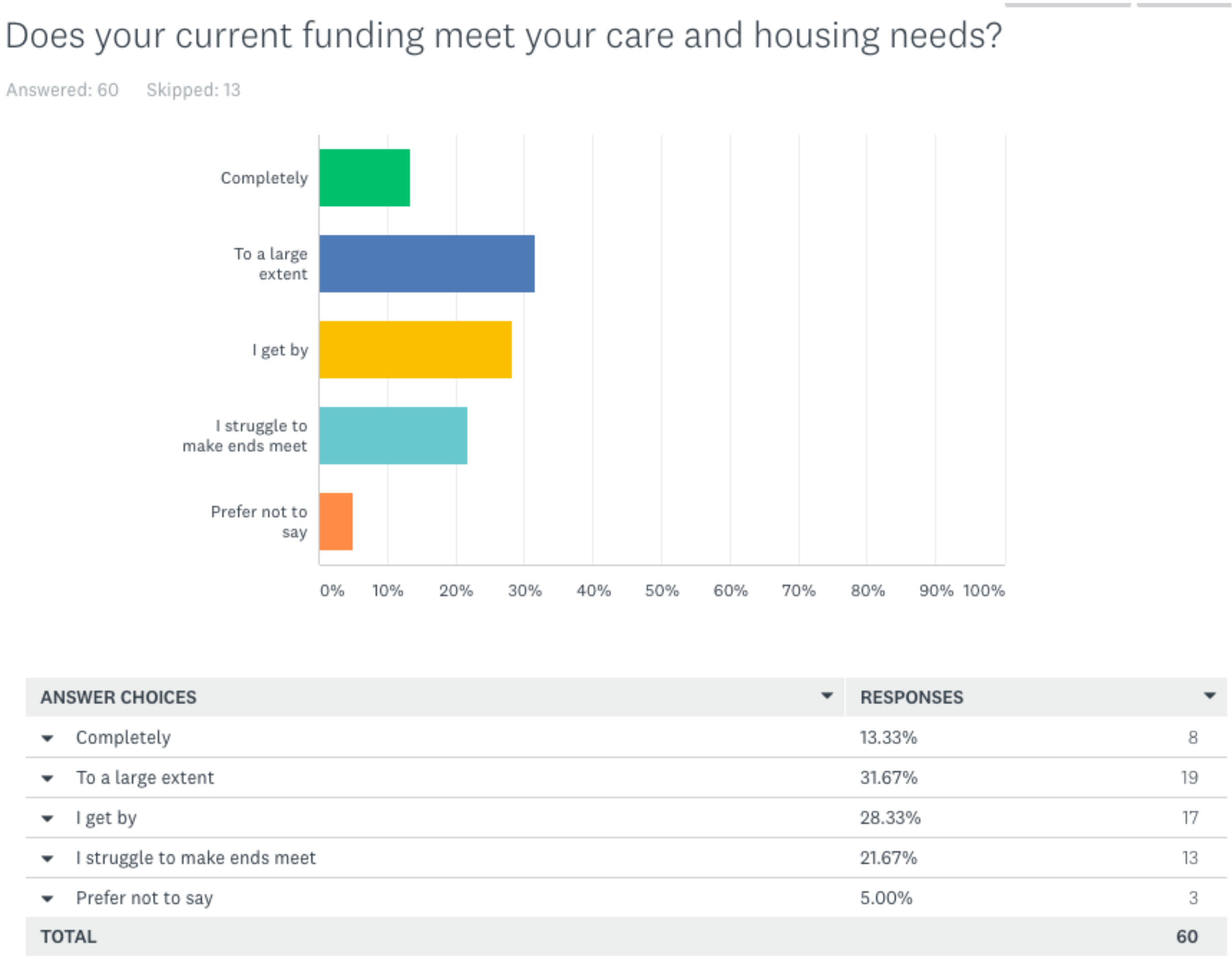
A total of forty-eight respondents (81%) prefer some inclusive activities – an important point to note in designing future residential services, particularly as barriers (as identified in the free-text responses) were transportation, cost, and requiring assistance.

A further obstacle to participation that was raised in the free-text responses to the question regarding barriers was physical health, including mobility issues. This raises issues of accessibility – not only in terms of the activity involved but how the service provider accommodates those with physical disabilities/mobility issues.

8. Finance

54 of 60 respondents indicated that they did qualify for Disability Tax Credit from the Canada Revenue Agency. One respondent did not qualify and five had not applied.

Respondents were asked whether their current funding met their care and housing needs: completely, to a large extent, I get by, and I struggle to make ends meet. 56 respondents answered the question, with two preferring not to say.



Does your current funding meet your care and housing needs?

Answered: 60 Skipped: 13

ANSWER CHOICES	RESPONSES	
Completely	13.33%	8
To a large extent	31.67%	19
I get by	28.33%	17
I struggle to make ends meet	21.67%	13
Prefer not to say	5.00%	3
TOTAL		60

Of the five participants who completed the survey on their own behalf, four reported that they 'get by', with one reporting that s/he 'struggles to make ends meet'. Of these, three lived at home with parents, and two in adult special care facilities.

Among family respondents, this question prompted a far higher number of free-text responses than other questions, suggesting that funding is of significant concern. In all, there were 19 free-text responses, all of which indicated that financial support of parents played a significant role, and many, that if the person were living independently, current funding would be inadequate. This was a frequent response from family respondents regardless of at what level they thought current funding met needs. For example, of the family/friends respondents (n=55) who reported that current funding met the adult with intellectual disabilities' needs completely or to a large extent (27/55), there were eight free-text responses by this sub-group (that is, 30% of the 50%) that indicated that this was only so because the person with intellectual disabilities was in effect subsidized by parents.

Funding is thus a significant issue, especially if one looks to the future when the person with intellectual disabilities no longer lives in the parental home.

> *My funding pretty much covers my current needs as I live in my family home with my parents. If this was not the case and I needed to fund my own housing (even with the extra funding I would get by not living with my family) I would not*

> *be able to fund my own housing. It's not an option for me because of that. I would be living below poverty level.*
>
> *Lives at home with parents. [My son] receives in the $600 range. Since he lives at home, he is cared for and provided for by us - his parents. I suspect the amount he receives would not go far in the "real" world.*
>
> *Current funding would not cover costs if not living at home.*
>
> *Based on the funding my daughter receives she might be able to provide food and some health and beauty aids (ex. Diapers, wipes, shampoo, deodorant etc.) independently. Some of the most basic needs (ex. Housing, clothing, transportation, etc.) cannot be achieved on her own with her disability funds from Revenue Canada.*

The issue of funding becomes more apparent when we look at those respondents who are planning to move within the next five years. Of these (n=20), 12 (60%) indicate that they currently ‘get by’ or ‘struggle to make ends meet’, even when parents are providing financial support.

Funding is a theme that also emerged strongly during interviews (see later).

9. L’Arche

Of the 60 respondents who completed the question as to whether or not they had heard of L’Arche, only 24 reported that they had. This suggests that work is required to raise the profile of L’Arche in order to generate support for the development of a L’Arche community.

Of those 24, 65% expressed interest in living in a L’Arche community, and 55% in receiving support from a L’Arche community. Interestingly, of those respondents who reported not having heard of L’Arche (n=36) 11 were interested in living in a L’Arche community, and 18 in receiving support from a L’Arche community. Assuming that these respondents had followed the link provided to information about L’Arche or had found information from some other source (rather than responding out of ignorance), this suggests that there may be more significant interest in L’Arche should it be more widely known.

Qualitative study data

The following table shows the main themes identified in the interview data, together with the sub-themes. This ‘at a glance’ guide may be used as a quick reference point in discussing the findings of the study.

Main Themes	Sub-themes	Indicative Quote
Non-profit organizations are a fundamental support for families.		*So, I joined a group at NBACL...what I found was an agency that, or an association I guess would be a better word, that was mobilizing and thinking forward because they knew that there was this wave of adult children who were getting older and parents were getting older and so and I learned an awful lot from other parents.* (WTC009)
Challenges navigating ‘the system’ for services and/or supports.	Lack of transparency and access to support through governmental agencies.	*And, you know, sort of, so you could learn to navigate the system. Because the system is not user friendly.* (WTC009) *I said, “No, you’re going to tell me what’s out there.” “I’m not going to go fishing, because you know what’s out there.* (WTC007)
Funding as a barrier/challenge.	a) Minimal monthly income support. b) Provincial savings resulting from caring for their child at home, rather than choosing an institutional (or government funded) setting.	*But I guess what I was going to say is that if we took [him] and put him in an institution I know they, they charge like three thousand dollars a month or whatever and all the, the costs are very high for that kind of care right? but I’m just saying at the same time you know, they, they have a pension which is so minimal it isn’t funny, and like it doesn’t even cover the cost. I guess one time someone said something to me about, like [my husband] said, “Do you realize that if you put [your son] in a group home or something that person would be getting almost three thousand a month for looking after him? And you get 600.* (WTC004)
	c) Need for adequate remuneration for support services and the resulting practice of subsidizing support worker wages to retain trained workers.	*You’re not going to get anybody for eleven thirty-five and hour so [my daughter] spends most of her disability pension helping the rate of pay.* (WTC015)

Challenge of working with support agencies for in-home caregiver support.	a) Difficulty obtaining consistent and compatible caregivers through agencies.	*Yeah, yeah, we've, we've tried the I think, not recently, but there had been the care agency and that didn't work because you may not get the same worker, the worker isn't available when our needs are there and so what we've developed now is the, the companions that are with [her] it's team work and it's flexibility and everybody works together. But she meets them, like [our daughter] will meet them ahead of time and give her approval…See through a care agency what happens is you don't know who you're going to be [getting]…*(WTC006)
	b) Inconsistent training and education of workers.	*I don't blame the folks I think I want to blame is that we don't require enough education for those personal workers to be in those environment therefore you've got what you've got…they're not properly trained.* (WTC014)
Experiences of diagnostic overshadowing as a barrier.		*I would like to think that they would look at the person before they would look at a diagnosis…they have to stop thinking that "this is autism" and have to start looking at the individual. (WTC005)*
Challenge to find appropriate housing for adult child with intellectual disabilities.	a) Eventual necessity of finding alternate living arrangements.	*…But you know someday you'll be gone, or too, too ancient to deal with it properly, or just too much of a financial reality."* (WTC011)
	b) Varying timeframe for finding alternative housing.	*Yesterday. Like I don't know what you mean what's feasible? Probably four or five.* (WTC013) *I don't think I can carry her for a long time but certainly I can for a while, but so it will have to be a transition in the next eight to ten years.* (WTC016)
Inadequate and/or unsuitable housing models available in Fredericton area.	a) Particular concerns with respect to special care homes.	*I started to look what was out there and that's when I found out there's not a whole lot out there.* (WTC014) *I think the group home situation in Fredericton is deplorable* (WTC012)

	b) Limited options for those requiring higher levels of care (e.g. 24/7 care) and fear/ disagreement of placement in a nursing home.	*Because he requires 24/7 care, there's very few people that can provide it. That's the reality of living with that combo, combination of conditions.* (WTC011) *[My daughter] would need quite a bit of support but [both my children] need support with their peers like [my daughter] does not need to go into a nursing home but that's where social development wants to place her. That's the first, you know, that's their first line of defense if anything should happen she's going to a nursing home.* (WTC016)
Housing is more than a building: in search of a home-like environment.	a) Staff care about the individual and the work they do.	*Yeah, I think my biggest concern for housing is not housing not the building per say it's what happens inside that building. Inside that building you've got to have people that just don't want to come and stay so many hours for the pay check it doesn't work that way and never will. You need somebody that's interested and wants to do the job…somebody who is devoted and gets along with their client well at the same time, you know, being a person that can be in control and to do activities.* (WTC015)
	b) Staff are appropriately trained and paid.	*It's not just building a facility it's what comes with it right. Bricks and mortar's one thing but how can we make sure that they've got proper primary care would be the big thing I would be looking at…* (WTC014)
	c) Clean.	*I'm looking for a place that, that have a, first of all, it looks like, or should be, clean. So, like some of the places you walked in and your shoes would stick to the floor. If you didn't have them laced on they would stay right at the door…* (WTC012)
	d) Quality of life and care.	*And I think that's what I'm hoping for her in the future that somebody would see that as a, you know, as taking care of her as not, not a burden or a chore or a job that, that there is value in her, yeah.* (WTC002)

