



Listening to Learn

Understanding the Needs of Adults with
Physical Disabilities Living in Burlington
Area Throughout their Lifespan

December 2011

Prepared by Supported@Home Burlington and SHS Consulting with funding from the Wellesley Institute

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Additional Notes

The views and opinions expressed in this publication do not necessarily reflect those of The Wellesley Institute.

Names of participants have been changed to uphold confidentiality.

The Listening to Learn project engaged adults with physical disabilities in Burlington in a meaningful conversation about their experiences relating to housing, services and overall quality of life.



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Executive Summary

The Listening to Learn project engaged adults with physical disabilities in Burlington in a meaningful conversation about their experiences relating to housing, services and overall quality of life. Supported@Home Burlington initiated this project as part of their person-centred approach to service design and delivery. The group plans to use this research to improve their proposed service delivery model for housing and service hubs for adults with physical disabilities in Burlington as they seek to improve the client experience.

A number of qualitative research methods were used within this project to amplify the voices of adults with disabilities and their families including: interviews, focus groups, photovoice, and a community forum event. Twenty-eight individuals have actively participated in the initial research process and twenty-eight additional individuals participated in the community forum event.

Key themes that surfaced from the research include:

1. Home of Choice
2. Range of Valuable Supports
3. How Services are Delivered
4. Connecting with the Community
5. Fostering Independence
6. Accessible Design
7. Systemic Issues and Advocacy

The following key issues arose from the research:

- Many individuals are currently not living in their home of choice .
- Many adults with disabilities require timely assistance at unexpected times.
- There are a range of supports important to maintaining quality of life that are outside of the scope of the basic spectrum of in-home services.
- Participating in organized activities is a high priority for many.
- Informal connections to activities and people are critical.
- Families and informal caregivers look for ongoing connection with support providers.
- Navigating the fragmented system of support services on one's own is

extremely difficult.

- There is a lack of communication and coordination between support service agencies.
- Finding the appropriate balance between independence and support is major factor in quality of life.
- Participants value flexibility within service provision.
- A consistent, trusted relationship between support staff and individuals is important because of the intimacy of the situation.
- Many individuals seek greater involvement in decision-making around support service provision.
- Travelling around the community and accessing community spaces is important.
- Burlington is generally considered a welcoming and accessible environment.
- Transportation is a critical gateway to accessing community resources.
- Common space in residences need to be accessible and support social well-being for all residents and visitors.
- There are a range of large scale systemic issues that create significant barriers for persons with disability that need to be addressed.

The analysis of the key themes, issues, suggestions for moving forward, and client profiles led to the development of an analytical discussion. The discussion focuses on the importance of the following key factors in ensuring adults with physical disabilities have a high quality of life:

- Provide choice
- Provide support for overall wellness
- Provide services that support independent living
- Nurture the relationship between staff and clients
- Foster seamless navigation and coordination of services
- Incorporate accessible design features
- Encourage interaction with the community
- Provide adequate resources
- Embrace the model of person-centred care

Supported@Home Burlington will utilize input and stories from this research to improve their service delivery model and assist in enhancing the quality of life for adults with physical disabilities.





Introduction

The purpose of the Listening to Learn project is to engage adults with physical disabilities in Burlington into a meaningful conversation about their perceptions and experiences related to housing, services and overall quality of life.

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As part of Supported@Home Burlington's person-centred approach to service design, the group is looking to better understand the experiences of adults with physical disabilities in order to improve their proposed service delivery model for housing and support services so that it best meets clients' needs. The goal of this project is to ensure that the needs of adults with disabilities are at the centre of the design and that their

input is integrated into the decision-making process.

The research question explored within the project is, "How can Supported@Home Burlington meet the full range of needs of adults with disabilities in Burlington?" To help answer this question, a variety of qualitative research methods were used to gather stories and perspectives from twenty-eight individuals. The results provide rich and valuable insights into the lives of adults with physical disabilities in Burlington and offer critical direction and feedback to Supported@Home Burlington and other service providers.



Background

Supported@Home Burlington is a collaboration of seven forward-thinking service providers in Burlington, Ontario looking to change the future of support services for adults with physical disabilities in Burlington.

This multi-stakeholder group is comprised of a number of partners including: March of Dimes Canada, Cheshire Independent Living Services, MS Society Halton Region Chapter, AbleLiving Services, Rotary Club of Burlington Lakeshore, Hamilton Niagara Haldimand Brant CCAC, and the Joseph Brant Memorial Hospital.

This group is in the process of developing and refining a collaborative service delivery model for housing and support services for adults with physical disabilities. Together they are working toward the creation of a network of four service hubs in neighborhoods throughout Burlington. The hope is that these hubs will include supportive

housing with a full basket of services, shared office space for service providers, as well as an outreach service team.

Supported@Home Burlington recognizes that to fully embody the client-centred approach, listening to what adults with physical disabilities have to say about their experience with accessible housing and support services is essential. Through the process of this research Supported@Home Burlington is seeking to refine their service design and improve the service provision for adults with physical disabilities living in Burlington.

Community Context



Burlington has a significant lack of affordable and accessible housing for adults with physical disabilities. Individuals and families are leaving Burlington because there is not enough supports and appropriate housing to meet their need. In fact, this is why Supported@Home Burlington was originally started. In Burlington, there are long and growing waiting lists for assisted living facilities and services, forcing some individuals to remain in the hospital until appropriate housing is available.

The cost of housing in Burlington is high compared to other cities in Ontario. Households that rely on the Ontario Disability Support Program (ODSP) and the Canada Pension Plan (CPP) as their main source of income find it nearly impossible to afford market housing in the city.

Certainly there are many services already in place within Burlington to support adults with disabilities, but these services are fragmented, there are critical gaps, a growing need, and limited funds.

The following are some key statistics and information that highlight the compounding issue around housing and supports for adults with physical disabilities as of 2011:

- Burlington has 23 supportive housing units for adults with physical disabilities and 65 adults with disabilities receiving outreach services. (1)
- There are over 100 households on the waitlist for these services in Burlington. (2)
- Only 6% of supportive housing units in Halton Region are designed specifically for adults with physical disabilities. (3)
- The gap between Ontario Disability Shelter Program's shelter allowance and average market rent is almost double the rent of a one bedroom apartment. (4)
- The cost of having someone wait in the hospital is approximately double the cost of providing 24/7 assisted living care by a non-profit organization. (5)

All of these factors contribute to the need for a collaborative and strategic approach to improving the housing and support services for adults with physical disabilities in Burlington. In order to find the best way to make this happen, listening to and learning from adults with disabilities is critical.