		If we can find a place where she can be at home with other people, you know, in a community where everyone is regarded as, you know, an equal or, or, or worthwhile that's our hope… not she'll just go and sit in front of the TV in her room in her rocking chair. (WTC013)
Seeking individualized housing models.		*It needs to be anything but pigeon holed. There needs to be choice…it needs to be as mindful and close to what a typical person would go through.* (WTC005)
	a) Proposed 'village' model.	*I see it as a multi, multi-level, multi-functional campus, if you like. Okay, I envision it like the Dutch have for the Hogeweyk village for Dementia over in, in Holland.* Okay, *I'm very intimately aware of that, and I went, "Oh my god, that's what would be nice." Gated, maybe, yes, okay, because some require safety, but you have your different parts of your campus, much like the Shannex here for our seniors. The most severe that need the seven/24 care, supervision, but we need it to be staffed and run by people that are specifically trained and certified to work with this type of clientele… And maybe, you know, have experiences in a little movie theatre, or a little bowling alley, or a little shopping centre, or just to get out and get around, and, but they can be in a safe parameter.* (WTC007)
	b) En suite/Granny suite model. *Logistical concerns with respect to the management and trust of the home. Some participants questioned if these might be roles either WTC or L'Arche, if established, could adopt.	*We're looking at renovation or an addition so that he has his own space on our home. So that he has his own space which is going to keep government cost down because he's only going to need a couple more hours a day because with technology he can be in his space, I can be in my space and I can still know that he's okay.* (WTC005)

Inconsistent awareness of, and interest in, L'Arche model.		*Well, we're a little familiar with the L'Arche…We don't know the details of that and whether or not I mean, we, we anticipate it would be a certain model, but just don't know what, flexibility they have within the L'Arche model to provide a group setting.* (WTC008)
	a) Expressed interest in L'Arche model.	*I was just wondering if it'd be better to have a community like L'Arche where they are integrated into society more and not just shut away.* (WTC013) *I certainly would like to know more like if it got up and running and there was more of a yeah certainly that would be something I would be interested in for one or both or yeah, yeah.* (WTC016)
	b) Importance and appeal of non-segregated living in a community setting, a foundational principle of L'Arche.	*…If your only with other people with disabilities what you learn best is to be handicapped. And so, if you're with other people who aren't handicapped like she'll, she'll see things, she'll there are certain expectations in a sense and if she's interested she'll want to do some things too and, and just, just to be a part of it.* (WTC006)
	c) Importance of not creating a segregated environment.	*So I don't know what their options are, I've never seen a L'Arche community, I've read and seen a lot about it and I know some of them are quite large and, and they seem to be all segregated communities, you know, and that the all the people living there are all handicapped, but I don't know if that's the right answer in 2017 or not.* (WTC003)
Slow transition to alternative housing essential.		*Probably some flexibility on the part of the, the program, you know, like we talked about incremental change working with the school and that sort of thing so one possibility instead of like starting cold turkey in an apartment by yourself seven days a week would be to start slower whatever that looks like and maybe, you know, weekends at home or maybe some, yeah, just so easier might be flexibility and I don't know that it doesn't exist, yeah but that would continue to make it a successful transition I think if there was.* (WTC001)

Housing needs may change over time.		*"We're talking about when you go to university you go into one sort of living environment and you grow and you go into a different living environment. So those options have to be available."* (WTC005)
Gap in services: continued management of caregivers and activities once in alternative housing.	Is this a role L'Arche and/or WTC could adopt?	*If the parent is not available to help manage that, then who is going to manage that? Is the question in most families' minds, that I've heard. That's the gap. Well, one of them.* (WTC010) *… you know, their son or daughter is living in an apartment, and with the help of NBACL it's being supported and all of that, but the parent plays a large role and when and if the parent is no longer there, is there an organization or a somebody who can take on that role to make sure that their son or daughter is still supported in the way that it had been developed originally. So right now, government doesn't take that role and NBACL provides some sort of, but without the parent participating there would be a large deficit. So, if there is no parent involved, is there some organization who would be that centre so they would see that [he] keeps getting supported…But, is that something that Willow Tree, or L'Arche, could take on as a role?* (WTC010)
Desire for adult child with intellectual disability to have continued involvement in activities and community once in alternative living environment.		*I want him to still have access to his art, his music, his courses, his swimming, his physical training, his, the things that are of value to him.* (WTC005)
Do not want to burden siblings.		*I'm not going to live forever and I don't want to put it on my daughter, she has her own life to live, live and she's very much aware of her siblings and wants to be there to support her siblings but she still needs to live her life.* (WTC016)

Able to participate in community, though structural arrangements prevent inclusion at times.	a) Transportation.	*Transportation. I keep waiting for driverless cars so that [my son] can get in and just punch a button and go where he needs to go…and volunteers.* (WTC010)
	b) Support.	*Yup, but he has to be with somebody. He just can't go out on his own and do it, he has to have adult supervision, responsible, knowledgeable supervision. But with that very big caveat, yes he can.* (WTC011)
	c) Disagreement in community regarding definition of "inclusion" versus "integration."	*And Fredericton's not an inclusive community, so it's really difficult. Where do you see individuals? When you think of Fredericton where do you see them? I had this with a minister of Social Development in the past and he says, "Well see, I see them at the mall on, you know, payday." I said, "Yeah," I said, "they're all together, right?" "Yeah," says "and I see them Saturday morning bowling." "They're altogether, right?" Yeah. I said that's isolation. He looked at me. I said, "Unless you're seeing these individuals engaged in activities with their age peers or in the community, not congregated you are not being inclusive… it is very individualized, there should be more community focused programs.* (WTC005) *Yeah, it's the term now is not just being in the community, it's being* ***of*** *the community.* (WTC008)
Informing policy and professional relationships.	a) Desire for professionals and decision-makers to listen.	*I would like them to actually take the time, in a non-rushed environment, and just talked to us. Get to know what it's like from day to day, and just take the time, and quit trying to put a label on right away. You need a label, but just quit—it's not to rush…Just, and, listen to, listen to the parents, or whoever the caregiver is.* (WTC007)

	b) Convey empathy and reflect understanding.	*The professionals who helped me were the professionals who understood. Who took the time to show empathy, and even if, if they didn't know, when they said, "I don't know what to do." That was worth everything. And, the empathy, for us, that was huge.* (WTC008)
	c) Improved services and resources for adults with intellectual disabilities.	*So, I guess those three things. Money. Resources. Better training and remuneration for support workers. (WTC009)*

Findings and discussion

The following is a detailed exploration of the key themes arising from the interview data. These data give life to the responses in the survey, and insight into the issues, concerns, and challenges faced by adults with intellectual disabilities and their carers.

Care-giving

In discussing their experiences of caring for their adult son and/or daughter with intellectual disabilities, parents often used descriptive words such as "difficult" (WTC011), "demanding" (WTC004), and "extremely challenging" (WTC001). It was apparent that while these families have faced challenges in caring for their child (and in some cases children), parents were fulfilled and found joy throughout the process. "*So, it's a, it's a challenging, yet rewarding kind of existence*" (WTC011).

In sharing about their experiences of caring, a dominant theme of advocacy emerged.

> *I always felt like I was the warrior mom, and I know I was.* (WTC008)
>
> *If, if as, as parents or caregivers or whatever your title is if you're not on top of things the patient be it your daughter or your brother or your dad or mom will suffer because nobody's the advocate right they can't speak for themselves so you become the advocate and you got to and it's, it's a, it's a tough battle, you got to have a lot of energy, you got to be able to speak up and hold your ground and do a lot of this research, research on your own to be able to speak, you know, somewhat intelligently about the matter when you meet with the whoever, you know, your meeting and most people have a job to do right like you have your own job and this becomes like two jobs like.* (WTC014)
>
> *No, I was part of the group that lobbied the government, wrote nasty letters, picketed and protested- was very vocal… We did more than just focus on parenting, we advocated and lobbied.* (WTC007)

When asked what had been most helpful in caring for their daughter and/or son, a dominant theme emerged as the majority of participants identified non-profit community organizations [e.g. NBACL, Opal, Special Olympics, Jobs Unlimited etc.] as a fundamental support in their caring experience. Participants shared how these non-profit organizations both, assisted with the facilitation of services, and were a means of social support.

> *I would say that the first most helpful thing was Jobs Unlimited to secure employment after high school for both of my kids.* (WTC009)
>
> *We just love the Special Olympics. They're family. They, they are family, and we've met a lot of really good friends that we will keep for life.* (WTC007)
>
> *He's involved, well, it's all Special Olympics that he goes to, we worked with, NBACL, all in his growing up years, they were a huge support, huge, huge support for us.* (WTC008)

> *So, I joined a group at NBACL, and it's a support group for parents of adult children with disabilities and that was a real eye opener for me, because what I, what I found was an agency that, or an association I guess would be a better word that was mobilizing and thinking forward because they knew that there was this wave of adult children who were getting older and parents were getting older and so and I learned an awful lot from other parents.* (WTC009)

Some participants also identified neighbours and friends as helpful resources; *"Very, very, very supportive neighbours. Extremely. I get a little weepy because, of, you don't live in neighbourhoods like that every day"* (WTC007). Others shared how helpful, and essential, respite and in-home supports have been throughout the years; *"The respite, it was, it was huge. Without that, I know, because I didn't have, I had siblings here but they all had young families as well, so they couldn't provide, we didn't have anyone else who could provide any support, so, that, that helped us"* (WTC008). Others also identified positive and helpful relationships with the Department of Social Development; *"Gosh, when I think of it, that was one of the primary things. That that connection to Social Development, immediately, that was huge. They were, they were very helpful"* (WTC008).

Four significant challenges emerged from the data, with the majority of participants indicating that they had faced one or more of these: issues in navigating the system, issues regarding funding, issues with support agencies, and 'diagnostic overshadowing'.

1) Navigating 'the system'

A strong theme among participants was the difficulty of navigating 'the system,' as these participants highlight:

> *...but there would be somebody in the group that might say, "Are you aware of this?" And, "This is what I did." And, you know, sort of, so you could learn to navigate the system. Because the system is not user friendly.* (WTC009)

> *Kind of like a patient advocate, in a sense, right? Helping them through the system...because life can be really stressful when you're the primary care givers, then you only have one person to deal with.* (WTC001)

A number of parents identified a lack of transparency and access to support through governmental agencies as a barrier and challenge and shared how they are often unaware of what services and funding are available:

> *Well, in a, in a perfect world, it would be just exactly what I said in terms of, you meet with a social worker, you identify what the needs are, and a program would be developed to make, to meet those needs. Instead of having to, like there's a lot of energy required to keep on coming and keep on coming and pushing and asking until it actually happens. It takes a lot of energy... And then there's a certain amount of money that's allocated for certain things and yet when I find out, like when I talk to people at Social Devel---or people in my support group, when you sit around the table, somebody can say, "Well this is what I get." "And this is what I get." "And this is what I get." And you realize*

> *that you're not getting everything that you can, that you want for your child... That's right. Because they don't want to tell us what's available, right.* (WTC009)
>
> *That was always the biggest thing, it's like, even though Social Development was great, you know, it was good, but it was always like, they had the cards and we had to guess what they had.* (WTC008)
>
> *...if I can find the support, they will provide the funds. But I don't know where to find that support, I don't know who does it.* (WTC008)
>
> *I dragged it out of them, because of who I am. I said, "No, you're going to tell me what's out there." "I'm not going to go fishing, because you know what's out there. Tell me. This is your job, not mine." I said, "I'm here as a parent. And I'm here as a parent that got a voice, what about the parents that don't have a voice and don't know enough to stand up and ask these kinds of questions?* (WTC007)
>
> *Making her do more, more administrative work. I think that's what a concern is, is that there's no we're unaware of and it's hidden like you have to go looking for them for the help and support and the money and it's not like somebody sits down and tells you ok well she's entitled to this and this and this oh well these are also our programs.* (WTC013)

2) Funding

In sharing their experiences of caring for their daughter and/or son, participants identified funding as a challenge. Funding was discussed in terms of a) the monthly funding received by families to care for their child, as well as b) adequate remuneration for support services.

a) Monthly funding

Participants shared the difficulties of receiving minimal monthly support to care for their daughter and/or son and the personal investment they have made in their care. Participants also noted the provincial savings resulting from caring for their child at home, rather than choosing an institutional (or government funded) setting.

> *...and [we] spent a lot of money over the years. A lot of money, like re-mortgage the house twice to be able to do this.* (WTC007)
>
> *If [he] lived with you, what you would receive for funding, or what he would receive for funding is greater than what we receive for funding now. He's, it's a, there's a deduction for him living here with us, but if he lived with you, you do better. But if we, I mean, you get more money... I think the government has to, some policy has to be changed to allow parents who have grown up with their children and have been in a situation where they're, trying to do the best for their child, and it's expensive, or it can be expensive, and this is an opportunity for at least the parent to know that, that they can do better for their child.* (WTC008*)*

> *But I guess what I was going to say is that if we took [him] and put him in an institution I know they, they charge like three thousand dollars a month or whatever and all the, the costs are very high for that kind of care right? but I'm just saying at the same time you know, they, they have a pension which is so minimal it isn't funny, and like it doesn't even cover the costs… I guess one time someone said something to me about, like [my husband] said, "Do you realize that if you put [your son] in a group home or something that person would be getting almost three thousand a month for looking after him? And you get six hundred.* (WTC004)

> *So, I know that they're housing individuals outside of this province at astronomical cost, and I'm asking for this… I mean they don't have to worry about his medical, his prescriptions because we pay those because we're fortunate enough to have a really good insurance plan. So, we can take care of that, whereas if they had him, we're talking ten, twelve thousand dollars a year on top of housing and all those other things.* (WTC005)

b) Adequate remuneration for support services

Participants noted that while there was a need for support services and workers, though the nature of the work can be challenging and demanding, support workers are remunerated poorly, which creates problems in attracting properly qualified, caring staff.

> *I don't think support workers get paid enough money for the hard work that they do. I think we would get better people in the profession if there was some kind of remuneration that was, more, you know, can you make the same amount of money at McDonalds as you can working at the special care home, or working as a support worker or, whatever the case may be? I don't know, I think it's pretty close.* (WTC009)

> *And the other thing is those poor people are not paid the salary the wages no, are not there.* (WTC014)

> *R: Well I don't know if you know this but they pay an agency like eighteen plus dollars an hour and the agency…*
> *I: Pay eleven…*
> *R: Yeah… and my son is worth more than that… I negotiated with the government for her to have twenty bucks an hour.* (WTC005)

> *I know people that are getting more money, respite because like they're given ten dollars, respite paying somebody ten dollars to come and take [her] for a few hours a day once in a while but there's nobody who's going to work for ten dollars an hour wiping her bum, taking her swimming, feeding her, cleaning her that's, that's not a minimum wage job that's like below minimum wage and so I guess it's ten sixty-three and we, we pay the other eighty cents or ninety cents that's the minimum wage. But still that's not, she needs somebody who is trained and that and for them [government] that would be more money.* (WTC013)

As a result of the inadequate remuneration for support workers, and the challenges this presents, the majority of participants discussed the practice of subsidizing support worker wages to retain properly trained individuals.

> *Yeah, when we did that, that what he's talking about is when we were doing respite I wanted someone responsible that I could depend on and what and, and so I subsidized the what the government would pay so that we could get someone for a half decent wage.* (WTC004)
>
> *I hire privately. I put an ad on Kijiji or in the paper, it used to be in the paper, now Kijiji is free, so. I put it on there and I'll get calls, I bring that person in for an interview…I'll usually try to interview at least three so that I can pick and choose what would suit her best, her needs, eh. And I hire them, and I get funding, she gets funding from them for minimum wage and then I up that by three or four dollars more on the hour, which is kind of taxing.* (WTC010)
>
> *You're not going to get anybody for eleven thirty-five an hour so [my daughter] spends most of her disability pension helping the rate of pay.* (WTC015)
>
> *I can't pay somebody what they [government] are offering, I have to pay more…* (WTC002)

This issue is aggravated in that there seems, also, to be inequity between families and agencies in the allocation of resources in order to provide support services:

> *Social Development gives more money to the agency than they do privately so when we used to hire privately what would happen in order for us to get a qualified person to come in we would have to come out of pocket.* (WTC016)

3) Support agencies

The majority of participants described the challenges of working with support agencies for in-home caregiver support. Participants shared the importance of having consistent and compatible caregivers, with training.

a) Consistency

> *I think our biggest issue is consistency, so finding the right person that kind of can get to know her needs is always a problem for us... there's a high level of anxiety when she is with somebody that doesn't know her… it's a stress to find the right people.* (WTC002)
>
> *This lady is a retired person and she's not going to go back to university or take on another job, so yeah, she's been there eight or ten years I think so yeah and that's important, you know, to have that continuation of the same person so.* (WTC003)

> *The reason I hire privately is because I found with agencies there could be anybody, a different person every day coming through the door. and that person you haven't interviewed and gave all the info about your person, what their likes, dislikes or habits or bad habits, good habits, whatever, what their needs, you can't tell that every time they come through the door, it's going to take quite a while. Mine would be very anxious to get out the door with that person, but when she comes back she may not want to go with that person again, but she may not have that same person the next day. Which is not a good thing.* (WTC010)
>
> *And not through the workers' fault it. It's the agency and how they work some people maybe they give them three hours in the morning and three that same person would not be the one that would come back the next day so there, there's always a strange face so you don't get a chance to interview that person to tell them more about the situation and the needs and, yeah, the needs of the person that they'll be working with that because they may never see them a person again but by the same token they need to know what even if they're only there for three hours. Great turnover of workers through agencies yeah. Just doesn't work well.* (WTC015)

b) Compatibility

> *You know, we just kind of have to go by how he behaves if somebody is working, and you know, if it's a good match for him or not? And then, changes in workers, that's also been hard for him, he's had a number of workers. And you know, it's not their fault, it's through, you know, they're students and they may be here for a couple of years and then they go, but he forms relationships with them so it is, that's really, that's, sad, I think.* (WTC008)
>
> *So, one day I was talking to [him] and, and he was not sleeping at all when he was with her, he was just constantly, it was getting to be a real nightmare. And so finally I said to Garret one day what do you think of so and so and do you like working, "Well she's nice but…" and I said, "Do you want to change workers?" And I'd never asked [him] that before in all the years. "Yes." And it's, it's a personality thing, like you know, some people, you know, you've got to match them to the personality, you can't make them fit with each other. And this person like I said, I like her I think she's a nice person but she was not the match for [him].* (WTC004)
>
> *Yeah, yeah, we've, we've tried the, I think, not recently, but there had been the care agency and that didn't work because you may not get the same worker the worker isn't available when our needs are there and so what we've developed now is the, the companions that are with [her] it's team work and it's flexibility and everybody works together. But she meets them, like [our daughter] will meet them ahead of time and give her approval…See through a care agency what happens is you don't know who you're going to be [getting]…*(WTC006)

c) *Training*

In discussing support services, participants expressed the need for training and education of caregivers, but also indicated that they had experience inconsistency of training and education of workers as a barrier in utilizing support services:

> *If I had my druthers I'd have all private people because agencies are…they're not, they're not trained and they're only there until they find something else.* (WTC005)
>
> *I don't blame the folks I think I want to blame is that we don't require enough education for those personal workers to be in those environments therefore you've got what you've got…they're not properly trained.* (WTC014)
>
> *Now this girl is private because we couldn't find anybody with the training through an agency.* (WTC005)
>
> R2: *Theoretically they've been trained and...*
> R4: *Yeah, we haven't used an agency because the agencies that I know of don't have experience with the kind of situation where we want them to be in.* (WTC010)
>
> *The main thing is to have trained personnel.* (WTC011)

4) **Diagnostic overshadowing**

Diagnostic overshadowing is the term used when professionals overlook, or attribute, mental and/or physical symptoms as part of the intellectual disability. Although participants did not use the term 'diagnostic overshadowing' this process was apparent in their accounts of interactions with others, emphasizing the importance of treating those with intellectual disabilities as valuable individuals, and as more than a diagnosis.