(1) Region of Halton website www.halton.ca Housing for those with Special Needs.

(2) Service provider waitlist data as of July, 2011.

(3) Halton Region. (2010). Joint Municipal Housing Statement: Phase 1 Demand and Supply Analysis.

(4) Ontario Disability Support Program Act (1997) & Canada Mortgage and Housing Corporation Rental Market Report GTA (2010).

(5) Cost estimates based on Joseph Brant Memorial Hospital & AbleLiving data.

Purpose and Objectives



The overall purpose of this research was to listen to and learn from adults with physical disabilities in Burlington about their experiences related to housing, support services and quality of life.

The goal of this study is to facilitate the integration of the diverse perspectives of adults with disabilities into Supported@Home Burlington's planning of service delivery.

The objectives of this research are to:

- Determine the health, service, and housing needs of adults with disabilities, directly with and from these individuals
- Use the input, stories, and feedback from these individuals to drive the development and refinement of Supported@Home Burlington's service delivery model and business plan.



Research Design and Methods

The intent of this case study was to understand the experience of adults with physical disabilities and ensure their voice is at the centre of the service design process. The project involved four qualitative methods of gathering data:

1. Interviews
2. Focus groups
3. Photovoice
4. Community forum and exhibition

A number of participants participated in more than one of the methods; for example, photovoice participants were recruited from interviews and focus groups.

This methodology was developed and refined through close collaboration with the Community Based Research Centre's Research Ethics Board in Vancouver, BC. Conversations with the research ethics board helped to improve the accessibility of the process for participants and ensure all parties were respected. For each of the methods, participants were provided with information explaining the process in clear, simple language and verbal consent was obtained from each participant before proceeding.

Interviews

Conversational interviews were conducted with adults with physical disabilities in the location chosen by the participant. In these open-ended interviews, informal conversations took place about the following general topics:

- What their typical day looks like
- Their experience with support services
- Their needs and desires for support
- What is and isn't working in terms of design inside and outside of their home
- Things that are really important to their quality of life
- Their ideal living situation

Researchers included phone interviews and email questionnaires as an option for participants to improve accessibility to participating in the project.

Focus Groups

Focus groups were conducted with a number of adults with physical disabilities and their family members in Burlington and area. Participants were asked to collectively envision improved housing accessibility

and service delivery. Focus group target participants were expanded to include family members as their valuable and unique perspectives supported and added depth to the stories heard directly from adults with physical disabilities.

Photovoice

The photovoice component of the research included having adults with physical disabilities take photos in response to the following key questions:

- What enhances your quality of life (e.g. home modifications, equipment, services, people, activities)?
- What current barriers do you have to improving your quality of life (e.g. limitations of home, service limitations)?
- What is your ideal living situation (e.g. good examples of housing, good examples of modifications, services available elsewhere)?

In addition to taking photos, participants either documented their impressions and thoughts around each photo or verbally discussed them with the researcher. While it was originally planned that participants would provide their responses and analysis through a workbook document, accom-

modations were made based on individual preferences and abilities as to how photos were taken and described. Participants were given total control over what pictures they took and had the opportunity to review their photos and remove any photos that they did not wish to share.

Community Forum and Exhibition

Supported@Home Burlington hosted Transform, a community forum and exhibition, in December 2011, where community members discussed the perspectives of adults with disabilities brought to life through this research and provided input into Supported@Home Burlington's proposed delivery model. At this event, themes and insights from the research were showcased as well as photographs and stories from the photovoice component. There were approximately twenty-eight attendees that ranged from service provider staff, clients, community organizations, community advocates, funders, and housing developers. This provided community members with the opportunity to learn from the research and offer suggestions around how some of the findings can be acted on in Burlington.



Participant Demographics

There were a total of twenty-eight participants in the initial research study, including 10 individuals who participated in interviews or photovoice and 18 individuals who participated in focus groups. An additional twenty-eight individuals participated in the Community Forum Event.

As discussed in the research design, some participants were engaged in more than one method. The totals for participation in each initial research method are as follows:

- Interviews: 10 (five in-person interviews, three phone interviews, and two interview questionnaires were completed through email)
- Focus Groups: 3 (two through community agencies, one supportive housing project)
- Photovoice: 3 (two participants that currently reside in supportive housing, and one individual that resides in a modified unit and receives outreach services)

Participants ranged in age from younger adults to seniors. There was a mix of male and female participants, although there were more female than male participants. Participants were mainly individuals with a physical disability, but a few caregivers, family members, and support staff also participated. Most participants lived in Burlington but, there were a small number of participants interviewed that would like to live in Burlington and are from cities nearby such as Oakville, Hamilton and Mississauga.

Participants had a wide variety of living situations, including:

- General housing with parents or another family caregiver
- General housing receiving outreach services
- Accessible housing receiving outreach services
- Supportive housing in an accessible housing unit with in-house support services



Participants had a range of abilities and health conditions, including living with cerebral palsy, multiple sclerosis, survivors of stroke, visual impairment, and using non-verbal communication.

This research reflects the stories of the individuals who participated in the process. Due to project constraints, capturing perspectives from individuals with a complete range of abilities and ethnicities was not possible. Thus, the results are not fully representative, but offer an important window into many shared experiences and desires of adults with physical disabilities in the Burlington area.

The research question explored within the project is, "How can Supported@Home Burlington meet the full range of needs of adults with disabilities in Burlington?". The results provide rich and valuable insights into the lives of adults with physical disabilities in Burlington and offer critical direction and feedback to Supported@Home Burlington and other service providers.

Results: Key Themes

Seven themes were identified through synthesizing the conversations with participants and understanding their stories:

1. Home of Choice
2. Range of Valuable Supports
3. How Services are Delivered
4. Connecting with the Community
5. Fostering Independence
6. Accessible Design
7. Systemic Issues and Advocacy

Home of Choice



A strong theme throughout the interviews was participants' desire to live in the home of their choice.

"It's a tough decision to give up your home; people want to stay as long as they can. It all comes down to assistance."

— Research Participant

A strong theme throughout the interviews was participants' desire to live in the home of their choice. Many individuals described alternative living arrangements that they would prefer to live in if circumstances were different. There was a wide diversity of desired housing choices based on individual circumstances and preferences.

A number of participants mentioned affordability as a factor in whether or not they are able to live in their home of choice. For instance, one participant would prefer to live in seniors housing with supports:

"I could be more independent if I could move into seniors supportive apartments. That is if it isn't \$2,400 a month. I'd go if I could afford it, and that's one of the cheaper ones. If you have any savings, you could afford it. I save my money and have a bit, but it would be gone."

Others mentioned that they would prefer to stay in their current home for as long as possible, and that this is only possible if adequate supports are available.

Other younger participants currently living with their parents have a goal of moving out of their parent's home to increase their independence. Due to long waitlists for supportive housing, these participants were unsure when they would be able to move out on their own.

Some participants were concerned about what will happen with their living situation when their disability progresses. They stated that they want to be or need to be in long term care. Privacy and lack of space in long term care homes was a concern to some participants.

Key Issue:

Many individuals are currently not living in their home of choice because of lack of available options and others are worried about their housing options in the future.

Suggestion for Moving Forward:

Ensure that all adults with disabilities in Burlington can live in their home of choice.



Theme 2

The Range of Valuable Supports

“Everyone has different needs.”

— Research Participant

Participants provided detailed accounts of informal and formal types of support they are currently receiving and types of support that would enhance their quality of life. A notable theme is the diversity of support needs and preferences communicated by participants. This section describes a wide range of supports articulated by participants as important. These supports include formal services, such as personal support, homemaking, and wellness supports, as well as informal supports and activities such as personal activities, family and friend support, and spiritual support.

Assistance for Daily Living

Some individuals feel they receive enough assistance for daily living while others felt that the amount of services they were receiving was not enough. Some have a Personal Support Worker (PSW) visit once or twice a week, while others have a PSW visit three times or more per day. A few participants did not have access to a PSW and relied on informal support. Those participants who lived in supportive housing had at least one PSW available twenty-four hours per day. Others who were not currently residing in supportive housing felt they would want a staff person there at all times for safety reasons. Further, it was suggested that it would be beneficial to have staff on call who are familiar with the residents if a scheduled staff is not available.

Personal Services

Participants who do receive assistance with daily living either as outreach or as a part of supportive housing received a range of personal services. For instance, PSW's tended to assist participants with getting in and out of bed, getting dressed, showering and bathing, and occasional medication reminders. One participant indicated that they had thought they would be eligible for personal services upon discharge from the hospital, but were told that their situation was not urgent enough to receive funding for services.

Homemaking Services

Many of the individuals who received personal services also received homemaking services, such as laundry, changing the bedding, and cleaning the house. Support staff also assist individuals in meal preparation and cleaning the dishes.

Assistance Between Scheduled Bookings

Participants identified that sometimes there was a need to contact staff for personal assistance in between their daily scheduled bookings. One supportive housing facility uses a pager system while another has a buzzer with an intercom. Participants generally expressed appreciation for a notification system. Some individuals commented on wait times with the pager system that can be up to approximately half an hour and it was suggested that it is likely based on staff funding cuts.

Key Issue:

In addition to a variety of personal supports and homemaking, many adults with disabilities require timely assistance at unexpected times throughout the day and night.

Suggestion for Moving Forward:

Offer timely, flexible assistance around the clock.

“I find it really difficult. If I had my choice and if I had my meals made for me, I'd probably eat better, and would be on time with my pills.”

— Research Participant

Wellness Supports

“Sometimes I just want someone to chat with.”

— Research Participant

Participants identified a wide range of supports that would improve their overall well-being. Some participants receive wellness supports, but many identified these supports as something they would like to have. One of the key themes throughout the discussions was the ability to do more wellness related activities or supports as staff or volunteers are available. Many of the desired wellness supports include having assistance with various activities and areas of their lives that go beyond the traditional personal assistance and homemaking.

“Someone to Talk To”

A frequent theme throughout the research was the desire for individuals to have someone to talk to. Participants mentioned that sometimes it is nice to have someone to chat with, and that they are not able to talk with staff about anything too personal. It was indicated that it would be beneficial to have someone in the building, a staff or volunteer, who would be available to talk or go out for a coffee.

Shopping

A number of participants mentioned shopping, especially grocery shopping, as an area where they currently receive formal or informal support or would benefit from increased support. There is a diversity of preferences related to how individuals would prefer to shop: have someone shop for them and deliver it to their home, order online, go shopping with someone who can assist, or shop on their own and have some assistance with certain tasks such as packaging food to keep longer. It was also important for individuals to live close to shopping that is accessible.

Assistance and Activities Outside the Home

Similar to shopping, a number of participants identified that it would be helpful to have assistance getting around outside of their home and within the community. For instance, participants identified that having someone to accompany them to the doctor's, hospital or train station would be beneficial.

Others mentioned that they would benefit from having someone to go for walks with or to take them to recreational activities, such as swimming. Some participants have outreach services that include staff accompaniment out into the community, but clients are to find their way to the meeting place on their own, and often do not have a method of transportation to be able to meet the staff person. One participant made the suggestion of having an on-call staff or volunteer during certain hours of the day that they could contact if they needed to go out and run errands.

Nutrition

Some participants mentioned the importance of nutrition for their overall wellbeing. Participants described how their level of nutrition was based on what the staff were able to cook or what they were able to cook themselves. A few participants mentioned that they often have frozen or processed foods and that the importance of nutrition has not been communicated as something to consider by their health professionals.

Additional Homemaking and Wellness Supports

Participants identified a number of other homemaking and wellness supports that would enhance their quality of life. Each recommendation is unique to the individual. The following are activities that individuals identified as wanting support with to improve their overall wellness and quality of life:

- Cleaning baseboards and walls
- Completing odd jobs
- Managing bills
- Keeping track of appointments
- Going to the bank
- Attending health related workshops and lectures
- Offering bereavement and counseling
- Training in computers
- Finding employment
- Writing a letter
- Painting
- Baking
- Hair-styling (in-house)
- Offering an exercise program
- Organizing the space to fit individual needs

Key Issue:

There are a range of supports important to the wellbeing and quality of life of individuals that are outside of the scope of the basic spectrum in support services.

Suggestion for Moving Forward:

Broaden service offerings to meet the needs of the individuals and provide a variety of non-traditional supports important for individual wellbeing.



Informal Supports and Activities



Art work painted by a participant.



“It’s like I have
second family.”