> *I can remember when [he] started to self-injure because he never did until he was in his preteens and I went to our family doctor and said there's something amuck he's doing this.* ***"Well he's Autistic****." I said "Yeah, he's eleven years old I've known that for a number of years but this is not [his] autism, right now this is something else." And it took us a long time a long, long time …It was a medical based issue that was causing the self-injurious behaviour. And, of course, knowing behaviour you would know that once it develops it's really hard to extinguish. So, we had a number of, a number of years and then it happened again later and that's…he lost his vision do to inappropriate examination because he was going to, I was taking him regularly and I'd say like, "What's going on, like he doesn't seem to be, his gate's not, his motor… like he's off." "Oh no, everything looks good, everything looks good." I said, "Are you sure you're getting a good look? Because [he's] not always cooperative." "Yeah, yeah, no everything looks good." And knowing what I know now I should have pushed.* (WTC005) (our emphasis)

> *Trying to get, sometimes to try and get the service system to understand the value of the person…really does understand. In fact that was one of the problems in the school is that they wouldn't make plans for the* ***program they'd make plans around her and talk about her in front of her and never include her in the conversation*** *and it was the most frustrating thing. So, if you're talking about challenges, that was a challenge, to get the schools first, and then other people who were involved with her to understand that you talk with her and to plan with her.* (WTC006) (our emphasis)
>
> *So I would like to think that they would look at the person before they would look at a diagnosis…they have to stop thinking that "this is autism" and have to start looking at the individual. (WTC005)*

Housing

With respect to housing, the majority of participants' children with intellectual disabilities currently live at home, while some have found alternative housing in the community. Participants whose child(ren) have moved out of the family home describe the lengthily and challenging process of accessing suitable housing, emphasizing the limited resources available to help families through this process. When asked what the process of finding housing was like, participants responded, "*Oh, it was, it's a nightmare*" (WTC009) and "*it was terrible*" (WTC012).

For participants with children living outside of the home, for example in a special care home or independent apartment, parents expressed they liked that both, they and their child(ren) had increased independence, knowing their child's needs were being met, and the assurance that their son and/or daughter would be taken care of if something were to happen to them.

> *So, it's, it's amazing, it's just crazy good. It really is. It's unbelievable. And he's happy where he is and I have to admit, I'm happy to be by myself, I really am. I like being by myself and as far as I'm concerned that's how it's going to stay I know. I was very happy... I know [he] is okay now. It's, I just shake my head, it's just, it's unbelievable, what a feeling.* (WTC010)

When asked what they liked best about their current living arrangements, parents with a child(ren) at home described that they liked knowing their child was safe, loved, participate in activities, and are properly taken care of (e.g. in terms of dietary and medical needs); as this participant expressed:

> *I know [he] is protected, his needs are getting met, he's in an open environment where if any negative, if he ever gets upset, or anything, negative behaviour of something, we know how to approach it, not forcefully, tactfully and with a method: the ABA method.* (WTC007)

For participants whose child(ren) are still living at home, all expressed the eventual necessity of finding alternate living arrangements, as illustrated by the following quotes:

> *I think we had a good program of course at home so one on one care for her but we had to make a call, not because we couldn't do it anymore, it's because for future, you know, you're not getting any younger.* (WTC014)

> *"…But you know someday you'll be gone, or too, too ancient to deal with it properly, or just too much of a financial reality."* (WTC011)

> *She works from eight thirty until four every day and comes home and joins the family and that's about it, you know, it's as I say, it's our life and if, if I had my druthers I would wish that, that's the way it would continue but you and I both know as we're getting older that that's, some decisions have to be made, so. As I said if my husband and I could keep it the same way it is then that would be fine but we don't want her to be in a traumatic situation to something happen to, you know, one or both of us, you know, so. I would like to look into some different living options while we're still can support her in that, you know, and ease her into it if possible, so. Well that's pretty much it in a nutshell.* (WTC003)

While most participants described the necessity of alternative housing, many also discussed their son/daughter's independence as a motivating factor to finding housing outside of the family home, as this participant expressed: "*But I'm going to guess that, , that as time moves on, he'll want to be more independent, we will want him to be more independent, for his sake, and for our sake as well."* (WTC008)

Responses varied when asked about the time frame for securing alternative housing arrangements. Ideally, some participants identified they would like to find alternative community housing for their child(ren) as soon as possible.

> *Yesterday. Like I don't know what you mean what's feasible? Probably four or five years and I mean if it takes ten because it's going to be a what we have to do is make awareness.* (WTC013)

> *Well basically now. So we're starting, yeah we're starting this transition now in April.* (WTC006)

> R1: *Yesterday.*
> R2: *[laughing] [Our son] would like yesterday.* (WTC004)

However, others identified a longer time frame, *"I would like to see something within the, the next ten years, because [he] needs it"* (WTC007), and *"I don't think I can carry her for a long time but certainly I can for a while, but so it will have to be a transition in the next eight to ten years"* (WTC016). Some participants expressed they are in the "beginning phases" and recognize the process of securing housing for their child(ren) might be lengthy: *"I've been thinking about this a lot lately and I think this is the year that we're going to start the process. So that would be my five to seven-year plan."* (WTC005)

The majority of participants expressed that the housing models available in the Fredericton area are limited and/or are not suitable or ideal for their child(ren):

> *Because we need a residence, we need good, proper places for our children to live… because right now in my opinion there is not a fit place in this city, or*

> *province, for my son, our son, to live... ... I know there's nothing out there not that will give him the level of care and quality that I want him to have.* (WTC007)
>
> *I started to look what was out there and that's when I found out there's not a whole lot out there.* (WTC014)
>
> *This is how desperate, because we looked hard, because we were so disappointed in the special care home, per se. We just gave up, we said, this is, they're dumps. I even put an ad on Kijiji…I was just grasping at anything.* (WTC012)
>
> *[She] is not going to be living in a community, in a single with a supported living, you know, with a just one roommate because they won't it takes more than one. [She] takes a village.* (WTC013)
>
> *I mean there's nothing out there to look for other than a special care home and somebody's room in somebody's basement and I don't think that, that's definitely not what we're looking for.* (WTC003)
>
> *Alternate Family Living Arrangements, basically like a foster home really…very much. But you see that's just sort of transferring all of our situation to another family, you know, and I just don't think that's a good model because one, it's not his family and two, it's not developing his independence and skills and so I would like to see just a broader range of community around him.* (WTC001)

Of the available housing options in Fredericton, supported independent living arrangements (e.g. apartment with appropriate supports), specifically with portable rent subsidies, and alternate family living arrangements (AFLA) were discussed as the most ideal choices. However, participants noted the barriers to both of these options, including limited portable rent subsidies and finding candidates for AFLA. In discussing housing options, a theme emerged amongst participants surrounding concerns with special care homes in particular; "*I think the group home situation in Fredericton is deplorable*" (WTC012). Concerns identified included cleanliness and nutrition (WTC008), social isolation (WTC007), and individuals being unable to continue working as a result of the funding structure (WTC009, WTC003).

Further, some participants noted that there are limited housing options for adults with intellectual disabilities who require a higher level of care, *"So she needs total twenty-four-hour care seven days a week. To find such a facility that is not a nursing home per se is also a struggle"* (WTC014). *"Because he requires 24/7 care, there's very few people that can provide it. That's the reality of living with that combo, combination of conditions"* (WTC011). In exploring housing options for individuals requiring increased levels of care, participants shared their fear of, and disagreement with, the possibility of having their child live in a nursing home or other inappropriate facility.

> *R2: I do fear is, anyone, but certainly [our son], ever being placed in a senior's home. That's a great, great fear. I would never want to see that.*
> *R1: Yeah that's a model that we don't really see would work for him at all.*
> *R2: No, no but it does happen here…Because people don't have, any other place for them to go.* (WTC008)

> *So you have a number of kids that are in psychiatric care units or long term care facilities that are being managed. They are not living, they're being managed.* (WTC005)
>
> *[My daughter] would need quite a bit of support but [both my children] need support with their peers like [my daughter] does not need to go into a nursing home but that's where Social Development wants to place her. That's the first, you know, that's their first line of defence if anything should happen she's going to a nursing home.* (WTC016)

When asked what they would look for in future housing for their son and/or daughter, participants described a home environment where the staff care about the individual and the work they do, where staff are appropriately trained and paid, where it is clean, and the home and individuals are active and present in the community.

> *It's not just building a facility it's what comes with it right. Bricks and mortar's one thing but how can we make sure that they've got proper primary care would be the big thing I would be looking at and I'd be questioning and challenging and it's a lot of pieces that have got to come together.* (WTC014)
>
> *I just want him to have his life that he has at home, but not at home.* (WTC007)
>
> *Yeah, I think my biggest concern for housing is not housing not the building per se it's what happens inside that building. Inside that building, you've got to have people that just don't want to come and stay so many hours for the pay cheque it doesn't work that way and never will. You need somebody that's interested and wants to do the job…somebody who is devoted and gets along with their client well at the same time, you know, being a person that can be in control and to do activities.* (WTC015)
>
> *I'm looking for a place that, that have a, first of all, it looks like, or should be, clean. So, like some of the places you walked in and your shoes would stick to the floor. If you didn't have them laced on they would stay right at the door…they certainly need painting, you know, looks bad, you know, holes in the walls or it's really, really filthy dirty and I can't imagine what the food would be like… I'm looking for caring people, people who are running the home not just for the money but they look like they care, they show an interest, they're friendly."* (WTC012)

Participants identified a number of concerns with respect to future housing for their child(ren), including: 1) Continued management of caregivers and activities, 2) Continued involvement in activities and community, 3) Quality of care and life, 4) Not burdening siblings, and 5) the limited housing models based on individualized needs.

1. Continued management of caregivers and activities

A number of participants noted they organize and manage both, their son and/or daughter's activities, and caregivers. They expressed concerns about who will take on this responsibility once they are no longer able to. Regardless of whether their daughter and/or son lived at home or in an alternate setting, this was a common theme amongst participants suggesting a gap in services and housing. Further, many participants questioned if this was a role either WTC or L'Arche could adopt.

> *But those kids would be absolutely lost without me… we've talked about this in our, in our family support group from NBACL… I have said this in that, 'you know what, I hate to say this, but I almost wish my children would die before me, because then I wouldn't have to worry'… when I said it, they went, 'Oh God, yes, I feel the same way.'* (WTC009)
>
> *One of the things I've heard parents talk about when I've been at different meetings is that there's, , you know, their son or daughter is living in an apartment, and with the help of NBACL it's being supported and all of that, but the parent plays a large role and when and if the parent is no longer there, is there an organization or a somebody who can take on that role to make sure that their son or daughter is still supported in the way that it had been developed originally. So right now government doesn't take that role and NBACL provides some sort of, but without the parent participating there would be a large deficit. So, if there is no parent involved, is there some organization who would be that centre so they would see that [he] keeps getting supported and he has a friend living with him or whatever, that [her daughter] has the support she needs 24hrs a day, in order to stay where they are. Or you know, [her son] or whatever must need some sort of support in order to, you know, whether it's somebody helping him financially or you know, looking at his, that sort of thing. But, is that something that Willow Tree, or L'Arche, could take on as a role?* (WTC010)
>
> *Well if you need a new person yes that is actually one of the issues that if one person gets sick there is a gap in her support that can't easily be filled. You have to then essentially put out an ad and find somebody else. That is actually one of the biggest concerns.* (WTC006)
>
> *And it's really not so much a challenge to move into your own place, whether it's bought or rented or whatever, or it's an apartment or whatever, to move into that, if you already have networks and you have community connections. So those are the things that, the, I'd be looking for L'Arche to support those three aspects.* (WTC010)
>
> *If the parent is not available to help manage that, then who is going to manage that? Is the question in most families' minds, that I've heard. That's the gap. Well, one of them.* (WTC010)

2. Continued involvement in activities and community

Participants emphasized the importance of their child(ren) remaining active in the community and continuing to participate in the activities that bring them happiness and quality of life. There was a fear that when parents were no longer able to facilitate these activities their son and/or daughter would experience social isolation and reduced quality of life.

> *I hope they keep, get my son outdoors as much as possible. I certainly hope they provide him with the kind of evidence based interaction and structure in his environment, his daily life.* (WTC011)
>
> *…that she is treated well and has the rest of her life fairly happy as happy can be and to be kept busy not sitting in a corner or hear all these horror stories about these buildings that house disabled people and they eat their breakfast and go back sit on the side of the bed till dinner time, hope that never happens to [my daughter].* (WTC015)
>
> *I want him to be involved, I want people to know him, I want him to be, having a healthy lifestyle, being active, and being accepted and belonging.* (WTC008)
>
> *I want him to still have access to his art, his music, his courses, his swimming, his physical training, his, the things that are of value to him.* (WTC005)
>
> *He's not working right now but has had work there and had one job for twenty years. He bowls with the regular bowling team, he plays pool with a regular pool bunch, he does hockey games, you maybe see him at the Aitken Centre handing out programs, he's got a good life. Our concern is that that good life continue when we're not here.* (WTC010)
>
> *So, I don't want any housing situation to ever move [our son] backwards and take away any of his skills or if in, you know, in the independence that you've achieved thus far.* (WTC001)

3. Quality of care and life

A theme amongst participants was the concern that their daughter and/or son will not be loved and properly cared for. Participants expressed a desire for their child(ren) to be in a loving home environment where they are treated with dignity and respect, and as citizens.

> *[My son] always asks, "what do you want for me?" and "what do you see me doing?" And my thing is, it's always the same answer, "just for you to be happy and healthy somewhere with people that love you." …or what you'd like to see in your home? And I turned around and looked at him and he said, "I want someone who smiles at me and hugs me like my mom."* (WTC004)
>
> *If we can find a place where she can be at home with other people, you know, in a community where everyone is regarded as, you know, an equal or, or, or worthwhile that's our hope… not she'll just go and sit in front of the TV in her room in her rocking chair.* (WTC013)
>
> *And I think that's what I'm hoping for her in the future that somebody would see that as a, you know, as taking care of her as not, not a burden or a chore or a job that, that there is value in her, yeah.* (WTC002)

The theme of vulnerability and safety emerged amongst participants in discussing future housing, as these participants highlight:

> *That he's going to get neglected. That his needs aren't going to get met. That he's going to be abused. That he's going to be vulnerable and be taken advantage of.* (WTC007)
>
> *I have to feel comfortable with their ability to make sure he's safe and not to take advantage because that's a huge thing too… [my husband's] fear is physical safety and all these things that happen to people in these environments, and rightfully so.* (WTC005)
>
> *Like, I mean, as long as we knew that he was in a safe place and properly looked after.* (WTC004)

A number of participants also expressed concerns regarding the lack of regulatory enforcement of housing options available for adults with intellectual disabilities. *"So that's the other thing I'm like really somebody should put rules and regulations, you know, the department should do that,"* (WTC014) and *"They would eat in the dining room, they would inspect the kitchen, they would look at the, the people to make sure that you know, they didn't have bed sores and they, you know, they looked like they were cared for. So, so there was a, I guess it was a procedure in place to make those homes acceptable for the people living there"* (WTC012).

4. Burdening siblings

A large majority of participants noted that despite having other children, they did not believe it was the children's responsibility to care for their brother and/or sister with intellectual disabilities.

> *I don't want them to feel they have to stay here and be here for [him].* (WTC008)
>
> *I'm not going to live forever and I don't want to put it on my daughter, she has her own life to live, live and she's very much aware of her siblings and wants to be there to support her siblings but she still needs to live her life.* (WTC016)

5. Individualized housing models

Overwhelmingly participants discussed the need for individualized housing options for adults with intellectual disabilities.

> *…housing and, and support is so individualized. Like, it's, for every, like I have two kids who have various living situations that are vastly different but meet their needs at this point."* (WTC009)
>
> *And that's why it has to be individualized. Whether it's L'Arche umbrella, or whatever it is, it has to be around the individuals.* (WTC010)

> *…we've talked about it just a few times, but, and what kind of models would work, and it's so, based on their needs. It's so individual what would work, you know.* (WTC008)
>
> *It needs to be anything but pigeon holed. There needs to be choice…it needs to be as mindful and close to what a typical person would go through.* (WTC005)
>
> *The evidence has to be there to support how we approach people with these challenges and how they're going to live their lives. And it's very important, and I'll say it over and over again, look at how things are playing out and don't just put people somewhere and assume it's going to work for them or blame them if it doesn't.* (WTC011)
>
> *But I think awareness is really where it's at and the government will see that one shoe doesn't fit all.* (WTC013)
>
> *Because these children or adults are individuals we're all different as an individual and so they all require different needs different situations… a lot of times it's boxy and you have to fit into that box but when you're talking about somebody with intellectual disabilities and, and often that, that isn't just what you're talking about is intellectual disabilities. Intellectual disabilities might be a part of it but it comes with a bunch of other things attached so you have to be able to really, you know, come out of the box in many ways and, and look at the whole picture.* (WTC016)
>
> *R1: One size does not fit all, so the flexibility of something like the DSP is a very good thing, Disability Support Program.*
> *R2: And the portable rent subsidies really a good step.* (WTC001)

Other models

As a result of the above identified concerns, a number of participants envision, and in some cases have created (or plan to create), alternative and unique housing arrangements to meet the specific needs of their son and/or daughter. Suggested alternative models include a village model and en suite/granny suite additions to the family home.

1. Village model

It doesn't look like a square box. Like there's different models available in the world and in, in Europe, I believe in the Netherlands they have, like for dementia they have a village concept which is enclosed, so you have an interior that's open but you have structures around it so that people just can't wander off into dangerous scenarios…A centre based in Fredericton, which would include instruction and training for people who work in different facilities, it would also provide permanent residential care for people like my son… this network so that you could have higher functioning autistic persons who could live in an apartment with minor assistance or oversight, and a group home concept for *moderately challenged autistic persons and have it as a network with a centre…*(WTC011)

I see it as a multi, multi-level, multi-functional campus, if you like. Okay, I envision it like the Dutch have for the Hogeweyk village for Dementia over in, in Holland. Okay, *I'm very intimately aware of that, and I went, "Oh my god, that's what would be nice." Gated, maybe, yes, okay, because some require safety, but you have your different parts of your campus, much like the Shannex here for our seniors. The most severe that need the seven/24 care, supervision, but we need it to be staffed and run by people that are specifically trained and certified to work with this type of clientele… And maybe, you know, have experiences in a little movie theatre, or a little bowling alley, or a little shopping centre, or just to get out and get around, and, but they can be in a safe parameter.* (WTC007)

So, for me I, I see like a little community, a gated community. I don't think that's segregation. It could be seniors living in there, it could be low income living in there but a gated community that makes it safe, and I almost see like an octopus. I see like a centre mainstay where it could be like community room, dinning, you know, shared services exactly with arms out to little individualized environments. We have technology now, we have so many things that eliminate people feeling like they're being managed. (WTC005)

2. En suite/Granny suite

Like I know that's another model, there is someone that we know, one of our, one of the families, like their plan is to have an apartment, or have a, like a granny suite, and I think with the granny suite then they would have, , not a life coach, but somebody who, a roommate, that would help that person. And that, like, that does, that sounds like an interesting thing to do. (WTC008)

I would love—it's too bad that we didn't have a home that was a little more granny suited. Kind of, okay, sort of. (WTC007)

…and through [NBACL] we put together this plan, five years ago already, to have our house converted into a basically [our daughter's] home and we will then move into the basement, which we've already set up as an apartment for ourselves… and if [she] doesn't need the home then of, of course we expect not to be here anymore. I mean this is a long-term plan and as she would, it doesn't really matter to us very much what would happen to the home afterwards, if somebody else used it. And the other thing is because it's her place, her home, she doesn't have to leave if a relationship breaks down with her support worker, it's the support worker that gets replaced not her so. (WTC006)

We're looking at renovation or an addition so that he has his own space on our home. So that he has his own space which is going to keep government cost down because he's only going to need a couple more hours a day because with technology he can be in his space, I can be in my space and I can still know that he's okay. (WTC005)

Participants who identified an en suite/granny suite as the ideal housing model to suit their child(ren)'s needs, also expressed logistical concerns with respect to the management and trust of the home. Some participants questioned if these might be roles either WTC or L'Arche, if established, could adopt.

> *R1: But we have, and we're just in the process now of finding a live-in but what we are still needing, what we're doing ourselves, all, any, any of the management of the home and stuff is still our responsibility…And we sort of written up a support trust for her, I mean put it into her will and a property trust so the house would actually be hers…as long as she needs it. But like I say the management of the home is still in fact not taken care of, that's the missing piece.*
>
> *R2: So, that's right we're wondering, and that's right and that was one thing that we thought oh I wonder if it would be possible for Willow Tree to be involved in that in, in being that agency for a, a property management.* (WTC006)

Making the transition

In discussing the transition from living in the family home, overwhelmingly participants emphasized the importance of a slow transition to new housing.