— Research Participant

Personal Hobbies and Activities

Participants were passionate about a variety of different activities that they like to do in their personal time. Some of the personal activities mentioned include:

- Writing
- Reading or listening to books
- Playing cards
- Painting
- Sports
- Music
- Going to the lake

Some participants described active social lives, including attending many social activities in Burlington. While, a number of participants indicated that they are quite busy, others would like to be a bit more social if there was extra support available.

Some of the informal social activities described by participants were:

- Going out for dinner
- Bowling
- Shopping
- Spending time with friends
- Swimming
- Sleepovers with friends or relatives

Spiritual Support

A number of participants described finding support through a church to which they belong. Some participants live close to the church and this was seen as very important. A few participants described examples of where their church was supportive; for example, one participant described how members of their congregation helped paint his bedroom. Also, the church was

a welcoming community to be engaged in – where, for example, one participant is currently writing for the church newspaper.

Family/Friend Support

The value of informal support from family and friends was a reoccurring theme throughout the discussions with participants. Family and friends provided a wide range of support including homemaking assistance, emotional support and enjoyable social interaction. Some also act as the primary caregiver taking on the lead role in ensuring the individual is supported. Participants mentioned that if support is needed, they have friends or family that can be called on for help, but many try to do as much as they can on their own. Other participants had less ability to ask for support from friends or family.

A few family members who participated in the research indicated that it would be helpful if the family was included in communication with the service providers, such as when there are health changes or events that have taken place where the family or individual could assist in supporting the overall well-being of their family member. For younger adults, it was mentioned that it would be important to keep parents in-

involved with certain roles, such as managing finances, to help support the smooth transition to independence.

An emphasis was placed on ensuring that there is more support for caregivers. Primary caregivers described the need for respite for their increasing exhaustion. For instance, a primary caregiver of a stroke survivor, indicated,

“The caregiver needs time out. There’s no respite for caregivers, unless you pay.”

It was suggested that it would be helpful to have a support group for caregivers, including a support group for spouses and children of a family member who may have received a recent diagnosis.

Of those who currently reside in supportive housing, some found support from other residents in the building. Residents look out for each other and provide ongoing emotional and social support. A couple of residents in buildings throughout Burlington would informally take on more of a lead role in supporting other residents.

Key Issue:

Individuals expressed the importance of informal connections to hobbies, areas of interest, and fulfilling activities, as well as the value of maintaining connections friends and family. Families and informal caregivers look for ongoing connection and support from support providers.

Suggestion for Moving Forward:

Support individuals in making informal connections within the community. Become a platform that empowers and supports connections and ongoing communication with family and friends.



'Eric' is shown here holding a train ticket. He takes the train often to visit his family.



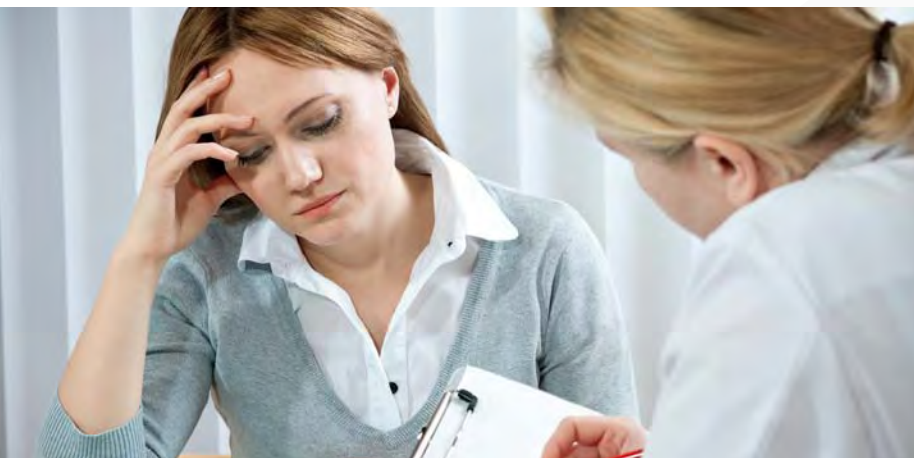
Participant Story

"Updates on 'Eric's' health and well being is a good thing for us. I know the staff are busy but if there was a letter or something when changes happen either at the house or personally with Eric it is a good thing to keep us updated."

— Eric's Sister

'Eric' lives in an assisted living home in Burlington. He loves living in Burlington, and has a close relationship with his sisters and mother who live in Toronto. It is important for him to be able to visit them, and sometimes transportation to get there can be an issue. Eric's sisters help support him by talking on the phone to him every day, visiting him every week, and going on outings and trips together. It is important to Eric's sisters to have meaningful, ongoing communication with the staff who work with Eric to ensure they are all on the same page on how to best support Eric.

How Services are Delivered



Participants had as much to say or more about how services should be delivered as they did regarding which services should be offered.

Navigating the System

A number of participants described their experiences with navigating the system. Some participants had their services coordinated by the hospital or other agencies that they already had connections with. Other participants tended to discuss navigating the system as something that had to be done on their own. Phrases were used such as “I don’t know who to speak to”, “It’s a bit of a shuffle trying to find the right people to speak to”, and “We felt totally left out, I didn’t know where to go”. Feelings of fear and abandonment were described.

Participants had suggestions for ways in which navigating the system could be easier. It was recommended that it would be helpful if there was one agency, coordinator, or one phone number that anyone could go to with every question. As one participant says,

“You need a coordinator. Someone to guide you through the maze. Someone that can coordinate all of the different areas and programs.”

Other suggestions include having a resource binder available for residents or clients that is accessible and would provide information on all of the available services and facilities.

Key Issue:

Navigating the fragmented system of support services on one’s own is extremely difficult and often leaves individuals feeling frustrated and forgotten.

Suggestion for Moving Forward:

Offer one key point of access that connects individuals with all of the necessary services and answers questions along the way.

Participant Story



“I called a lot of places and they would say “we don’t have that program in your area” and that was the end of the conversation.”

— ‘Vanessa’

‘Rohan’ had a stroke two years ago and his primary caregiver is his wife, ‘Vanessa’. He has impairments to his mobility and has difficulty walking without support. When Rohan was discharged from the hospital, an agency came to his home only a few times and they did not hear back from the agency after that. When Rohan contacted the agency, he was told that his case was not critical enough to be able to access their resources.