> *So, he has to be put in those situations and you have to observe him to find out, is he changing, is his attitude changing in a positive way. If it's a negative change, then maybe he's not liking being in the situation.* (WTC008)
>
> *Oh, I think a gradual move so it, you know, not just I'm home one day in my bed at night and then the next night I'm in a strange place with strangers I think the staff have to be integrated to, to each person and as parents or caregivers there should be plenty of involvement and especially when there's hiring to interview.* (WTC015)
>
> *Probably some flexibility on the part of the, the program, you know, like we talked about incremental change working with the school and that sort of thing so one possibility instead of like starting cold turkey in an apartment by yourself seven days a week would be to start slower whatever that looks like and maybe, you know, weekends at home or maybe some yeah just so easier might be flexibility and I don't know that it doesn't exist, yeah but that would continue to make it a successful transition I think if there was.* (WTC001)
>
> *Meet the staff, ask the questions. Tour the place. What's it going to be like here. Give [him] a trial run, okay. Transition. Let him spend a night, once a week, like gradually build it up. He might surprise me and say, "Goodbye." You know. But you know, sort of a nice transition, speak to the people, have an open relationship, you know.* (WTC007)
>
> *It would be slow transition he'd go be able to try it out and go home, so what did you think? Oh, I don't like it. Oh yeah, I'm going to go back and, you know, I think it would be really good to have not just wait till the caregivers and those people drop dead or, or go elsewhere. Like these things are, have been up and running for a while.* (WTC013)

> *Because it will be a huge, and that's why, it's not, the transition that I'm looking at is more for me than really for him because I think that he could go live somewhere supported right now but I wouldn't live well.* (WTC005)
>
> *I don't want to transition that's going to fail and I know the possibility is there that it will fail but I want to make sure that we put all things in place that will make it as successful as possible.* (WTC004)

Many participants also expressed an understanding that their child's housing needs might change as they age. *"We're talking about when you go to university you go into one sort of living environment and you grow and you go into a different living environment. So those options have to be available."* (WTC005), and *"We won't see the initial housing choice cast in stone it's just, you know, for the next step, you know, next phase and maybe even that particular housing choice might see a few different roommates over ten-year period of time before there might be some other kind of housing arrangement, but we don't need to look too far ahead we just do the next thing"* (WTC001).

L'Arche

When asked about L'Arche, the majority of participants were unaware and/or unclear on what the L'Arche model entails:

> *Yes, yes, but I'll be the first one to say, I haven't actually read up a whole lot and studied L'Arche to kind of get my head around it to speak any more than just a basic bare minimum. I hear it's good.* (WTC007)
>
> *"Well, we're a little familiar with the L'Arche…We don't know the details of that and whether or not, I mean, we, we anticipate it would be a certain model, but just don't know what, what flexibility they have within the L'Arche model to provide a group setting."* (WTC008)
>
> *I really don't know a whole lot no.* (WTC016)

However, some participants were already aware of L'Arche and identified it as the ideal housing option for their daughter and/or son.

> *I think L'Arche would that's why [she] is still living at home waiting, we're waiting for L'Arche because I think once we get it going I look at it as a safe haven maybe if you like, you know, but let's hope anyway.* (WTC015)
>
> *Our dream is that [she] lives in community with people who are experienced with that, with other people like other people, intellectuals, variable intellectual abilities like Down syndrome or whatever because those are people who are accepting. I don't know if you talked to [her mother] but her dream was to someday be part of a living community in the Larch idea where she would be safe.* (WTC013)
>
> *…but I am looking at the L'Arche community, the Willow Tree yeah. That's, you know, been kind of, I know they're in their infancy, like they're very, very new but that would be something that I would probably make me feel more*

> *comfortable with her being in a faith based, you know, atmosphere that, that's, more so than just a group home… instead of it just being a job it's people are there because they, they want to be there, they want to, they want to serve, they want to these, you know, see people with disabilities as, as a blessing instead of a chore or a burden, yeah.* (WTC002)

> *I laid awake last night thinking about what we were going to talk about today and I thinking about what, what the ideal solution would be and, and I guess I just have to reiterate that I don't know what the ideal solution would be and, and hopefully this L'Arche group will work out to something. From the meetings that I went to it seemed like they were going to come up with a host of different living solutions rather than just one you know, and so that, that's really important and I think that might just be something that will fill the bill.* (WTC003)

Similarly, few participants were aware of WTC. This suggests more community awareness regarding both might be beneficial. However, once the concept of L'Arche was explained to participants, many expressed how, depending on the adopted model, it could be an ideal living arrangement for their son and/or daughter, and one they would consider.

> *I really hope this happens. I really, really do. I really would like [my son] to be part of it.* (WTC007)

> *And yet, yeah, I think there is still another step of improvement and we see L'Arche generally starting to move in that direction to other models including the supported independent living arrangements.* (WTC001)

> *I was just wondering if it'd be better to have a community like L'Arche where they are integrated into society more and not just shut away.* (WTC013)

> *I certainly would like to know more like if it got up and running and there was more of a yeah certainly that would be something I would be interested in for one or both or yeah, yeah.* (WTC016)

Participants discussed the importance and appeal of their daughter and/or son living in anon-segregated community setting, a fundamental principle of L'Arche.

> *Absolutely that he, I wouldn't, I could never see him in a group home where he was only with people who had developmental disabilities, or physical disabilities… definitely being around neuro-typical people, that's really important for him, so important.* (WTC008)

> *…If you're only with other people with disabilities what you learn best is to be handicapped. And so if you're with other people who aren't handicapped like she'll, she'll see things, she'll there are certain expectations in a sense and if she's interested she'll want to do some things too and, and just, just to be a part of it.* (WTC006)

> *You raise a fun point too, is that a lot of the homes have a similar level of functioning so if somebody functions at so basic a level, everybody is going to function at that level, in my belief. So, if you have people that come in and out*

> *that work, people that are independent, you're going to have a, I think a higher level of function. Like [my son] models his behaviour on what he observes as well, in a lot of ways.... I guess I'm coming back to the, if you have a mix it's, it's kind of nice to see. Now, that would be the ideal setting and I don't know if that's going to exist or not, maybe it will hopefully.* (WTC012)

> *Yeah but that's really what I would love to see happen like even cause again talking about both my children different needs but still very much that you know, peer community sort of lifestyle yes, yeah would be instead of this very separate kind of living… but the downfall of that for me is that my son at fifteen is a bit of a chameleon so if he's with other intellectual disabled people he tends to take on some of their characteristics and, and personality…I tend to find he doesn't thrive as himself when he's in those situations he is better to be with more peers…because yeah he becomes more of a chameleon and that's not, that's not always a good thing for him.* (WTC016)

Participants whose children are already living outside the family home also expressed an interest in a L'Arche community setting for their son/daughter. "*So, if the L'Arche home gets, you know, gets going, I, I would definitely look at that…so, I do hope that that comes to fruition*" (WTC009).

There were, however, some identified concerns about L'Arche. Participants expressed the need for those "working" in the home to be trained (WTC007) and some participants expressed the importance of not creating a segregated environment.

> *L'Arche over time has been segregated, small communities that are wonderful within themselves, but not so much part of the community… But I would really hate to see us building a building and putting people in it, no matter how good the people are, and no matter how wonderful John Vanier was... From what I know of L'Arche, now I don't know what the committee is talking about, but I've known of a lot of L'Arche communities and they are beautiful, but segregated... So that's it's truly of the community, in the community, community being responsible. Not these very good people loving people with disability. There's a lot of that in L'Arche, "Oh, we're very committed, we're very loving, we're very good to you." But it's, life is more than that, that's a subset of, of a community… and community is very different from that, real community is different from that. I mean that's ideal and it's nice if you're in a religious sect or something, but it's not real life for real people.* (WTC010)

> *If we go back twenty years or thirty years when we first heard about L'Arche and we heard about Jean Vanier, read his books and stuff, and we thought, this is a possibility, and it sounded like a good model and the only sticking point for us was that it was sort of a congregated group kind of setting and it wouldn't suit, but otherwise it seemed like the principles were pretty well in line.* (WTC006)

> *So, I don't know what their options are, I've never seen a L'Arche community, I've read and seen a lot about it and I know some of them are quite large and, and they seem to be all segregated communities, you know, and that the all the*

> *people living there are all handicapped, but I don't know if that's the right answer in 2017 or not.* (WTC003)
>
> R3: *And I think originally the vision that I have read about in France, with L'Arche or whatever, is that even though they said they were in the community, the community was all L'Arche. It was several houses, it had a store, it had this it had that, that was the vision way back when. And so they never left that little area at all and the whole area was L'Arche.*
> R5: *Yeah, it was a community, but not in the real world.*
> R3: *No, not in the regular community. It was their own community.* (WTC010)

Two participants also discussed their concerns of the security of housing for their child under the L'Arche model: *"I think it was probably though we haven't yeah, I think that was primarily in it and the fact that it would be a place that, I don't know enough about how much security there is for the person who's living there in case. Like the ones at were initially set up by John Vanier, they were people who were working and contributing and [our daughter] wouldn't really be contributing*" (WTC006).

Community inclusion

A number of participants reported that they did not think that New Brunswick and Fredericton were particularly inclusive communities:

> *And Fredericton's not an inclusive community, so it's really difficult. Where do you see individuals? When you think of Fredericton where do you see them? I had this with a minister of Social Development in the past and he says, "Well see, I see them at the mall on, you know, payday." I said, "Yeah," I said, "they're all together, right?" "Yeah," says "and I see them Saturday morning bowling." "They're altogether, right?" Yeah. I said that's isolation. He looked at me. I said, "Unless you're seeing these individuals engaged in activities with their age peers or in the community, not congregated you are not being inclusive… it is very individualized, there should be more community focussed programs.* (WTC005)
>
> *We have a very rigid mindset in New Brunswick and everyone waves a community and inclusion flag back and forth and shakes their pompoms and so forth, but they don't really look at the evidence basis for how that's working in all cases. That's a very big problem.* (WTC011)

For most participants, inclusion is not simply a matter of being present at, but participating and having a voice in, what goes on:

> *Yeah, but I think that wider inclusion, well going back to integration versus inclusion, is inclusion is actually they're participating in, they are not just in the building. Like sometimes special needs kids are in the school building, so that's integration, now they need to be actually learning and included and, you know, participating in all what's going on and they're not just stuck in a room somewhere, you know, kind of thing and that, you know, what's best for them so. So, but anyway, that's not to criticize that, but it's ok at least we're in the building, so now let's work towards making the education more inclusive.* (WTC001)

> *Yeah, it's the term now is not just being in the community, it's being* ***of*** *the community.* (WTC008)
>
> *I think that the inclusion component is, is paramount. To be able to continue to support that, to strengthen it, because it is, is part of not just the school system, but it's also, in the society. That has to translate from schools into the community. Yeah. And there's a lack of the inclusion aspects in the community. There is some of it, but I think we have to develop that more.* (WTC008)

When asked about inclusive community activities, participants, for the most part, reported their child(ren) were able to participate in a range of activities, with other individuals with intellectual disabilities, and those without.

> *Like when [he] goes to art he's with neuro-typical people. When he goes to all these places they're not activities- aren't for individuals with challenges or individuals with autism or intellectual disabilities other than the Opal social and the Best Buddies and Special Olympics. Everything else that he engages in during the day is with neuro typical individuals.* (WTC006)
>
> *…and then to me that's not really a community because they're not really mixing with other people they're kind of within their own little group which , you know, as much as that's, you know, they're inclusive they're not, they're not really integrated, you know, cause there's not other people mixing in that little group it's just , you know, a group of special needs people with one person, you know* ***where I would like to see like, you know, if they're all going to eat supper together there should be a mixture of people****.* (WTC016) (our emphasis)

The range of responses with respect to community activities suggest it is not the type of activities that are available that prevent inclusion, but more structural arrangements, particularly transportation and support.

> *Transportation. I keep waiting for driverless cars so that [my son] can get in and just punch a button and go where he needs to go…and volunteers.* (WTC010)
>
> *He has challenges trying to get involved with physical activities, transportation, going to, coming from, getting to. So, getting involved in outside activities is a major challenge for him.* (WTC010)
>
> *But see, we live just a little bit out of town, we're not right in the city. If we were right in the city, I, you know, I'd kind of jump on it, but we're, we're, we're, ten minutes out. And to have someone that would, could come out—because the other thing is, if you're going to have someone to do that, then usually you've got to drive the person there and it's, you might as well do it yourself.* (WTC007)
>
> *Yup, Could they? Yes, with support. They need a way of getting there and they need a way of getting back, and in the beginning, to start something new they would need to have somebody go with them.* (WTC009)

> *… but he has to be with somebody. He just can't go out on his own and do it, he has to have adult supervision, responsible, knowledgeable supervision. But with that very big caveat, yes, he can.* (WTC011)

There was some disagreement amongst participants about what encompassed "inclusivity," and a significant division with respect to the definitions of community inclusion versus community integration.

> *But we, we've run into a few, and one of them is Special Olympics is not very inclusive. And they are shocked when they are told that. "Oh, we include all people with intellectual disabilities." But you're not inclusive to bring other people in who are not intellectually challenged, so there's, there's no, so, we've had issues with them in that regard...* (WTC008)
>
> *And NBACL, because I had nothing to do with them for a long, long, long, long time, because we were this with inclusion and they were that with inclusion.* (WTC007)
>
> *The bigger challenge or issues that I see are once, once people with Developmental Disabilities are living independently is to get involved in the community and to feel like they're contributing members. I'm, I'm sorry, not to feel like, to be. To be contributing members of their communities. And I don't see that living together in a family like setting, I don't see that, that's just, that's just confined.* (WTC010)
>
> *Right on because they can give a lot and, and you don't know until you've tried and you say oh we can benefit so they can contribute to society it's just to find how…. So, you just keep at it and you in, in, introduce them or implicate them in, in the common things that you do as a as a society and that's what I would say. The day you push them aside and institutionalize them that's the day we're you know, we, we've failed royally as a society so.* (WTC014)

Informing policy and professional relationships

When asked what they would like policy-makers and/or professionals to know about their experiences of caring for their daughter and/or son, there was a variety of responses. A number of themes emerged, including a) a desire for professionals and decision-makers to listen, b) for them to convey empathy and reflect understanding when working with families and developing policies and procedures impacting those with intellectual disabilities, and c) to have improved services and resources for adults with intellectual disabilities.

> *The professionals who helped me were the professionals who understood. Who took the time to show empathy, and even if, if they didn't know, when they said, "I don't know what to do." That was worth everything. And, the empathy, for us, that was huge.* (WTC008)
>
> *Well it wouldn't hurt them to learn that they don't really know what it's like until it's a 24/7 deal…it's very difficult.* (WTC011)

> *I would like them to actually take the time, in a non-rushed environment, , and just talked to us. Get to know what it's like from day to day, and just take the time, and quit trying to put a label on right away. You need a label, but just quit—it's not to rush…Just, and, listen to, listen to the parents, or whoever the caregiver is.* (WTC007)
>
> *I don't know if I'd like them to know or not, but the reality is they're responsible for some hardship of people with severe challenges because they don't care enough to look at it and take it seriously and deal with the evidence of how things work now, and how it could work better for them. It's very easy to just wag a flag with a title on it and find the cheapest way to do things. But if it's all that can be done then that's all that can be done. But if other things could still be done then they should, if they're conscientious, they should exercise their conscience and take an evidence based hard look at the realities of it, and try to figure out what's going to work better and listen to people who also care and who have knowledge of it.*" (WTC011)
>
> *So, I guess those three things. Money. Resources. Better training and remuneration for support workers.* (WTC009)
>
> *And then the people that are in power, they just don't realize what or if they do they just don't care, what people go through, you know.* (WTC004)

Further, it is important, according to some participants, not only to be listened to with empathy and understanding, but that they, and/or the adult with intellectual disabilities be involved in the decision making:

> *I think one thing they probably need to know that every family situation is an individual situation and that parents and caregivers or whatever should participate in, in making those decisions with the person they're supporting and there just isn't one little bucket that fits all. And that funding sort of probably has to be more mobile with people so that you can take it from one place to the other.* (WTC010)
>
> *But one thing about policy making to me, I really, I believe that if you're going to set up a policy whoever is going to be using and applying that policy should have a say in it.* (WTC012)

Final remarks

The data from both the survey and qualitative interviews were rich and provided detailed information about the housing needs and preferences of adults with intellectual disabilities, which could be used to begin informing Willow Tree Community's planning and development of a L'Arche model in the Fredericton area. From the data we have identified a number of considerations.

1. Location: Participants stressed the importance of being close to friends, activities, and transportation. This suggests any housing provision provided by WTC should be within close proximity to the town centre. Location is a key consideration when it comes to inclusivity, safety, and security. Though some of these issues are structural (e.g. transportation) careful consideration of location can ameliorate, to some extent, current accessibility concerns.

2. Model: When asked about their ideal housing, participants indicated a preference for a range of models. Although some of these drew on aspects of the traditional model of community living of L'Arche, primarily participants expressed a desire for independent living in smaller groups. Some participants raised alternative models, such as the village model based on Hogeweyk.

3. Staff: In discussing support services (both within a facility and extramural) participants emphasized that such staff should be properly trained and remunerated. Further there was a desire for consistency and compatibility so that relationships can be developed and maintained over a good length of time.

4. Raise awareness: It was noticeable that a good number of participants had limited, if any, knowledge of L'Arche and for a small number of participants, awareness was a much larger societal issue, i.e. one barrier to inclusion is the lack of awareness among the general public of those with intellectual disabilities. These findings suggest WTC might want to consider further awareness raising as part of their remit.

   > *…a lot of just the general public don't have any sort of knowledge or background, history with dealing with somebody with autism so…it makes it hard to, to take them out and just not people just even look at you and stuff right because he knows. He's confronted people. You don't learn anything about you know, that kind of stuff growing up and through elementary school and I think that's when you should be learning is, you know, grade two, three, four and then by the time you get into five, six, hit puberty go into middle school then you'll have an understanding, right? I think that would be pretty awesome.* (WTC017)

5. Other services: A number of participants indicated it would be helpful to have a single centralized source of information, advice, and direction in terms of both housing and care. Additionally, in sharing about future concerns, participants discussed care coordination and management as a gap in current services.

6. Should Willow Tree Community wish to engage in further research as part of their development plans, it is worth nothing that the Social Sciences and Humanities Research Council now have a 'Partnership Engagement Grant'

program which allows for relatively easy collaboration between universities and local groups, and are designed to respond to the immediate needs and time constraints facing organizations in non-academic sectors. Grants are for between $7000 and $25000 and can be used to answer questions that will enable local organizations make decisions or address specific needs.

In producing this report, we hope the information contained therein will aid WTC in their endeavors.

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de Fredericton

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APPENDIX 1 - The questions asked in the housing needs and preferences survey

Welcome

If you are an adult with an intellectual disability* or have an adult family member with an intellectual disability who is living at home or in a residential facility we would like to hear from you. This study aims to find out about the housing needs and preferences of adults with intellectual disabilities. This information is of critical importance to help ensure that housing and services best reflect the actual needs of families in our area. For this information to be accurate, it is important that we hear from as many individuals with intellectual disabilities and their families as possible. The study results will be used in planning and to receive funding for housing and other services for individuals with intellectual disabilities. Full details about the project can be found at: wp.stu.ca/narrativestudies. At the end of the survey you will be asked whether or not you wish to be contacted about a second part to the project. This is entirely voluntary and you can still complete and submit this survey without agreeing to this.

We will ask you questions about yourself, your daily life, your current and future housing, and housing preferences. There are only two questions that you must answer: these are marked with a red *. After that, please answer as many questions as you feel comfortable in answering. If you do not feel comfortable answering a particular question, just leave it blank and move on to the next question. The survey will take about 30 minutes to complete. If you are a family member completing the survey on behalf of an adult with an intellectual disability we encourage you to respond to the questions in conjunction with him/her, so to include him/her as much as possible, and generate responses reflective of his/her thoughts and wishes.

You do not have to give your name or contact details to complete this survey – it can be completed anonymously. At the end of the survey, if you decide you are interested in participating in an interview regarding your experiences, you will be asked for your contact details. These details will be separated from your responses to this survey, so that no-one will be able to link your answers with you personally.

Once you have submitted the survey, your answers will be included in the research. If you have not given your contact details, or once your contact details have been removed, there will be no way to identify your responses. You cannot, therefore, withdraw your information from inclusion in the project. In submitting this survey you are giving consent for us to use your responses.

*** The government define intellectual disability as "a term that describes lifelong challenges in learning and/or communication usually present from birth or a young age that restrict a person in their activities of daily life".**

"Please note that this survey is hosted by "Survey Monkey" which is a web survey company located in the USA. All responses to the survey will be stored and accessed in the USA. This company is subject to U.S. laws, in particular, to the U.S. Patriot Act that allows authorities access to the records of internet service providers. If you choose to participate in the survey you understand that your responses to the questions will be stored and accessed in the USA. The security and privacy policy for Survey Monkey can be viewed at http://www.surveymonkey.com/".

Before you continue, please read the following:

I agree that by completing and submitting this survey my responses can be used for the purposes of the research
I understand that if I do not wish to answer a particular question, I may leave it blank
I understand that no responses will be recorded until I submit the survey
I understand that once I have submitted the survey, it is not possible to withdraw my responses from the project
I understand that all responses are anonymous.

If you have any questions about the survey, please contact: Dr Clive Baldwin or Michelle Greason, St Thomas University. Tel: 506 452 9596 Email: baldwin@stu.ca or hdwjw@stu.ca

By clicking 'Next' you are agreeing to the above.

This project has been made possible by an Impact Grant from the Fredericton Community Foundation to Willow Tree Community, and is conducted in partnership with the Centre for Interdisciplinary Research on Narrative, St Thomas University.

* 1. Due to time and current resources, this survey currently only covers the greater Fredericton area. We thus need to know whether you live in one of the following postcode areas.

Do you live in the area covered by one of the following postcodes? (You do not need to say which one. By answering 'yes', you are simply indicating that you live in the area covered by this survey).