Vanessa and Rohan have spent the past two years trying to navigate on their own. Vanessa has spoken to many people and hit many roadblocks along the way. Through her research, Vanessa found a fitness program for Rohan. He can walk on his own now, which is something he couldn’t do before taking the class. Vanessa also found a friendly phone call program for Rohan so that he can have someone to talk to since he is home on his own quite often. They are still looking for access to outreach services. They do not know where to look anymore.

Coordination of Services

Participants also discussed the importance of coordination between the services they are currently receiving. A number of participants receive multiple services from different agencies. Some participants indicated that there is little, if any, coordination between their home support service programs. This has caused preventable miscommunication between the clients and staff, and inconveniences for the client. Also, participants indicated times where the work that is supposed to be done does not get completed due to lack of coordination. Participants sometimes feel as though they are telling the same story to many different people.

Key Issue:

There is a lack of communication and coordination between support service agencies.

Suggestion for Moving Forward:

Offer a seamless, integrated experience between services with ongoing communication and coordination between services.



Balancing Independence with Appropriate Supports

The need for individuals to have a balance between independence and receiving suitable supports was clearly identified. Most participants indicated that their independence is very important, and that they want to be independent as much as possible. A number of participants positively described their current situation as one that allows for independent living but is also one where assistance is available when needed.

Participants described the importance of support services and activities that result in greater independence, such as taking a cooking class or assistance with organizing their space so that it can be more accessible and well utilized.

Key Issue:

Finding the appropriate balance between independence and support is major factor in the quality of life of individuals.

Suggestion for Moving Forward:

Work with individuals to determine the appropriate balance of independence and support.

Flexibility

The importance of flexible service provision and the impact of heavily regulated services were discussed by many of the participants. The need for flexibility in how, when, and what services are received was a clear theme.

Participants had varying experiences with the flexibility or rigidity of services received. Some participants greatly valued their ability to tell staff what is most important for them. Participants who were quite happy with their services indicated that staff are accommodating to their current needs rather than working from a rigid 'to do' list. Participants spoke positively of situations where attendants are willing to change the time of the visit or when attendants ask if there are any specific things they can help with.

The services are provided with the understanding that circumstances can change on a frequent basis. For instance, one participant who is quite satisfied with outreach services she receives, indicated that,

"She will ask what's on the agenda today... I know exactly what I want her to do that day. She'll go out on errands for me, after that she'll ask what else she can do. I've never been told 'no'"

Others spoke of a lack of flexibility in the services they receive. A number of participants described being told, "that's not something we do", "we're not allowed to do that", or "you're responsible for that". Participants indicated that often they felt that the request was minor, or the request was something that they thought the staff were able to do. A number of participants said that some organizations have too many rules. Experiences were described where individuals are not able to attend certain events or eat at a proper time because the time of the staff visits are not able to be changed. One participant's experience is described:

"We want independent living but need more support for some things, like getting a Kleenex. The staff will say 'we don't do that.' The rules are so rigid."

Key Issue:

Participants value flexibility within service provision and many are frustrated with the rigidity of what is possible.

Suggestion for Moving Forward:

Allow flexibility in service provision to ensure staff are able to best meet individual's needs.

The Role of Staff

“Someone with a disability is requiring services that are not normal. They are incredibly intimate with support staff. If you have the same person, you develop a trust, and there’s continuity, you know them and they know you. It’s difficult to say “no, please do it this way” and explain why. It’s more intimate than making love with someone.”

— Research Participant

As participants are most closely connected to the staff who provide their services, many participants had comments about the important role that staff play in their quality of life and the quality of services that are received.

Trust and Continuity

A theme that stretched across many conversations was the importance of the client-staff relationship. Participants felt a strong need for consistency in the staff who work with them. A few participants described that they do not like having different people working with them every day. They feel that the trust that develops with staff is important to maintain, and it is only possible when they are working with the same staff. Participants indicated that continuity is important because of trust, intimacy of the care provided, and it results in greater productivity in the time they are provided. Some participants feel that they are “forever training”.

Power, Respect, and Advocacy

Participants felt strongly that the attitude of the staff is very important. In general, a number of individuals commented that they have had a very positive experience with the staff who provide their services. Getting along with staff was a considerable indicator of quality of life of the clients. Participants made comments towards staff

such as calling them a “godsend”, “I don’t know what I’d do without them,” and that staff “don’t get paid enough”.

Others focused on the importance of being treated with respect. Some participants have had experiences where they were treated in an undignified manner, or felt like a staff member did not care about them. Comments were made indicating that staff could listen to them more rather than do what they think is best without asking first. Establishing a basic level of accountability between staff and client was suggested to be critical.

A number of participants described times where either they or friends have been fearful to advocate for themselves. Some participants feel that they are not allowed to be fussy for fear that their services will be taken away, that it will impair their relationship with their care worker, or they don’t know who to talk to about their concerns.

Key Issue:

Establishing a consistent relationship with trust and mutual respect between support staff and individuals and nurturing a positive connection is important because of the intimacy of the situation.

Suggestion for Moving Forward:

Work toward an environment where all staff and clients have a positive relationship based on trust and mutual respect.

Involving Residents in Decisions

A number of participants desired to have more involvement in decision-making regarding both staff and programming. Participants suggested including clients in the interview and orientation process for staff and involvement of residents in the building in determining what programming they would like to see.

Key Issue:

Many individuals seek greater involvement in decision-making around support service provision.

Suggestion for Moving Forward:

Offer clients the opportunity to provide input and participate in decision-making around how and what programs are provided, as well as staffing.

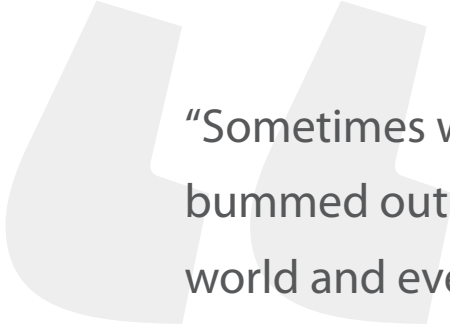




Theme 4

Connecting with the Community

Most of the participants identified the importance of being able to go out into the community and feel a part of the community, but at the same time identified barriers to being able to so.



“Sometimes when it’s hard to get out, and there’s no one to take you out, you get bummed out. That’s when you get lonely, you feel like you’re so detached from the world and everyone. I don’t want to go out every day, but when you really want to go out, you can’t keep calling people, other people have things to do too.”