E3A
E3B
E3C
E3E
E3G
E5L
E6B
E6C
E2V
Yoho Lake

○ Yes

○ No

Who is this survey about?

We are interested in finding out about the housing needs and preferences of adults with intellectual disabilities. We would like to know who is completing this questionnaire, and the age of the primary caregiver.

* 2. On whose behalf are you answering this survey?

○ Myself

○ A family member

○ A friend

3. What is the age of your primary caregiver?

○ 21 to 29

○ 30 to 39

○ 40 to 49

○ 50 to 59

○ 60+

○ Prefer not to answer

About you

In this section, we ask some basic questions about you. If you are answering this survey on behalf of someone else, please answer the following questions as they relate to the individual with an intellectual disability.

4. What is your age (the person with an intellectual disability)?

○ Under 21
○ 21 to 29
○ 30 to 39
○ 40 to 49
○ 50 to 59
○ 60+

5. What is your gender?

○ Female
○ Male
○ Gender variant/Non-conforming
○ Prefer not to say

6. Are you

○ Married?
○ Single?
○ In a common law relationship?
○ Widow/widower?
○ Prefer not to say

7. What is your language preference?

○ English
○ French
○ Other (please specify)

☐

8. Do you qualify for the Disability Tax Credit from Canada Revenue Agency?

○ Yes

○ No

○ Have not claimed

○ Prefer not to say

9. Does your current funding meet your care and housing needs?

○ Completely

○ To a large extent

○ I get by

○ I struggle to make ends meet

○ Prefer not to say

Is there anything you would like to tell us about funding for care and housing needs?

Your daily life

The next set of questions are about your daily life.

10. Do you need assistance with any of the following? On a scale of 1 to 5, with 1 being 'Little', and 5 being 'Total', please say how much help you require.

	None	1	2	3	4	5
Hearing	○	○	○	○	○	○
Seeing	○	○	○	○	○	○
Communicating	○	○	○	○	○	○
Walking	○	○	○	○	○	○
Eating	○	○	○	○	○	○
Cooking	○	○	○	○	○	○
Dressing	○	○	○	○	○	○
Personal hygiene	○	○	○	○	○	○
Reading	○	○	○	○	○	○
Taking medication	○	○	○	○	○	○
Financial planning	○	○	○	○	○	○

11. Are you able to spend time independently (without assistance)?

○ Yes

○ No

12. Are you employed?

○ Yes

○ No

13. If yes, to Q12, please indicate approximate hours per week

14. Do you do volunteer work?

○ Yes

○ No

15. If yes to Q14, please indicate approximate hours per week

16. If yes, to either Q12 or Q14, please tell us what sort of work you do?

17. What type of job setting (paid or volunteer) best matches your abilities and interests?

	Excellent fit	Good fit	Poor fit	Not a fit at all
Retail store	○	○	○	○
Office	○	○	○	○
Restaurant/cafe	○	○	○	○
Artist workshop	○	○	○	○
Woodworking workshop	○	○	○	○
Landscaping/outdoor maintenance	○	○	○	○
Farming/forestry	○	○	○	○
Childcare/senior care	○	○	○	○

Other (please specify)

18. What sports, hobbies, and social programs **do you** participate in? Please tick all that apply.

☐ Art classes

☐ Music

☐ Theatre

☐ Cooking classes

☐ Tennis

☐ Track and field

☐ Church

☐ Basketball

☐ Bowling

☐ Hockey

☐ Swimming

☐ Fitness classes

☐ Skiing

☐ Special Olympics

☐ Best Buddies

☐ Opal Drop-in

☐ Others (please specify)

19. What other activities **would you like to** participate in? Please tick all that apply.

- ☐ Art classes
- ☐ Music
- ☐ Theatre
- ☐ Cooking classes
- ☐ Tennis
- ☐ Track and field
- ☐ Church
- ☐ Basketball
- ☐ Bowling
- ☐ Hockey
- ☐ Swimming
- ☐ Fitness classes
- ☐ Skiing
- ☐ Special Olympics
- ☐ Best Buddies
- ☐ Opal Drop-in
- ☐ Others (please specify)

20. What barriers, if any, prevent you from participating in these activities? Please tick all that apply.

☐ Transportation

☐ Cost

☐ Availability

☐ Difficulty making initial contacts

☐ Needing assistance/"buddy"

☐ Behavioral concerns

☐ Lack of confidence

☐ Needing to learn basic skills

☐ Previous bad experience

☐ Others (please specify)

21. Do you prefer inclusive or segregated activities?

○ Inclusive (activities involving people with intellectual disabilities and those without)

○ Segregated (activities involving only people with intellectual disabilities)

○ Both Inclusive and Segregated

○ No preference

Why?

Where you live now

The next four questions ask about the type of place you live now.

22. What best describes your current home?

○ Home with parents/family

○ "Granny suite" with support from parents/family

○ Living with a family other than your own (alternative family living arrangement)

○ Renting a room and sharing facilities (e.g. bathroom, kitchen, laundry) in a rooming/boarding house without formal support

○ Own apartment/house with live-in caregiver

○ Own apartment/house without live-in caregiver

○ Living with one other resident (sometimes called co-housing) receiving support from a live-in caregiver

○ Living with one other resident (sometimes called co-housing) receiving support, without a live-in caregiver

○ Group home with 3 to 5 residents

○ Group home with 6 or more residents

○ Adult residential facility - Nursing Home

○ Adult residential facility - Special Care Home

○ Other (please specify)

23. Do you regularly spend time at another home/facility (ie respite care)?

○ Yes

○ No

If yes, please give details

24. Do you hope to move into new living arrangements in the next

○ 1 - 2 years?

○ 3 - 5 years?

○ 6 - 10 years?

○ 10 - 20 years?

○ Not at all

25. If you do plan to move, have you started this process?

○ Yes

○ No

The future

The next set of questions are about what you would like in the future

26. The following is a list of current possible housing options. What would best describe your future preferred living arrangement? (please select your top 3)

☐ Home with parents/family

☐ "Granny suite" with support from parents/family

☐ Living with a family other than your own

☐ Renting a room and sharing facilities (e.g. bathroom, kitchen, laundry) in a rooming/boarding house without formal support

☐ Supported independent living with a live-in caregiver

☐ Supported independent living without a live-in caregiver

☐ Living with one other resident (sometimes called co-housing) receiving support from a live-in caregiver

☐ Living with one other resident (sometimes called co-housing) receiving support, without a live-in caregiver

☐ Group home with 3 to 5 residents

☐ Group home with 6 or more residents

☐ Adult residential facility - Nursing Home

☐ Adult residential facility - Special Care Home

☐ Other (please specify)

27. Please rank your three preferences in order

☐ Home with parents/family

☐ "Granny suite" with support from parents/family

☐ Living with a family other than your own

☐ Renting a room and sharing facilities (e.g. bathroom, kitchen, laundry) in a rooming/boarding house without formal support

☐ Supported independent living with a live-in caregiver

☐ Supported independent living without a live-in caregiver

☐ Living with one other resident (sometimes called co-housing) receiving support from a live-in caregiver

☐ Living with one other resident (sometimes called co-housing) receiving support, without a live-in caregiver

☐ Group home with 3 to 5 residents

☐ Group home with 6 or more residents

☐ Adult residential facility - Nursing Home

☐ Adult residential facility - Special Care Home

☐ [Insert text from Other]

28. What are your main reasons for considering a new living arrangement? Please tick all that apply.

☐ More independence

☐ More community involvement

☐ Aging caregivers

☐ Financial reasons

☐ Needs not being met

☐ Not enough support in current living arrangement

☐ Anticipate needs for new/increased supports in future

☐ Closer to transport/work/resources

☐ Closer to activities/friends

☐ Others (please specify)

29. What challenges do you have/anticipate in seeking a new living arrangement? Please tick all that apply

☐ Financial

☐ Caregiver support

☐ Transportation

☐ Accessibility (ie ramps, elevators, etc.)

☐ Personal safety

☐ Other (please specify)

30. Do financial concerns prevent you from accessing your preferred housing option?

○ Yes, financial concerns prevent me from accessing my preferred housing option

○ No, financial support is sufficient for me to access my preferred housing option

If you would like to make any further comments about finance and housing, please do so.

What would you like your home to be like?

Here we ask you about some of things that are important to you in your home.

31. How many people would you like to live with?

○ Alone

○ 1 other person

○ 2 - 5 others

○ 6 - 10 others

○ More than 10 others

32. Would you prefer caregivers to (Please tick all that apply)

☐ Live in?

☐ Work in shifts?

☐ Be a family member?

☐ Be a friend?

☐ Be a person with professional qualifications?

☐ Be the same person all the time?

33. On a scale of 1 to 5, with 1 being 'Not at all' and 5 being 'Very', how important to you is it to have your own

	1	2	3	4	5
Bathroom	○	○	○	○	○
Laundry	○	○	○	○	○
Kitchen	○	○	○	○	○
Living area	○	○	○	○	○
Bedroom	○	○	○	○	○

34. Would you like to share meals with other people?

○ Yes

○ No

35. Would you like to be involved in the management of your home?

○ Yes

○ No

36. What other things are important to you in your choice of home?

L'Arche

L'Arche is an International Federation of communities founded by Canadian-born Jean Vanier. In these homes people who have intellectual disabilities and those who come to assist share life and daytime activities together in family-like settings that are integrated into local neighbourhoods. To learn more about L'Arche: www.larche.ca

37. Are you familiar with L'Arche?

○ Yes

○ No

38. Would you be interested in

☐ Living in a L'Arche community

☐ Receiving support from a L'Arche community

Is there anything you would like to add?

39. Please use the box below to add anything you would like to say about your housing needs and preferences, or hopes and concerns regarding transition from home.

Other matters

Please read the information below.

40. We would like to interview between 20 and 30 people about their experiences. Interviews will take about an hour to an hour and a half, and will be conducted at a place convenient for you. Full details can be found at: wp.stu.ca/narrativestudies. If you are willing to be contacted about being interviewed about your experience of, and goals, for housing support in Fredericton please give your contact details below: These details will be separated from your responses to the questions above by the research team. If selected for interview, we will contact you before 30th June 2017.

Name

Company

Address

Address 2

City/Town

State/Province

ZIP/Postal Code

Country

Email Address

Phone Number

41. If you would like to receive a summary of the findings of the research, or an invitation to the public presentation of the findings, please give your contact details below. These details will be separated from your responses to the questions above by the research team. If you have have completed your address for Q41 above, you can simply write 'As above' in the 'Name' box below'.

Name

Company

Address

Address 2

City/Town

State/Province

ZIP/Postal Code

Country

Email Address

Phone Number

And finally...

Thank you for completing this survey. By clicking 'Done' you will submit your responses and they will be included in the research.

It is important to have as many people as possible take part in this project. If you know anyone else (an adult with an intellectual disability or a family member of such) who would might contribute, please encourage them to fill out this survey.