— Research Participant

Freedom to be out in the Community

Participants identified having freedom to be able to get out in the community as very important to their quality of life. Many participants do not want to be inside their house all of the time, but participants differed in their abilities to go out. Participants who were able venture out in the community, whether independently or with support, found great value in this. Others wanted greater ability to be out but face obstacles such as transportation or requiring the support of having someone with them. Participants’ level of ability to get around outside of their house was considered a factor in overall mental and social well-being.

Key Issue:

Ability for individuals to be out in the community can have a significant impact on quality of life.

Suggestions for Moving Forward:

Provide clients with support that allows for opportunities to access community spaces.



Transportation

Many participants specifically mentioned access to transportation as a significant issue in their lives and a barrier to being able to do many of the things they would like to do. The cost, accessibility, and availability of transit were listed as barriers.

For instance, the City of Burlington has a service for adults with physical disabilities which provides door-to-door drop off and pick up for the same cost as public transit. Most participants use this service and are satisfied with it. Although, some felt that a barrier to the service is that they have to book a ride a few days in advance. In addition, participants felt that sometimes the service schedule did not fit their schedule.

Also, after they are dropped off at their destination, there is no one available to help once inside the building. Some participants identified that it would be helpful to have someone help with pushing the elevator button. Taking a cab can be quite expensive for many of the participants.

Key Issue:

Transportation acts as a gateway to accessing community resources and many individuals consider transportation a barrier.

Suggestion for Moving Forward:

Brainstorm ways in which transportation can be provided in a more accessible manner.

Participant Story

'Patricia' had booked the accessible transit van in advance of her doctor's appointment, however the doctor rescheduled and it wasn't enough time to change the scheduled booking with the transit van. As a result, Patricia had to take a cab which cost her \$36 instead of spending \$3 on the accessible transit van.

Burlington Community

Participants had very positive comments about the Burlington community. Many individuals felt that most places in Burlington are accessible for a wheelchair, such as the bowling alley, parks, and some restaurants. Also, it was felt that residents of Burlington are very friendly and helpful.

Participants also mentioned the importance of location of their home. A few participants greatly enjoyed that they are close to a lot of important amenities such as a bus stop, pharmacy, library, shopping, grocery stores, and parks.

Key Issue:

Burlington is generally considered a welcoming and accessible environment for adults with physical disabilities.

Suggestion for Moving Forward:

Consider proximity to amenities when choosing a site for supportive housing.



Fostering Independence

"I have a good quality of life – I have my independence. I am self directed, that's important to me. That's the crux of it all. I don't have someone telling me what to do."

— Research Participant



A theme throughout discussions with individuals was pride in how they have kept their independence in many aspects of their lives and maintaining dignity. This was shown through many examples such as pride in decorations and furnishings in their home, qualifying for rent subsidy but still paying full rent, and working with attendants on tasks when possible.

In addition to programs and services that may be provided by service providers as described in The Range of Valuable Supports, participants identified other methods to promote independence.

Responsibilities



"I find I need someone to do 'for'. I love me, but you feel better when you're taking care of someone else whose needs are as important as your own. When I was stuck at home from work because of MS, I needed someone that relied on me. So I got a cat, and it was the best decision I ever made. I like to do things for her. It's someone who looks to you and thinks, you're important to me."

— Research Participant

A number of participants identified that they have significant ongoing responsibilities in their lives. The types of responsibilities varied widely between participants. Some individuals act as caregivers for others. For instance, one participant is a single mother of three, while another helps an aging mother. Another participant goes shopping for other seniors in her building and organizes social activities for the building. Participants who are younger adults described how they are taking on more responsibilities around the home, such as

making lunches, doing the laundry, or cutting the grass, to help prepare to live independently. A few participants also actively volunteer in the community.

A common theme during the interviews and focus groups was the importance of pets. Many participants were eager to discuss their love for their pet and how much their pet means to them. Participants talked about the ways in which they care for their pet.

Access to Technology

Many participants identified the importance of technology to enhance their independence and quality of life. A number of participants use modern forms of technology such as cell phones and the internet. Some participants mentioned that they would like more training on the computer. A few participants indicated that they use specialized equipment, such as a special computer mouse or keyboard, a computer that talks, or audio books.

Key Issue:

It is important for adults with disabilities to have the ability to keep independence as much as possible.

Suggestion for Moving Forward:

Facilitate and support opportunities where individuals have self-control and personal responsibilities.



“People can do anything if they put their mind to it. If they have the right equipment they can do anything”

— Research Participant



Theme 6

Accessible Design

The way in which a home is designed can greatly influence the level of independence and safety that a resident will experience. Participants described details of the accessibility level of their home and modifications they have made to their home to make it more accessible. The following section describes design and equipment features that either help or hinder the individual's quality of life.

Doors and Doorways



“People have different ideas of what accessibility is.”

— Research Participant

Many participants identified both doors and doorways as areas for improved accessibility. Participants indicated that the doorways in their home could be wider (standard doorways are not wide enough) and that even an extra few inches in a doorway could make a huge difference. Some participants who use a scooter or wheelchair had power doors to their room or unit while others did not. Accessible buildings had power doors at all entrances.

One of the supportive housing buildings uses cards to open the main doors. The sensor located near the door recognizes the card and the door will open automatically. A useful feature is that the card does not have to be held up to the sensor; it is recognized if it is in a bag or wheelchair pocket. Another supportive housing building has an automatic door remote with two buttons: one for the unit and one for the lobby door.

Unit

In general, participants would benefit from a bit more space in their home. A unit that is open concept on one floor would be ideal for some participants. Participants also mentioned that they would like a unit that has privacy and could accommodate visitors.

Bedroom

Some participants use a ceiling lift to get in and out of bed and may also have a hospital bed. Some participants who use this equipment were responsible for purchasing it. Closets which hold hangers within reaching distance are very beneficial. One participant described the benefit to a 'super pole', which helps her move around in bed.

Kitchen

There are many design and amenity features in the kitchen which could either assist or act as a barrier for individuals with physical disabilities. To begin with, it is important to have both an accessible stove and fridge. An accessible fridge was described as one that is designed so the refrigerator and freezer are side by side rather than have high handles that cannot be reached. One participant found that she cannot reach beyond the front door of the fridge. An accessible oven was described as one that has handles that open the stove like a door, rather than downwards. One participant has an oven that is built into the wall and finds it is most useful this way. Also, a few participants mentioned the danger in using the two back burners for someone who uses a wheelchair. A flat top stove could also be a danger for someone with a visual impairment since the pots and pans slide easily.

Kitchen cupboards were also identified frequently as a barrier. Many participants mentioned that they are not able to reach the cupboards but that there was also not adequate cabinet space at a reachable level. Moveable shelves or countertop were suggested as alternatives that would be more useable.

In general, many participants would prefer a full kitchen, however some participants, especially some younger adults or those who have staff prepare their meals full time, would prefer a kitchenette with a shared large kitchen.



A participant shared that she cannot reach anything beyond the front door of the fridge, and as a result cannot store any food in most of the fridge.



“This building is supposed to be built with people with disabilities in mind but it’s not accessible enough for people in wheelchairs”

— Research Participant



“It is nice to be able to get outside on the balcony to sit amongst greenery and read my book.” - Research Participant



Bathroom

Participants identified a number of important features that they prefer in the bathroom. This includes a walk-in shower with a sturdy shower chair and grip bar, hand-held flexible shower hose, non-slip floors, and grip bars on either side of the toilet. It is also important that the counter is narrower than standard and built to allow a wheelchair to fit underneath.

Air Conditioning

A few participants mentioned the importance of having air conditioning, especially for individuals with health concerns. Providing fans would be a welcome alternative.

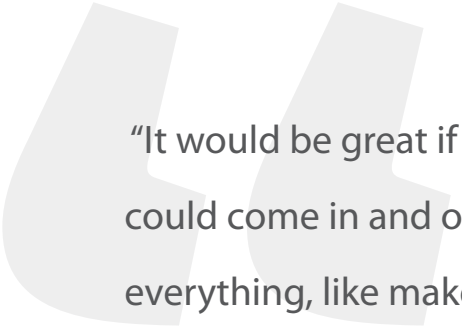
Balcony

A few participants who have a balcony really enjoy spending time on it and felt that there was enough room to manoeuvre. One participant has a balcony but cannot get through the door to be able to use it.

Assistance in Design

One of the supportive housing buildings has an intercom system where residents can press a button and staff respond through the intercom built into the wall. Residents really liked this feature, and one participant who does not have this feature in her home identified that having a buzzer to call staff is something that would be very helpful.

Building Interior and Exterior



“It would be great if someone could come in and organize everything, like make a room more spacious by working with the space, but make it more accessible for you.”

— Research Participant

Participants described many features inside and outside of the building that are important to accessibility and social well-being.

Elevators

Elevators seemed very important to participants, and to some was either a gateway for freedom or created isolation. Some important elevator features include sensors on the doors so they don't close on people, or having the elevator verbally announce the floor. Others had stories of isolation or dependence regarding the elevator. For instance, a few participants cannot lift their arms to reach the elevator button, so must depend on staff or a passer-by to push the button. Similarly, elevators controlled by a key are not accessible to residents with limited arm/hand mobility without staff assistance.

Common Spaces

Many participants described different types of common spaces that would be preferable in a supportive housing building. A number of participants would like to have a space to entertain family or friends. Others would like to have a common room with a television or have various forms of entertainment come into the building.

Some participants mentioned health and wellness related spaces, such as a complex with medial services on site, a space for

physiotherapy or counselling, a basketball court, and swimming pool.

Building Safety

A few participants mentioned the importance of building safety, including fire drills and inspections of living conditions.

Exterior

Participants described features outside of the building that they currently appreciate or would like to have in a future home. A few participants mentioned the desire for accessible outdoor spaces, such as a backyard with chairs and a barbeque, and raised garden beds which residents in a wheelchair can use. One participant benefits greatly from a tunnel that was built between her residential building and the church next door.

Key Issue:

Units, common and circulation space throughout the building needs to be accessible and support social well-being for all residents in the building and their visitors.

Suggestion for Moving Forward:

Fine-tune Supported@Home's design guidelines to incorporate findings from the consultation. Advocate for changes to the City of Burlington's accessibility guidelines, as appropriate.

Systemic Issues and Advocacy



“There’s a lack of people to help. I used to have five hours of support but it got cut back so now I have no hours.”

— Research Participant

There are issues for adults with physical disabilities at a system and society level which have contributed to difficulties for participants. The following section describes issues of funding cutbacks, income, and societal views of persons with disabilities, and the importance of efforts to bring greater awareness to the community.

Funding Cutbacks

Many participants felt that inadequate funding is a big issue and that it is the root cause of many of the problems they are experiencing. Participants told stories of how funding cutbacks are affecting their lives. They would describe how they used to receive a certain number of hours of support but that it has been cut back to very little to no services at all, even though their needs have not changed. Participants felt very grateful for the services they do have, but some felt that not a lot can get done in the one or two hours of services that they are allotted. A number of participants felt that staff do not have enough time for them.

Others felt that most people cannot afford to wait for funding to come. Individuals with certain health conditions may experience drastic changes and cannot wait months for funding approval. Some participants also indicated that they felt tired of hearing that things can’t be done to help them because of lack of funding.

Income

A few participants mentioned struggling with living on a fixed income. Some participants rely on ODSP and find that it barely covers basic needs. It was also identified that affording the cost of medication can be quite challenging.

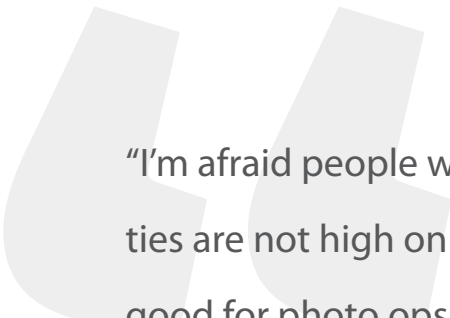
Societal Views of Persons with Disabilities

Participants had many comments about societal views and attitudes regarding physical disabilities. Some people felt that sometimes people don’t really understand what it means to have a disability, and may

feel excluded or put down by others. It was also felt by some that many decision-makers in the community talk about disabilities but don't do anything to help people with disabilities. It was thought that if adults with disabilities are out in the community more, or if people from the general community are included in the supportive housing program, it could help shift attitudes.

Advocacy and Awareness

Some participants felt they have a role to play in educating others and advocating for the needs of people with disabilities. Others identified that individuals in many types of professions that engage in public spaces require more education. Some participants felt that Supported@Home Burlington could have a role in advocating on behalf of adults with disabilities to the government.



“I’m afraid people with disabilities are not high on the list. We’re good for photo ops, but people don’t want to hear from us.”

— Research Participant

Key Issue:

There are a range of large scale systemic issues that create significant barriers for persons with disability that need to be addressed.

Suggestion for Moving Forward:

Advocate to funders the importance of providing adequate funding to support adults with disabilities and work to improve inclusion within the Burlington community.



Client Profiles

Discussions with many individuals with disabilities has led to a reflection on the diversity in circumstances between individuals with disabilities who require some form of support services. The development of client scenarios will assist in understanding how to best support individuals in their current situation and how to assist in transitioning to an alternate service plan or living environment. The list is not fully comprehensive but is a reflection of discussions with participants.

Currently Receiving Outreach Services

Individuals receiving outreach services are scattered throughout the city and are likely existing clients of service providers in the area. These clients may or may not be currently receiving adequate supports for their needs or living in adequate conditions.

Currently Receiving Outreach Services and Support from an Informal Primary Caregiver

Some individuals may receive outreach services but also have significant support from a primary caregiver. For the client and caregiver, there may or may not be a healthy balance between support from the service provider(s) and care provided by the caregiver.

Living in Supportive Housing

There are some individuals who currently live in designated supportive housing units that already have access to in-house support services and accessible housing. They are likely existing clients of service providers in the area.

Individual or Couple with Dependents

Some individuals have the major responsibility of being a parent while also requiring additional supports to assist in daily living. There may be additional or unique supports or housing types that would assist the individual in caring for their child or children.

Waiting in Hospital or Recently Discharged

Even though individuals waiting in the hospital were not able to be contacted directly for interviews, it is likely that individuals recently discharged from hospital would need to be connected with outreach supports. Also, there are individuals waiting in the hospital for alternate level of care housing or support, which includes supportive housing units.

No Access to Support Services

There are adults with disabilities in the Burlington community who do not currently have any formal support, and need access to services. These individuals are likely having difficulty figuring out if and where ser-

vices are available and may or may not have connections with any particular community organization in the area. These individuals may or may not have support from an informal primary caregiver.

In Transition: Recent Disability or Progressed Disability

Some individuals may have a recent, drastic, or progressed change to their health status. These individuals may or may not be already connected to a service provider.



Discussion



“I have a disability but it
doesn’t define who I am.”

— Research Participant

Through many discussions and exercises, the results show many different factors which can enhance or hinder the quality of life of adults with physical disabilities living in Burlington.

Provide Choice

There is such a wide diversity of needs between each person; it is impossible to provide meaningful services as a ‘one size fits all’ approach. Clients should be able to have influence and choice in many aspects of their lives, including the type and location of their home, the type of services and programming they receive, and how services are delivered.

Provide Support for Overall Wellness

Assistance with daily living and physical needs is very important, but there is a need to ensure inclusion of supports for overall wellness. Social and emotional needs are

important to consider and to incorporate into service plans. Health promotion is also essential to supporting overall wellness. Participants in the study provided a wide range of ways in which their well-being could be improved, reiterating the importance of addressing the unique needs and preferences of each individual.

Provide Services that Support Independent Living

Individuals in this study clearly articulated that they would like to keep their independence as much as possible. At the same time, it is most beneficial when appropriate supports are provided where necessary and where preferred, especially those related to enhancing independence. Flexibility in service provision and providing choice are key to ensuring the success of supporting independent living. It is important to recognize that needs and situations change, and that adapting to these changes is necessary to provide quality care.

Nurturing the Relationship between Staff and Client

Regardless of what happens behind the scenes, the client's main point of contact and experience of their services is through the staff person delivering the services.

Many assisted living services are quite personal, which highlights the importance of trust in the client-staff relationship. It is also important for clients to have consistency in who is providing care to maintain the client-staff relationship, ensure that the client is comfortable with who is providing care, and so that clients do not have to repeat their story multiple times to different people. It was also shown that little things can go a long way, such as asking how the client can be best supported each day.

Foster Seamless Navigation and Coordination of Services

When interacting with the community-based support services system, it is important that people have easy access points to enter into this space. It can be discouraging for people to hear 'no' or 'we can't help you with that'. Alternatively, it would be beneficial to have a system in place that connects individuals with all of the necessary services and can answer questions along the way. Once service delivery is in place, confusion over coordination of services can sometimes fall on the shoulders of the client.

Better coordination and ongoing communication between service providers and the client would diminish additional stress and inconveniences placed on clients while also creating greater efficiencies in service provision.

Incorporate Accessible Design Features

Incorporating accessible design into supportive housing units and the overall building will allow for greater independence and safety for adults with physical disabilities. Design features should go beyond current standards to reflect the realities of various mobility limitations. It would also be useful if certain features could be easily modified in the future to account for the diverse needs of people who will live in the unit throughout the years. Social and wellness spaces could also be included in the design of a supportive housing building.

Encourage Interaction with the Community

Greater interaction with the community would contribute to well-being and would lessen isolation that is sometimes experienced by adults with disabilities. Whether individuals are socializing, running errands, or bringing awareness in the community, the positive benefits appear to be significant for clients.

Provide Adequate Resources

Many of the issues described by adults with disabilities were correlated with service funding cutbacks. There needs to be enough resources to be able to provide quality services, especially since many of the suggestions for supports included the need for staff or volunteer time.

Embrace the Model of Person-Centred Care

The heart of these important considerations is the client. Focusing on the client's perspective will help address the identified important factors for enhancing the quality of life for adults with physical disabilities.



Conclusion

During the Transform Community Forum and Exhibition, the concluding event for this research, many ideas were shared on how the results of this study could be turned into action. These include:

- Refining the Supported@Home Burlington service delivery model to reflect the needs and suggestions brought forward by research participants.
- Sharing the results of this research with other service providers so that they can learn from and build on this work.
- Communicating key issues and advocating for change to funders, politicians, and government.
- Engaging and building awareness amongst local community organizations, faith-based groups, housing developers, and the general public.
- Exploring opportunities for partnership across sectors to address service gaps and turn the vision into reality.
- Addressing the concerns and ideas provided by service-users by improving the provision of existing services.

In general, Supported@Home Burlington will continue to use this report and the results of the research process to work toward their vision for person-centred housing and services for adults with disabilities. They will also collaborate with others interested in this research and eager to make change to improve the lives of adults with physical disabilities in Burlington and beyond.



Partners:



Prepared by:



